Implementation processes and outcomes in early intervention for eating disorders A multi-method investigation

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Implementation processes and outcomes in early intervention for eating disorders: A multi-method investigation

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Abstract

Background: Early intervention has the potential to prevent eating disorders (EDs) from seriously damaging sufferers' health and disrupting psychosocial functioning. Yet, the development and evaluation of early intervention approaches within EDs is limited. To the best of our knowledge, First Episode Rapid Early Intervention for Eating Disorders (FREED) and a modified version of it (Emerge-ED) are the only early intervention services for young people with recent-onset EDs. Previously, a pilot and a scaling-up study (FREED-Upscaled) demonstrated that FREED is feasible, acceptable, and improves outcomes. The overarching aim of this thesis was to continue to evaluate the implementation and effectiveness of early intervention services and FREED as it is scaled to ED services across England.

Method: Five key studies were conducted: (1) a scoping review of early intervention services in non-psychotic mental health disorders; (2) an evaluation of adherence to and use of the FREED service model (wait time targets and care package) during the multi-site FREED-Upscaled (FREED-Up) study; (3) a qualitative evaluation of early adopter FREED clinician attitudes and experiences of early intervention in EDs and FREED, with particular attention given to barriers and facilitators to implementation; (4) a Delphi study to evaluate the degree of consensus (or dissent) and perceived relative importance of factors (including early stage illness) used by clinicians and individuals with lived experience to prioritise patients in ED services; and (5) an evaluation of duration of untreated ED (DUED), wait times, and clinical outcomes of FREED during national scaling of the model (FREED-4-All) and in comparison to the benchmark findings of the earlier FREED-Up study.

Results: The main findings were as follows: (1) 66 documents describing and/or evaluating 22 early intervention services for non-psychotic mental health disorders were identified. These services typically targeted peak risk periods for the onset of mental health disorders, focused on increasing treatment accessibility and engagement, and provided multi-disciplinary treatment packages. The services were associated with significant improvements in clinical and functional outcomes, but comparative data to contextualise these findings were lacking as well as data on implementation and cost. (2) During the FREED-Up study, adherence to wait time targets was significantly higher for FREED patients relative to those receiving treatment as usual. Wait time

target adherence rates were ~90% for attempted engagement calls in <48 hours, ~50-60% were offered an assessment within 2 weeks, and ~30% were offered treatment within 4 weeks. The overall use of the FREED care package was high, but varied by component, diagnosis, and over time. Psychoeducation and dietary change components had the highest use, whereas attention to transitions was less well-used. (3) The interviewed FREED clinicians were positive towards and enthusiastic about early intervention in EDs and FREED, but also concerned about capacity and the impact of FREED on non-FREED patients. Clinician hope and enthusiasm were identified as key facilitators for the model. Features of the FREED model, evidence-base, and implementation strategy were important for developing enthusiasm and integrating and embedding FREED into the local context. Lack of capacity and competing demands were identified as the main barriers, hindering the implementation, integration and embedding (i.e., normalisation) of FREED. (4) Medical risk and overall severity were identified as the most important factors for determining patient priority in ED services by both clinician and lived experience groups. Clinicians tended to place a greater emphasis on physical risk, whereas the lived experience group focused more on poor mental health when determining patient priority. While qualitative comments suggest that both groups perceived early intervention as important, early intervention was only rated as a priority in the clinician group. Concerns about the impact of early intervention on the provision of services for patients with longer illness durations was frequently mentioned by clinicians and individuals with lived experience in the qualitative feedback. (5) DUED, wait time target adherence, and clinical outcomes were comparable, if not superior, in the national FREED-4-All dataset relative to the FREED-Up study, suggesting that FREED is replicating at scale. However, there was a small but significant increase in the average wait for assessment and treatment in the FREED-4-All cohort. Missing data were high in the national FREED-4-All data set, especially for clinical outcomes. These findings should therefore be regarded as tentative and re-evaluated once more data accrues.

Conclusion: The findings of this thesis provide some support for the continued scaling of FREED. Evidence thus far suggests that FREED is replicating at national scale in England and that early intervention is perceived as an important priority by clinicians, albeit to a lesser extent than immediate physical risk and illness severity. Altogether, the findings indicate that early intervention and FREED need to be adequately resourced to ensure that rapid treatment is feasible and does not disadvantage other patient groups.

Several key areas for further research were identified, including the need for more research on the comparative effectiveness, cost, and implementation of early intervention services, continued evaluations of implementation fidelity and feasibility of FREED, and methods of improving the collection of routine clinical data, and access to FREED services.

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Finally, and very importantly, I would like to thank all the participants that gave up their time and energy to take part in the research included in this thesis. Without you, this work would not be possible.

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Abbreviations

Abbreviations are reintroduced throughout this thesis to aid comprehensibility. In alphabetical order:

AADIS	Adolescent Alcohol and Drug Involvement Scale
ADS-L	Allgemeinen Depressionsskala (General Depression Scale)
AEDS	Adult eating disorder service
AESED	Accommodation and Enabling Scale for Eating Disorders
AHSN	Academic Health Science Network
AMHS	Adult mental health service
AN	Anorexia nervosa
ARFID	Avoidant/restrictive food intake disorder
ASI	Reiss-Epstein-Gursky Anxiety Sensitivity Index
ASRS	Adult Attention Deficit Hyperactivity Disorder Self-Report Scale
AtR!Sk	The Outpatient Clinic for Adolescent Risk-taking and Self-harm Behaviours
AUDIT-C	Alcohol Use Disorders Identification Test-Consumption Items
Ax	Assessment
b	Beta coefficient
β	Standardised beta coefficient
BAI	Beck Anxiety Inventory
BAS	Burden Assessment Scale
BED	Binge eating disorder
BDI-II	Beck Depression Inventory-II
BMI	Body mass index
BN	Bulimia nervosa
BPSS	Bipolar Prodrome Symptoms Scale
BQoLP	Berlin Quality of Life Profile
BSABS	Bonn Scale for the Assessment of Basic Symptoms
χ^2	Chi-squared test
CAEDS	Child and adolescent eating disorder services
CAGE	Cut-down Annoyed Guilty and Eye-opener Questions
CAMHS	Child and adolescent mental health services

CAT	Cognitive analytical therapy
CBT	Cognitive behavioural therapy
CBT-E	Enhanced cognitive behavioural therapy
CBT-ED	Cognitive behavioural therapy for eating disorders
CBT-T	10-session cognitive behavioural therapy for non-underweight eating disorders
CDS	Calgary Depression Scale
CES-D	Center for Epidemiologic Studies Depression Scale
CGI	Clinical Global Impression
CHA	Centres D'Hygiene Alimentaire
CIA	Clinical Impairment Assessment
CIDI	Composite International Diagnostic Interview
CORE-10/OM	Clinical Outcomes in Routine Evaluation-10/Outcome Measure
COVID-19	Coronavirus disease 2019
CPSS	Child Post-traumatic Stress Disorder Symptom Scale
CRI	Cologne Risk Index
CRT	Cognitive remediation therapy
DASS-21	Depression, Anxiety, and Stress Scale-21
DBT	Dialectical behaviour therapy
DERC	Dresden Early Recognition Centre
DERS	Difficulties in Emotion Regulation Scale
df	Degrees of freedom
DSM-IV/5	Diagnostic and Statistical Manual of Mental Disorders Fourth/Fifth Edition
DUED	Duration of untreated eating disorder
DUI	Duration of untreated illness
DUP	Duration of untreated psychosis
DUSC	Duration until first specialist service contact
EA	Emerging adult
ED	Eating disorders
ED-15	Brief eating disorder cognitions and behaviours measure
EDDS	Eating Disorder Diagnostic Scale
EDE	Eating Disorder Examination
EDE-Q	Eating Disorder Examination Questionnaire

EDNOS	Eating disorder not otherwise specified
ξ	Explanatory measure of effect size
EI	Early intervention
EIP	Early intervention in psychosis
EMDR	Eye-movement desensitisation and reprocessing therapy
EMS	The Early Motherhood Service
EPDS	Edinburgh Postnatal Depression Scale
EPIbipolar	Early Phase Inventory for bipolar disorder
EQ-5D-VAS	EuroQal-5 Dimensions-Visual Analogue Scale
ERQ	Emotion Regulation Questionnaire
ESPM	Eastern Sydney Perinatal Mental Health Service
EWA	Karolinska Project for Early Treatment of Women with Alcohol Addiction
FBT	Family-based therapy
FEMAP	First Episode Mood and Anxiety Program
FPT	Focal psychodynamic therapy
FUP	Flawed, uncertain, proximate, and sparse
FREED	First Episode Rapid Early Intervention for Eating Disorders
FREED-Up	FREED-Upscaled
GAF	Global Assessment of Functioning
GAIN-SS	Global Appraisal of Individual Needs Short Screener
GCC	Good Clinical Care
GP	General Practitioner
GSH	Guided self-help
HADS	Hospital Anxiety and Depression Scale
HAMD	Hamilton Depression Scale
HCL-32	Hypomania Checklist-32
hEIT	headspace Early Intervention Team
HoNOS	Health of the Nation Outcome Scale
HoNOSca	Health of the Nation Outcome Scale: Child and Adolescent
HYPE	Helping Young People Early
IAPT	Improving Access to Psychological Therapies
ICC	Intraclass correlation
ICR	Intercoder reliability

ICSRLE	Inventory of College Students' Recent Life Experiences
IES-R	Impact of Event-Scale Revised
IQR	Interquartile range
IT	Information technology
ITP	Interpersonal therapy
JBI	Joanna Briggs Institute
K10	Kessler Psychological Distress
K-SADS	Kiddie-Schedule for Affective Disorders and Schizophrenia
LDX	Lisdexamfetamine
LE	Lived experience
LEE	Levels of Expressed Emotions Scale
LGBTQ+	Lesbian, gay, bisexual, transgender, queer, plus
M	Mean
MADRAS	Montgomery-Asberg Depression Rating Scale
MANTRA	Maudsley Model of Anorexia Nervosa Treatment for Adults
MBT	Mentalization-base therapy
MCMI	Millon Clinical Multiaxial Inventory
MD	Mean difference
Mdn	Median
MDT	Multidisciplinary team
MINI	Mini International Neuropsychiatric Interview
MOS SF-36 PCS	Medical Outcomes Study Short Form 36 Physical Component Summary
N or *n*	Number of participants in the sample or sub-sample
NA	Not applicable
NEO-FFI	Neuroticism-Extraversion-Openness Five Factor Inventory of Personality
NHS	National Health Service
NICE	National Institute of Health and Care Excellence
NIDA-ASSIST	The National Institute on Drug Abuse Alcohol, Smoking, and Substance Involvement Screening Test
NPT	Normalisation Process Theory
OCD	Obsessive compulsive disorder
OMTP	Oral and Maxillofacial Trauma Psychological Service

OPOC	Ontario Perception of Care
OR	Odds ratio
OSFED	Other specified feeding or eating disorder
OYH	Orygen Youth Health
p	Probability value
PANSS	Positive and Negative Symptom Scale
PCL-C	Post-traumatic Stress Disorder Checklist Civilian Version
PD Unit	Panic Disorder Unit
PDKASQ	Personality Disorder Knowledge, Attitudes, and Skills Questionnaire
PDS-D	Post-traumatic Stress Diagnostic Scale
PDSS	Panic Disorder Severity Scale
PHQ-9	Patient Health Questionnaire-9
PJR	Patient journey record
PNDI	Postnatal Depression Intervention Program
PRIME-MD	Primary Care Evaluation of Mental Disorders
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for Scoping Reviews
PSPC	Paediatric Stepped Prevention Care Intervention
PSQ	Patient Satisfaction Questionnaire
PSYCHLOPS	Psychological Outcome Profiles
PTSD	Post-traumatic stress disorder
Q&A	Question-and-answer
QLESQ	Quality of Life Enjoyment and Satisfaction Questionnaire
RE-AIM	Reach, Efficacy/Effectiveness, Adoption, Implementation, and Maintenance
RCT	Randomised controlled trial
SCC	Stepped Collaborative Care Intervention
SCID-I	Structured Clinical Interview for Diagnostic and Statistical Manual for Disorders for DSM-IV
SCL-27	Symptom Checklist-27
SD	Standard deviation
SDS	The Sheehan Disability Scale
SE	Standard error

SIPS	Structured Interview of Prodromal Syndromes
SLaM	South London and Maudsley
SOFAS	Social and Occupational Functioning Assessment Scale
SPC	Stepped Prevention Care Intervention
SPEED	Setting Priorities in Eating Disorder Services
SPI-A	Schizophrenia Proneness Instrument-Adult
SSCM	Specialist Supportive Clinical Management
SSRI	Selective serotonin re-uptake inhibitors
STAI	Spielberger State-Trait Anxiety Inventory
STEPP	Screening Tool for Early Predictors of Post-traumatic Stress Disorder
t	t-test
T1	Time 1
T2	Time 2
T3	Time 3
TAU	Treatment as usual
THQ	Trauma History Questionnaire
TMF	Theories, models, and frameworks
TOC	Trauma Outpatient Clinic
TPB	Theory of Planned Behaviour
Tx	Treatment
T_y	Yuen-Welch test
UFED	Unspecified feeding or eating disorder
UK	United Kingdom
W	Kendall's coefficient of concordance
WEIRD	Western, educated, industrialized, rich and democratic
WSAS	Work and Social Adjustment Scale
YASR	Young Adult Self-Report
YES	Your Experience of Service
YRBS	Youth Risk Behaviour Survey
YSR	Youth Self-Report
YWC	Youth Wellness Centre
ZInEP	Zurich Early Recognition Program

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Dissemination of research

Publications incorporated into thesis

Chapters 2, 4, 6, and 7 have been published as papers in peer reviewed journals. The papers have been incorporated into the thesis. The formatting of each paper has been amended for stylistic consistency and additional details have been added to each chapter to provide greater clarity on the studies and their results.

Chapter 2: **Richards, K.,** Austin, A., Allen, K., & Schmidt, U. (2019). Early intervention services for non-psychotic mental health disorders: a scoping review protocol. *BMJ Open, 9*(12), e033656. doi:10.1136/bmjopen-2019-033656

Chapter 4: **Richards, K.,** Flynn, M., Austin, A., Lang, K., Allen, K. L., Bassi, R., Brady, G., Brown, A., Connan, F., Franklin-Smith, M., Glennon, D., Grant, N., Jones, W. R., Kali, K., Koskina, A., Mahony, K., Mountford, V. A., Nunes, N., Schelhase, M., Serpell, L., Schmidt, U. (2021). Assessing implementation fidelity in the First Episode Rapid Early Intervention for Eating Disorders service model. *BJPsych Open, 7*(3), e98. doi:10.1192/bjo.2021.51

Chapter 6: **Richards, K. L.**, Woolrych, I., Allen, K. L., Schmidt, U. (2022). A Delphi study to explore clinician and lived experience perspectives on setting priorities in eating disorder services. *BMC Health Services Research, 22*(788), 1-15. doi:10.1186/s12913-022-08170-4

Chapter 7: **Richards, K. L.,** Hyam, L., Allen, K. L., Glennon, D., Di Clemente, G., Semple, A., Jackson, A., Belli, S. R., Dodge, E., Kilonzo, C., Holland, L., & Schmidt, U. (2022). National roll-out of early intervention for eating disorders: Process and clinical outcomes from First Episode Rapid Early Intervention for Eating Disorders. *Early Intervention in Psychiatry, 17*(2), 202-211. doi:10.1111/eip.13317

PDF versions of the published articles are included in Appendix A.

Publications completed during PhD but not included in thesis

Austin, A., Flynn, M., **Richards, K. L**., Sharpe, H., Allen, K. L., Mountford, V. A., Glennon, D., Grant, N., Brown, A., Mahoney, K., Serpell, L., Brady, G., Nunes, N., Connan, F., Franklin-Smith, M., Schelhase M., Jones, W. R., Breen, G., & Schmidt, U. (2021). Early weight gain trajectories in first episode anorexia: predictors of outcome for emerging adults in outpatient treatment. *Journal of Eating Disorders*, *9*(1), 1-8. doi:10.1186/s40337-021-00448-y

Austin, A., Potterton, R., Flynn, M., **Richards, K. L.**, Allen, K., Grant, N., Glennon, D., Mountford, V. A., Franklin-Smith, M., Schelhase, M., Jones, W. R., Serpell, L., Mahoney, K., Brady G., Nunes, N., Kali, K., Connan, F., & Schmidt, U. (2021). Exploring the use of individualised patient-reported outcome measures in eating disorders: Validation of the Psychological Outcome Profiles. *European Eating Disorders Review*, *29*(2), 281-291. doi:10.1002/erv.2819

Conti, C., Di Francesco, G., Severo, M., Lanzara, R., **Richards, K. L.,** Guagnano, M. T., & Porcelli, P. (2021). Alexithymia and metabolic syndrome: the mediating role of binge eating. *Eating and Weight Disorders - Studies on Anorexia, Bulimia and Obesity*, *26*(6), 1813-1823. doi:10.1007/s40519-020-00964-x

Austin, A., Flynn, M., **Richards, K. L.,** Hodsoll, J., Duarte, T. A., Robinson, P., Kelly, J., & Schmidt, U. (2020). Duration of untreated eating disorder and relationship to outcomes: A systematic review of the literature. *European Eating Disorders Review*, *29*(3), 329-345. doi:10.1002/erv.2745

Allen, K. L., Mountford, V., Brown, A., **Richards, K. L.,** Grant, N., Austin, A., Glennon, D., & Schmidt, U. (2020). First episode rapid early intervention for eating disorders (FREED): From research to routine clinical practice. *Early Intervention in Psychiatry*, *14*(5), 625-630. doi:10.1111/eip.12941

Potterton, R., **Richards, K. L.,** Allen, K., & Schmidt, U. (2020). Eating disorders during emerging adulthood: A systematic scoping review. *Frontiers in Psychology*, *1*0, 3062. doi:10.3389/fpsyg.2019.03062

Conference and research presentations associated with thesis

Conference presentations:

Richards, K. L., & Woolrych, I. (2022). Clinician and Lived Experience Perspectives on Setting Priorities in Eating Disorder Services. Oral presentation at the Eating Disorder International Conference, UK.

PhD showcases:

Richards, K. L. (2019). The Clinicians' Perspective of FREED: A Protocol. Oral presentation at the Biomedical Research Centre (BRC) Obesity, Lifestyle and Learning from Extreme Phenotypes (OBELIX) Theme Showcase.

External meetings:

Allen, K. L., & **Richards, K. L**. (2022). FREED: Early Intervention for Eating Disorders in England. Oral presentation at the Eating Disorders: Delineating Illness and Recovery Trajectories to Inform Personalised Prevention and Early Intervention in Young People (EDIFY) Launch Event.

Richards, K. L. (2021). What Do Clinicians Think About Early Intervention for Eating Disorders?. Oral presentation at the Academic Health Science Network Early Intervention for Eating Disorder One Year Review.

Data included in Chapter 5 have been presented on multiple occasions to eating disorder clinicians during First Episode Rapid Early Intervention for Eating Disorders (FREED) training.

Internal meetings:

The research included within this thesis has been presented at departmental meetings at the Institute of Psychiatry, Psychology & Neuroscience, King's College London. Presentation titles included: (1) "The Spread, Adoption, and Replication of First Episode Rapid Early Intervention for Eating Disorders (FREED)", (2) "Assessing Implementation Fidelity in First Episode Rapid Early Intervention for Eating Disorders (FREED)", (3) "A Delphi study to explore clinician and lived experience perspectives in Setting Priorities in Eating Disorder Services (SPEED)".

Declaration of the candidate's role

Chapter 1: General introduction

The candidate conceptualised and drafted the chapter. Dr Karina Allen, Professor Ulrike Schmidt, and Michaela Flynn reviewed and provided constructive feedback on the chapter.

Chapter 2: Early intervention for non-psychotic disorders: A scoping review protocol

The candidate (Katie Richards) was responsible for the conception and design of the study and drafted the manuscript. Amelia Austin, Dr Karina Allen, and Professor Ulrike Schmidt contributed towards the conception and design of the study and read and substantially revised the manuscript. Constructive feedback was received from peer reviewers at *BMJ Open* and the manuscript altered accordingly.

Chapter 3: Early intervention service for non-psychotic disorders: A scoping review

The candidate (Katie Richards), Amelia Austin, Dr Karina Allen, and Professor Ulrike Schmidt were responsible for the conception and design of the study. The candidate conducted the systematic literature search, the de-duplication, and title and abstract and full-text screening. Amelia Austin and Luiza Grycuk screened 25% of the titles and abstracts and full-text documents in duplicate. The candidate charted and critically appraised all included documents. Amelia Austin critically appraised 25% of the articles in duplicate. The chapter was drafted by the candidate. The chapter was reviewed by Amelia Austin, Dr Karina Allen, and Professor Ulrike Schmidt who provided constructive feedback and suggested amendments.

Chapter 4: Assessing implementation fidelity in First Episode Rapid Early Intervention for Eating Disorder

The FREED-Up study was conceptualised and designed by Professor Ulrike Schmidt, Dr Karina Allen, Dr Victoria Mountford, and Danielle Glennon. The authors Michaela Flynn, Amelia Austin, Dr Katie Lang, Dr Karina Allen, Ranjeet Bassi, Dr Gabrielle Brady, Dr Amy Brown, Dr Frances Connan, Mary Franklin-Smith, Danielle Glennon, Dr Nina Grant, Dr William Rhys Jones, Kuda Kali, Dr Antonia Koskina, Dr Kate Mahony, Dr Victoria Mountford, Nicole Nunes, Dr Monique Schelhase, Professor Lucy Serpell, and Professor Ulrike Schmidt conducted the study, and collected and managed

the data. The candidate (Katie Richards) transferred the patient journey record data from paper into an electronic database, analysed the data, and drafted the manuscript with assistance from Professor Ulrike Schmidt and Dr Karina Allen. All authors reviewed and contributed towards the final version of the manuscript. Constructive feedback was received from peer-reviewers at *BJPsych Open* and the manuscript was altered accordingly.

Chapter 5: Early adopters of First Episode Rapid Early Intervention for Eating Disorders in England: A qualitative study

The study was conceptualised and designed by the candidate (Katie Richards), Professor Ulrike Schmidt, and Dr Karina Allen. The candidate recruited participants and conducted the qualitative interviews. The interviews were transcribed by the candidate and Luiza Grycuk with assistance from an automated transcription service. The interviews were coded and analysed by the candidate. Four interviews were independently coded by Mathew Phillips and compared to the candidate's codes to measure the trustworthiness of the analysis. Four study participants, Professor Ulrike Schmidt, and Dr Karina Allen provided constructive feedback on the results. The candidate drafted the chapter and Professor Ulrike Schmidt, Dr Karina Allen, and Michaela Flynn reviewed and provided constructive feedback on the chapter.

Chapter 6: A Delphi study to explore clinician and lived experience perspectives on Setting Priorities in Eating Disorder Services (SPEED)

The study was conceptualised and design by the candidate (Katie Richards), Dr Karina Allen, and Professor Ulrike Schmidt. The candidate and Isabel Woolrych were responsible for collecting and managing the data. The candidate analysed the data and drafted the manuscript. Isabel Woolrych, Dr Karina Allen, and Professor Ulrike Schmidt reviewed and provided constructive feedback on the manuscript. Constructive feedback was provided by peer reviewers from BMC Health Services Research and the manuscript was modified accordingly.

Chapter 7: National roll-out of early intervention for eating disorders: Process and clinical outcomes from First Episode Rapid Early Intervention for Eating Disorders

The study was conceptualised and designed by the candidate (Katie Richards), Dr Karina Allen, and Professor Ulrike Schmidt. The candidate and Lucy Hyam were responsible for collecting and managing the data. The candidate, Lucy Hyam, Danielle Glennon, Dr Giulia Di Clemente, Amy Semple, Aileen Jackson, Stefano Belli,

Elizabeth Dodge, Charmaine Kilonzo, Leah Holland, and Professor Ulrike Schmidt contributed towards the national implementation of FREED. The candidate analysed the data and drafted the manuscript with assistance from Dr Karina Allen and Professor Ulrike Schmidt. All authors reviewed and contributed to the final manuscript. Constructive feedback was provided by peer reviewers from *Early Intervention in Psychiatry* and the manuscript was altered accordingly.

Chapter 8: General overview

The candidate conceptualised and drafted the chapter. Dr Karina Allen, Professor Ulrike Schmidt, and Amelia Austin reviewed the chapter and provided constructive feedback.

Chapter 1. General introduction

Author contributions: The candidate conceptualised and drafted the chapter. Dr Karina Allen, Professor Ulrike Schmidt, and Michaela Flynn reviewed and provided constructive feedback on the chapter.

Eating disorders (EDs) are serious psychiatric illnesses characterised by abnormal eating and weight-control behaviours that substantially interfere with physical, social, and occupational functioning (American Psychiatric Association, 2013; Treasure, Duarte, & Schmidt, 2020a). EDs have a high mortality rate due to physical risk and suicide, and enormous social and economic costs for the individual, families, and wider society (Ágh et al., 2016; Franko et al., 2013; van Hoeken & Hoek, 2020). Despite considerable advances, the effectiveness of ED treatments remain modest with a significant minority of individuals developing a chronic and unremitting course (Andrés-Pepiñá et al., 2019; Eddy et al., 2017; Fichter, Quadflieg, Crosby, & Koch, 2017; Slade et al., 2018; Solmi et al., 2021b). There is a need for innovation and to enhance the effectiveness of existing evidence-based treatments through augmentation, tailoring, and targeting (Austin et al., 2021a; Adamson et al., 2019; Kan, Cardi, Stahl, & Treasure, 2019). Early detection and initiation of stage-specific treatments is widely perceived as beneficial in medicine and one possible avenue to explore (Currin & Schmidt, 2005). Indeed, recent trials of a novel early intervention service for EDs, namely First Episode Rapid Early Intervention for EDs (FREED), found that rapid, tailored treatment can improve outcomes (Austin et al., 2021b; McClelland et al., 2018). This thesis builds upon this work by using a multi-method approach (i.e., quantitative and qualitative methodologies) to investigate the implementation and outcomes of FREED as it further scaled across England, with particular attention given to individual and collective attitudes, implementation processes, and barriers and facilitators to implementation.

This introductory chapter first provides an overview of the clinical presentation, prevalence, onset, course, and current treatments for EDs. A rationale for early intervention in EDs, and a summary of existing early intervention approaches, including FREED, is then provided. Next, implementation science and the theories and frameworks used within this thesis are introduced. Lastly, an overview of the thesis aims, chapters, and studies are presented.

1.1 Eating disorders

1.1.1 Diagnoses

Seven Feeding and Eating Disorders are described in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5). These include anorexia nervosa (AN), bulimia nervosa (BN), binge-eating disorder (BED), avoidant/restrictive food intake disorder (ARFID), other specified feeding or eating disorder (OSFED), pica, and

rumination disorder (American Psychiatric Association, 2013). The latter two are not included in this thesis so are not described in detail.

1.1.1.1 Anorexia nervosa

Anorexia nervosa (AN) is characterised by intense fears of weight gain or becoming fat, distorted body weight or shape perception, and restrictive energy intake resulting in a significantly low body weight that is below minimally normal for age, sex, developmental trajectory, and physical health. Individuals with AN engage in persistent behaviours that interfere with weight gain and/or do not recognise the medical seriousness of their low weight or malnutrition. Food or eating or concerns about body weight or shape dominate self-evaluations, thinking, and behaviour. AN can be divided into two types: restrictive subtype, which is largely marked by food restriction and excessive exercise, and an impulsive binge/purge subtype, where individuals eat an abnormally large amount of food in a short space of time (<2 hours) and have a sense of loss of control over their eating (referred to as binge eating) and/or engage in compensatory activities to prevent weight gain, such as vomiting, or laxative misuse (American Psychiatric Association, 2013).

1.1.1.2 Bulimia nervosa

The hallmark features of BN are recurrent binge eating, inappropriate compensatory behaviours to prevent weight gain (e.g., vomiting, fasting, compulsive exercise, or laxative misuse), and body shape or weight concerns, which substantially impact self-evaluations and self-esteem. Binge eating episodes are often preceded by negative affect, stress, dietary restraint, and/or boredom and usually occur in secrecy, and until the person is uncomfortably or even painfully full. Individuals with BN consequently engage in compensatory or purging behaviours to prevent weight gain. The most common compensatory behaviour is vomiting. Binge eating and purging episodes must occur at least once a week for 3 months, on average, to meet diagnostic criteria and not occur exclusively during an episode of AN. Unlike individuals with AN binge/purge subtype, individuals with BN maintain a body weight at or above the minimally normal level for age and sex (American Psychiatric Association, 2013).

1.1.1.3 Binge eating disorder

The central feature of BED is recurrent binge eating episodes that occur at least once a week for 3 months, on average, without inappropriate compensatory or purging behaviours to prevent weight gain. Binge eating episodes must be associated with marked distress and three or more of the following features: eating much more rapidly

than normal, eating large quantities of food when not physically hungry, eating until uncomfortably full, eating alone or in secret because of embarrassment or shame about eating, and feeling disgusted, depressed, or very guilty after a binge eating episode. Similar to BN, the binge eating is often preceded by negative affect, stress, dietary restraint, and/or boredom. The binge eating should not occur exclusively during an episode of AN or BN (American Psychiatric Association, 2013).

1.1.1.4 Avoidant/restrictive food intake disorder

The primary diagnostic criterion for ARFID is avoidant and/or restrictive food intake associated with at least one of the following: significant weight loss or failure to obtain minimally adequate weight or height for developmental age, malnutrition and associated health impacts, dependence on nutritional supplementation or enteral feeding, and/or significantly impaired psychosocial functioning. The weight loss, nutritional deficiencies, and physical health consequences can be of comparable severity to individuals with AN. However, unlike AN or BN, the restrictive intake is not associated with distortions of, or excessive concerns about, body weight or shape, or fear of weight gain or becoming fat. Instead, the food avoidance or restriction maybe due to a lack of interest in eating or food, extreme sensory sensitivities to appearance, texture, smell, or taste, or concerns about aversive or negative consequences of eating (e.g., choking, gastro-intestinal discomfort, vomiting) (American Psychiatric Association, 2013).

1.1.1.5 Other specified feeding or eating disorder

Other specified feeding or eating disorder (OSFED) is a broad diagnostic category which is often given when an individual exhibits symptoms of a Feeding and Eating Disorder that cause clinically significant distress or psychosocial impairment but do not meet the full criteria for any specific disorder. OSFED is used when a clinician specifies the reason that the full criteria for a specific disorder have not been met. The term unspecified feeding or eating disorder (UFED) is used when a clinician does not specify the reason the criteria for a specific feeding and eating disorder have not been met. Examples of presentations that are included under the OSFED diagnosis are: atypical AN (all AN criteria are met but despite significant weight loss, weight is not significantly underweight for age and sex), BN and BED of low frequency or limited duration (<once a week and/or ≤3 months duration), purging disorder (recurrent purging episodes to influence shape or weight in the absence of binge eating), and night eating syndrome (recurrent episodes of night eating characterised by eating an excessive amount of food in the evening or upon awakening that cause considerable distress or

psychosocial impairment) (American Psychiatric Association, 2013). OSFED is a relatively new diagnostic category that evolved from the DSM-IV eating disorder not otherwise specified (EDNOS) category. EDNOS is similar to OSFED except it included BED and an atypical AN where all criteria except amenorrhea are met.

1.1.2 Prevalence, course, and outcomes

1.1.2.1 Incidence and prevalence

The overall incidence rates of ED range between 1 to 37 per 100 000 person-years. The incidence rate across different samples and diagnoses ranged between 1 to 270 per 100 000 person-years for AN, 0 to 300 per 100 000 person-years for BN, 35 per 100 000 person-years for BED, and 1 to 70 per 100 000 person-years for EDNOS. The overall incidence rate of EDs has remained relatively stable over the last few decades with some evidence of increasing AN in certain groups and decreasing BN. The precise mechanisms underlying any changes in incidence rates are unclear, e.g., better detection and diagnostic classification changes vs a real increase in incidence (Demmler, Brophy, Marchant, John, & Tan, 2020; Hoek, 2016; Keski-Rahkonen & Mustelin, 2016; Micali, Hagberg, Petersen, & Treasure, 2013; Smink, van Hoeken, & Hoek, 2012). However, recent data suggest a marked increase in the incidence and severity of EDs, particularly for young females and AN presentations, following the start of the coronavirus disease 2019 (COVID-19) pandemic (Agostino et al., 2021; Haripersad et al., 2021; Hyam, Richards, Allen, & Schmidt, 2023; Kurisu et al., 2021; Taquet, Geddes, Luciano, & Harrison, 2021).

Across 94 studies, the weighted mean lifetime and point prevalence of EDs was 8.4% and 5.7% for females, and 2.2% and 2.2% for males. The most frequent ED was OSFED/EDNOS with lifetime and point prevalence of 4.3% and 10.1% for females and 3.6% and 0.9% for males. This was followed by BED with lifetime and point prevalence of 2.8% and 2.3% for females, and 1% and 0.3% for males. For BN, the lifetime and point prevalence were 1.9% and 1.5% for females, and 0.6% and 0.1% for males. The lifetime and point prevalence of AN was 1.4% and 2.8% for females and 0.2% and 0.3% for males (Galmiche, Déchelotte, Lambert, & Tavolacci, 2019). While these studies suggest a higher frequency of EDs in females, there was only a small number of studies distinguishing males from females and many of the studies only included females. These estimates also do not include ARFID; there are very few epidemiological studies of ARFID, most of which focus on specific clinical and child/adolescent populations (Bourne, Bryant-Waugh, Cook, & Mandy, 2020; Micali &

Cooper-Vince, 2020). The 3- and 6-month and lifetime prevalence of ARFID has been estimated at approximately 0.3-0.5% (Chen, Chen, Lin, Shen, & Gau, 2020; Hay et al., 2017; Smink, van Hoeken, Oldehinkel, & Hoek, 2014).

1.1.2.2 Course and outcome

Most EDs emerge within the first three decades of life. The median age of onset for AN, BN, and BED are 17 years (interquartile range (IQR) = 14-22), 18 years (IQR = 15-22), and 20 years (IQR = 16-25), respectively. Approximately 80% of all individuals develop these disorders before the age of 25 years (Allison et al., 2021; Davies et al., 2021; Solmi et al., 2021a). The age of onset for OSFED has been estimated to range between 16-20 years and varies by subtype (Murray & Anderson, 2015; Mustelin, Lehtokari, & Keski-Rahkonen, 2016; Ng, Kuek, & Lee, 2018; Riesco et al., 2018; Stice, Marti, & Rohde, 2013). There are no population-based estimates of the age of onset for ARFID, however, some studies show that patients with ARFID tend to be younger (~11 years old) with a longer duration of illness, signifying an earlier age of onset (Strand, von Hausswolff-Juhlin, & Welch, 2019; Micali & Cooper-Vince, 2020; however, Nakai et al., 2017).

A review of 119 studies found that 47% of patients with AN recovered, 34% improved but remained symptomatic, and 21% continued to have a long-term chronic illness. AN recovery/remission increased linearly over time with 33% recovered in studies with <4 year follow-up, 47% in studies with a 4-9 year follow-up, and 73% in studies with >10 year follow-up (Steinhausen, 2002). Recent AN studies have found a 30-40% recovery rate in the first decade of illness, which continues to increase to 60-75% at 20-30 years post onset (Dobrescu et al., 2020; Eddy et al., 2017; Herpertz-Dahlmann et al., 2018; however, Fichter et al., 2017). Rates of recovery/remission were similar for BN with 45% classified as recovered, 27% improved but still symptomatic, and 23% continued to have a long-term chronic illness. Unlike AN, recovery/remission did not increase linearly with follow-up length. Studies with <4 year follow-up demonstrated a 39% recovery rate, 4-9 year follow-up had a 67% recovery rate, and >10 year follow-up had a 44% recovery rate (Steinhausen & Weber, 2009). A similar plateauing of BN recovery after 10 years has also been found in recent studies (Eddy et al., 2017; Quadflieg & Fichter, 2019). Studies on the course and outcomes of BED, OSFED, and ARFID are scarce. A recent Finish community cohort study found that ~40% of individuals with BED, OSFED, or UFED recovered at a 5 year follow-up (Silén et al., 2021). However, others have demonstrated more optimistic outcomes with

remission rates of 64% and 93% for BED and 60 to 89% for OSFED (Fichter, Quadflieg, & Hedlund, 2008; Keel, Gravener, Joiner Jr., & Haedt, 2010; Mustelin et al., 2016; Stice et al., 2013). Two studies with an 8- and 15-year follow-up of ARFID demonstrated a 52% and 75% remission rate (Lange, Ekedahl Fjertorp, Holmer, Wijk, & Wallin, 2019; Nakai et al., 2017).

Eating disorders are associated with high levels of medical and psychosocial disability and mortality (Klump, Bulik, Kaye, Treasure, & Tyson, 2009). Worldwide, EDs are estimated to account for 2.8% (3.3 million) of all healthy life years lost due to disability for mental health disorders. From 2007 to 2017 the years lived with disability for AN and BN have increased by 6 and 10%, respectively. This is in contrast to mental health disorders overall, where years lived with disability have decreased slightly (van Hoeken & Hoek, 2020). EDs can significantly interfere with participation in education and work, quality of life, psychological well-being, and interpersonal functioning (Beat, 2015; Hay et al., 2017; Stice et al., 2013; Sy, Ponton, De Marco, Pi, & IsHak, 2013; Tomba, Tecuta, Crocetti, Squarcio, & Tomei, 2019). Moreover, caregivers of individuals with EDs often experience high burden, anxiety, and lost earnings due to time off work (Beat, 2015; Martín et al., 2015; Rhind et al., 2016; Streatfeild et al., 2021). The burden of EDs are further heightened by high levels of psychiatric comorbidity, particularly mood, anxiety, and substance use disorders, which are associated with poorer outcomes (Fichter et al., 2008; Keshishian et al., 2019; Quadflieg & Fichter, 2019; Steinhausen et al., 2021; Udo & Grilo, 2019). Finally, one of the most unfavourable outcomes, premature death, is elevated in EDs with standardised mortality ratios for AN, BN, BED, and OSFED/EDNOS of 5.2-5.9, 1.5-1.9, 1.5-2.3, and 1.9-3.4, respectively (Arcelus, Mitchell, Wales, & Nielsen, 2011; Fichter et al., 2008; Fichter & Quadflieg, 2016; Himmerich et al., 2019; Quadflieg, Strobel, Naab, Voderholzer, & Fichter, 2019).

1.1.3 Treatments

First-line treatments for EDs are typically structured ED-specific individual and family-based psychological therapies (National Institute for Health and Care Excellence, 2017; Treasure et al., 2020a). Depending on risk and severity, treatments are provided in outpatient, day, and inpatient settings, and tailored to clinical presentation and patient preferences (e.g., acute vs chronic, simple vs comorbidities). Augmentations to evidence-based treatments, such as carer support and skills training, stage-specific

treatments, and brain-directed stimulation techniques, are promising avenues for enhancing outcomes and the maintenance of treatment effects (Treasure et al., 2020a).

1.1.3.1 Psychological

Eating disorder-specific family-based therapies (FBT) are recommended as the first-line treatment in evidence-based clinical guidelines for children and adolescents with AN (Treasure et al., 2020a). While FBT is effective and can reduce symptoms over time, only a limited number of studies favour FBT in terms of remission rates and weight gain relative to treatment as usual (TAU) and other psychological therapies (Fisher, Skocic, Rutherford, & Hetrick, 2019). In contrast, ED-specific individual psychological therapies dominate the treatment of adults with AN, including enhanced cognitive behavioural therapy (CBT-E), Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA), focal psychodynamic therapy (FPT), and Specialist Supportive Clinical Management (SSCM) (Zeeck et al., 2018). Specialist psychological treatments for adult with AN significantly improve weight, ED symptoms, distress, and psychosocial functioning over time. However, there is no clear superiority of one treatment over another, including specialised TAU, and remission rates are low, ranging from 14-32% at follow-up (Byrne et al., 2017; Hay et al., 2018; Schmidt et al., 2015; Schmidt et al., 2016c; Solmi et al., 2021b).

For young people and adults with BN and BED, clinical guidelines recommend ED-focused guided self-help, and individual or group cognitive behavioural therapy (CBT). In addition to these interventions, FBT is one of the first line treatments recommended for children and adolescents with BN (Treasure et al., 2020a). Indeed, meta-analyses support these recommendations as CBT and guided self-help (largely based on CBT) were associated with medium to large improvements in ED symptoms and depression relative to inactive controls. CBT-based interventions, particularly in group format, were also advantageous compared to other psychotherapies. However, post-treatment remission and abstinence rates were only moderate ranging from 40-50% (Hilbert et al., 2019; Slade et al., 2018; Svaldi et al., 2019). Two studies of FBT in young people with BN suggest that it is more effective than CBT and supportive psychotherapy for remission and ED symptoms, at least in the short term (Le Grange, Crosby, Rathouz, & Leventhal, 2007; Le Grange, Lock, Agras, Bryson, & Jo, 2015). For OSFED, clinical guidelines recommend providing the treatment for the ED it most closely resembles (National Institute for Health and Care Excellence, 2017). Preliminary evidence (e.g., case or feasibility studies) suggests that CBT and FBT

adapted to treat ARFID are acceptable and improve food intake, weight, and ED-related psychopathology (Dumont, Jansen, Kroes, de Haan, & Mulkens, 2019; Fischer, Luiselli, & Dove, 2015; Lock, Sadeh-Sharvit, & L'Insalata, 2019b; Lock et al., 2019a).

1.1.3.2 Pharmacological

To date, only two medications have been approved for EDs in some countries. These are the selective serotonin re-uptake inhibitor (SSRI) fluoxetine for BN and the stimulant lisdexamfetamine (LDX) for BED (Himmerich & Treasure, 2018). Both of these have been shown to significantly reduce binging and purging behaviours and increase remission rates relative to a placebo control, albeit to a lesser extent than CBT (Hilbert et al., 2019; Svaldi et al., 2019). The anti-epileptic medication topiramate also holds promise as it significantly reduces binging, purging, and psychological symptoms relative to a placebo control (McElroy, 2017; McElroy, Guerdjikova, Mori, & Romo-Nava, 2019). In contrast, there is a lack of high-quality evidence supporting the use of pharmacotherapies in individuals with AN and ARFID (Bourne et al., 2020; Miniati et al., 2016). Preliminary evidence suggests that low dose olanzapine, dronabinol, or exposure therapy plus D-cycloserine may be effective in improving weight gain but not psychological symptoms in AN (Andries, Frystyk, Flyvbjerg, & Støving, 2014; Attia et al., 2011; Himmerich & Treasure, 2018; Levinson et al., 2015). Case studies suggest that adjunctive buspirone, mirtazapine, and low dose olanzapine may facilitate weight gain and reduce anxiety, depression, and cognitive symptoms in ARFID (Brewerton & D'Agostino, 2017; Gray, Chen, Menzel, Schwartz, & Kaye, 2018 Okereke, 2018). A small (n = 15) double-blind, placebo-controlled study in young children with ARFID found that behavioural intervention plus D-cycloserine improved feeding by 39% compared to behavioural intervention alone (Sharp et al., 2017).

1.1.3.3 Emerging evidence and future directions

While the positive impacts of even moderate reductions in symptoms cannot be underestimated, there is still a pressing need to develop novel interventions or improve the effectiveness of existing treatments for Eds (Solmi et al., 2021b). Full remission and recovery following the best available ED treatments remains low to moderate with a sizeable number of individuals developing a chronic and unremitting course (Eddy et al., 2017). Many methods have been developed to enhance the effectiveness of existing evidence-based treatments for EDs (Treasure et al., 2020a). First, carer support and skills training delivered face-to-face, online, and/or over the telephone can improve patient and carer-related outcomes and reduce health care service use relative to TAU

(Hannah et al., 2021). Second, preliminary studies of cognitive remediation therapy (CRT) and other training interventions for the underlying neurocognitive, and psychosocial processes involved in EDs have demonstrated promising but mixed findings (Brockmeyer et al., 2019; Giel, Speer, Schag, Leehr, & Zipfel, 2017; Kim et al., 2018; Schag et al., 2019). Third, neuromodulation treatments, such as deep brain stimulation, repetitive transcranial magnetic stimulation, and transcranial direct current stimulation, show some promise in EDs, especially for mood, weight, and ED symptomatology in severe and enduring AN (Gallop, Flynn, Campbell, & Schmidt, 2022). Finally, rapid treatment tailored to the stage of illness may improve the effectiveness of existing evidence-based treatment in EDs and is the primary focus of this thesis (McClelland et al., 2018). The rationale for early intervention for EDs and the evidence-base thus far are outlined in the next section.

1.2 Early intervention

Early intervention is an umbrella term used to describe approaches where ill health or precursors of ill health are detected and treated as soon as possible. It is predicated on the idea that intervening early minimises distress and disruption, improves outcomes, or may even avert ill health altogether (Currin & Schmidt, 2005; Malhi, Bell, Hamilton, & Morris, 2021). Intervening when symptoms are mild and more amenable to change reduces the need for lengthy and invasive treatment, which could curtail the rising costs of health care (Muñoz, Mrazek, & Haggerty, 1996). Early intervention is intuitively appealing and for many physical disorders, with well-characterised pathophysiology, it has effectively reduced mortality and morbidity (Currin & Schmidt, 2005; Malhi, Bell, Hamilton, & Morris, 2021; McGorry, 2015). Given the enormous human and financial cost of mental health disorders, there have been strong ambitions to translate such approaches to mental health (Fusar-Poli et al., 2021; McGorry, 2015; McGorry & Mei, 2018).

1.2.1 Definition

Here, we define early intervention as treatments provided as early as possible for individuals with recent-onset subthreshold or threshold disorders. The term early intervention is often used interchangeably with prevention and indeed many prevention frameworks incorporate early intervention. The Institute of Medicine and World Health Organisation provide useful frameworks for conceptualising early intervention and situating it within the broader prevention and treatment of mental health disorders (Mrazek & Haggerty, 1994; World Health Organization, 2004). These frameworks

outline a continuum of interventions including primary prevention, secondary prevention (early or standard treatment), and tertiary prevention. Primary prevention aims to prevent symptoms from emerging in the first place and reduce population-wide incidence of disorder. Interventions at this level can be further divided into universal, selected, and indicated. Universal interventions are indiscriminately applied to the public or entire population regardless of risk. Selected interventions are targeted at sub-groups of individuals with elevated risk according to biological, psychological, or social markers, e.g., relatives of individuals with a disorder. Indicated interventions are provided for individuals with minimal but detectable signs or symptoms of disorder that do not meet diagnostic criteria. Secondary prevention seeks to reduce the incidence and time spent with symptoms through the early identification and treatment of individuals with diagnosable disorders. Finally, tertiary prevention relates to the longer-term care of mental health disorders through treatment and rehabilitation that aims to enhance quality of life and reduce disability and relapse (Mrazek & Haggerty, 1994; World Health Organization, 2004).

Our definition of early intervention largely fits within the remit of secondary prevention. However, the boundaries between the concepts overlap and some early intervention work could feasibly be described as indicated primary prevention (e.g., sub-threshold disorders). Although the focus of this thesis is on secondary prevention, all three components of this spectrum are complementary and contribute towards the goal of reducing the impact of mental health disorders (Fusar-Poli et al., 2021).

1.2.2 Early intervention in mental health

Early intervention in mental health has been most widely and enthusiastically researched and implemented in psychosis (McGorry & Mei, 2018). Early intervention in psychosis (EIP) began in Australia in the 1980s but is now considered standard practice in many jurisdictions, and large sections of national and international clinical guidelines are dedicated to the treatment and management of early psychosis (McGorry, Killackey, & Yung, 2008). EIP was developed in response to evidence demonstrating that prolonged periods of untreated psychosis were associated with worse symptomatic and functional outcomes, and that the first few years after illness onset were a critical period in which relapse and the risk of disability were high. There were also concerns that the wholesale application of interventions that were largely developed for persistently ill, older patients was inadequate or even harmful for young patients with early psychosis. EIP services are specifically designed to reduce the duration of untreated psychosis

(DUP), attend to the specific needs of young people with early psychosis, and limit disruptions to psychosocial functioning and development (McGorry, Edwards, Mihalopoulos, Harrigan, & Jackson, 1996). EIP is also based on the concept of clinical staging. In contrast to traditional diagnostic categories, dimensional clinical staging frameworks delineate the trajectory of illness into six stages, namely pre-morbid asymptomatic risk, attenuated, sub-threshold, and/or non-specific symptoms, early stage full-threshold disorder, persistent full-threshold disorder, and severe and chronic illnesses. Clinical staging enables distinct points in the illness trajectory to be identified and targeted by stage-specific treatments that address the underlying mechanisms and maintenance factors at that point in the illness trajectory. Progression from risk to chronic illness is not inevitable, and early intervention has been put forth as a means of halting this progression (Hartmann et al., 2021). To date, a comprehensive evidence-base of randomised controlled trials (RCT) and naturalistic "real-world" effectiveness studies consistently show that EIP services are superior to TAU in terms of symptomatic and functional outcomes and healthcare utilisation and costs (Aceituno, Vera, Prina, & McCrone, 2019; Chan et al., 2015; Correll et al., 2018; Lambert et al., 2017).

The work in psychosis has provided a proof-of-concept and a springboard for more extensive youth mental health and early intervention reform (Malla et al., 2016; McGorry, 2015). Some countries have developed transdiagnostic multi-component youth mental health services, which have a broad remit including early intervention and typically provide mental health, physical health, and social care services in a single location (Hetrick et al., 2017; McGorry & Mei, 2018; Settipani et al., 2019). High-quality evidence supporting these services remains limited, but largely indicate positive outcomes in terms of reaching under-served groups, high satisfaction, and better symptomatic and functional outcomes. However, a sizeable minority (~40%) with more severe or complex issues do not improve or worsen in these entry-level services (Hetrick et al., 2017; Settipani et al., 2019). Therefore, there is still a need to develop more specialised and intensive early intervention services to support young people with more severe and complex issues (McGorry & Mei, 2018).

There has been some progress in early intervention beyond psychosis and youth mental health services, however, this remains slow and limited (McGorry, 2015). EDs have largely been overlooked in mainstream discussions around early intervention (e.g., Fusar-Poli et al., 2021; Hartmann et al., 2021). The unique features of EDs and its

treatment, i.e., the significant physical health impacts/risks, the widespread societal idealisation ("thin equals health") and prejudice (fat-shaming) towards markers of EDs, and strong ambivalence towards treatment, may have contributed to this exclusion but are precisely why a more specialised early intervention approach for EDs is needed. The disparity may also stem from the chronic under-funding of ED research and treatment (All-Party Parliamentary Group on Eating Disorders, 2021; Schmidt et al., 2016a).

1.2.3 The case for early intervention for eating disorders

Drawing on parallels between psychosis and EDs, Currin and Schmidt (2005) first made the case for early intervention in EDs over 15 years ago. The main justifications were that EDs typically emerge in a sensitive developmental period (16-25 years old), that prolonged periods of poor nutrition and stress are detrimental to physiological and neurological functioning, and evidence of the impact of illness duration on outcomes. Each of these are elaborated on in the next section as well as new evidence relating to learning and habit formation.

1.2.3.1 Erosion of psychosocial capital

Eating disorder can substantially interfere with education/work, interpersonal relationships, and daily tasks and leisure activities (American Psychiatric Association, 2013; Bardone-Cone et al., 2010; Bohn et al., 2008; Treasure, Stein, & Maguire, 2015; Welch, Birgegård, Parling, & Ghaderi, 2011). As outlined by Treasure, Stein, and Maguire (2015), EDs can lead to an erosion of social capital. Rigid rules, repetitive binge-purge episodes, intrusive negative thoughts, and starvation can consume attentional resources and cause frustration and distress amongst friends and family. All of this can lead to a highly constrained and isolated life (McKnight & Boughton, 2009; Treasure et al., 2020b). Acute EDs are also associated with a range of cognitive and social-emotional processing deficits, including difficulties with inhibitory control, working memory, decision making, and emotional expressivity and recognition (Mason, Lesser, Dolgon-Krutolow, Wonderlich, & Smith, 2021; Smith, Mason, Johnson, Lavender, & Wonderlich, 2018). Prolonged periods of untreated EDs disrupt psychosocial resources and networks both directly by limiting participation in activities and indirectly through impaired cognitive and social-emotional processing. The erosion of psychosocial capital, in turn, can further maintain the ED, resulting in a vicious cycle of disability and distress (Treasure, Stein, & Maguire, 2015).

While developing an ED at any age can be devastating, a greater degree of overall disability and psychosocial cost may accrue if the onset is earlier and during

major developmental milestones (McGorry, 2016; van Hoeken & Hoek, 2020). Adolescence and emerging adulthood, the peak risk period for the onset of EDs, is a dynamic and developmentally sensitive period. In this age range, individuals tend to develop autonomy, educational and vocational skills, social networks, relationships, and consolidate their identity and sense of self (McGorry et al., 2022; Potterton, Richards, Allen, & Schmidt, 2020b). Developing an ED and delayed access to treatment at this age may have serious and long-term consequences for well-being and life trajectories (Currin & Schmidt, 2005). A delay in or lack of access to high-quality evidence-based mental health treatment for adolescents and emerging adults has been described as a "societal disaster" (Malla et al., 2018).

1.2.3.2 Physical impact of eating disorders

The acute and long-term physical consequences of EDs are vast and often become riskier and more severe the longer the illness persists. Physical complications include but are not limited to, gastrointestinal bleeding and paralysis, electrolyte imbalances, anaemia, osteoporosis, endocrine dysregulation, diabetes, hypertension, and cardiac arrhythmias and arrest. If left untreated the physical consequences can cause severe organ dysfunction, seizures, and death. The high mortality associated with AN is partly attributed to starvation-related medical complications. The medical complications associated with BN tend to be less frequently fatal, and are typically due to purging behaviours, such as self-induced vomiting, and laxative abuse. The complications associated with BED tend to be more long-term and secondary to obesity (Mehler & Brown, 2015; Mehler & Rylander, 2015; Olguin et al., 2017; Voderholzer, Haas, Correll, & Körner, 2020). Poor nutrition, high stress, and hormonal alterations can also impact brain structure and function (King, Frank, Thompson, & Ehrlich, 2018), which is particularly concerning given the high degree of brain development that occurs during adolescence and emerging adulthood (Blakemore, 2012; Pozzi, Vijayakumar, Rakesh, & Whittle, 2021; Raznahan et al., 2011; Shaw et al., 2008). Low weight and malnutrition in AN have been directly linked to global reductions in brain volume, cortical thickness, and the integrity of white matter tracks, which largely normalise on weight restoration and recovery (Frank, 2019; King et al., 2018; King et al., 2015; Nickel et al., 2018). Binge and purge frequency have been associated with lower cortical thickness in frontal, parietal, or cingulate regions, but whether these cause, or are a consequence of the ED remains unclear (Berner et al., 2018; Marsh et al., 2015; Westwater, Seidlitz, Diederen, Fischer, & Thompson, 2018). Alterations in brain

volumes and integrity may be linked with ED-related behavioural, learning, and developmental changes (e.g., Berner et al., 2018; King et al., 2015; Marsh et al., 2015).

1.2.3.3 Duration of illness

Duration of illness has long been hypothesised as a predictor of outcomes in EDs, indirectly suggesting that intervening early may enhance treatment outcomes (Currin & Schmidt, 2005). A seminal RCT conducted in the Maudsley in the 1980s provided some of the first evidence that intervening early may be beneficial (Eisler et al., 1997; Russell, Szmukler, Dare, & Eisler, 1987). The study randomised 80 patients with AN or BN to family therapy or individual supportive therapy. The patients were stratified into four groups: "early intervention" (age of onset ≤18 years and duration of illness <3 years), "late intervention" (age of onset ≤18 years and duration of illness >3 years), "late onset" (age of onset ≥19 years), and patients with BN. The proportion of patients categorised as having "good" outcomes at 1-year were 33% in the early intervention group and 20% in the late intervention group. At 5-year follow-up, this rose to 60% in the early intervention group and 30% in the late intervention group, highlighting the potential impact of early intervention on short and long-term outcomes (Eisler et al., 1997). There is some additional evidence in support of the association between long illness durations and poor outcomes. However, findings are inconsistent and often methodologically weak (e.g., retrospective studies, small samples, drop-out rates, confounding variables) (Ambwani et al., 2020; Forman et al., 2011; Reas, Schoemaker, Zipfel, & Williamson, 2001; Reas, Williamson, Martin, & Zucker, 2000; Schoemaker, 1997; Steinhausen, 2002). A recent systematic review and meta-analysis of 31 studies found no association between duration of illness and treatment outcomes. However, the authors warn that the findings need to be interpreted cautiously given the high degree of heterogeneity and low power for subgroup analyses (Radunz, Keegan, Osenk, & Wade, 2020). Duration of illness is also a sub-optimal indirect estimate of the utility of early intervention. Many of the included participants, especially in the longer illness duration group, may have repeated failed treatment attempts, and other variables may confound any association (e.g., age).

A more appropriate and direct metric for evaluating the utility of early intervention is the duration of untreated eating disorder (DUED), i.e., the time elapsed between the onset of the ED and first initiation of evidence-based treatment. The average DUED is long, ranging from 3 years in AN to 6 years in BED (Austin et al., 2020). To put this into context, the duration of untreated psychosis (DUP) tends to

range between 0.5 to 3 years (Oliver et al., 2018). There are very few studies evaluating the impact of DUED on outcomes; Austin et al. (2020) identified only three studies in their recent review. The first was a retrospective follow-up study of 38 women treated for AN approximately 22 years earlier. Among all the predictors, DUED was the only significant predictor of remission and was able to correctly classify patients as in remission 76% of the time (Andrés-Pepiñá et al., 2019). However, caution is warranted when interpreting these findings given the small and possibly biased sample. The other two studies were cross-sectional evaluations of the impact of DUED on BMI at intake (Bühren et al., 2013; Flynn et al., unpublished). Neither study found a significant impact of DUED on BMI. These findings are consistent with research from psychosis, which demonstrates that DUP has a limited impact on baseline characteristics (i.e., only on negative symptoms and self-harm risk) but had a higher and more widespread impact on outcomes at follow-up (i.e., associated with worse positive and negative symptoms, general psychopathology, remission, overall functioning) (Howes et al., 2021). Duration of untreated illness estimates are also confounded by individuals with more severe, risky, or disruptive symptoms having accelerated access to treatment. This confound is particularly potent for intake and baseline characteristics.

1.2.3.4 Learning and habit

Learning and reinforcement-related processes have been put forth as a transdiagnostic mechanism in the development, progression, and persistence of EDs (Cardi, Leppanen, Mataix-Cols, Campbell, & Treasure, 2019; Schaefer & Steinglass, 2021; Uniacke, Timothy, Foerde, & Steinglass, 2018). According to classic learning theory, behaviours that are rewarded or reinforced (e.g., increase positive and/or reduce negative feelings or outcomes) are more likely to be repeated (Skinner, 1938). It is also hypothesised that if a behaviour is consistently reinforced over time, then the individual will develop reward expectations, which summarise past experiences and further drive and motivate behaviour (Berridge, 2000). With sufficient repetition, the behaviour eventually becomes habitual, i.e., less sensitive to outcome and more dependent on learned cues and associations. Habitual behaviour is more automatic and fixed, requiring less cognitive resources and conscious effort (Dickinson & Weiskrantz, 1985). Among individuals with EDs, this theory suggests that behavioural symptoms, such as binge eating and dietary restriction, may, at least initially, be rewarding or reinforcing (e.g., distracting from negative emotions or restriction increasing feelings of control). This leads to repetition of behaviour and, over time, the formation of expectations and habits

that are less amenable to change or responsive to outcomes. This may explain the persistence of maladaptive behaviours in chronic EDs despite extremely negative consequences. While this theory has considerable face validity in EDs, evidence thus far is preliminary or indirect (Schaefer & Steinglass, 2021). There is some evidence indicating that individuals with AN, BN, or BED may have impaired reinforcement learning (e.g., lower responsiveness to reward, reduced flexibility in altering response to outcome) (Foerde et al., 2021; Grob et al., 2012; Voon et al., 2015). Self-reported measures of eating-related habit strength have also been associated with ED symptoms, clinical impairment, and duration of illness (Coniglio et al., 2017; Davis, Walsh, Schebendach, Glasofer, & Steinglass, 2020). A proof-of-concept RCT found substantially higher improvements in habit strength, ED symptoms, and food consumption following 12-sessions of a habit-focused intervention relative to supportive psychotherapy in AN (Steinglass et al., 2018). Moreover, a food exposure intervention within an inhibitory learning framework found significant improvements in BMI, ED symptoms, anxiety, and confidence to change in individuals with AN who engaged in safety and avoidance behaviours to reduce food-related anxiety (Cardi et al., 2019). Together, these data provide support for the notion that ED-related behaviours are learnt and habitual, rather than intentional, and that over time maladaptive behaviours may become more entrenched and less amenable to change.

1.2.4 Early intervention approaches in eating disorders

The above evidence suggests that intervening early, before ED-related thinking and behaviours become embedded in the person's bio-behavioural and psychosocial routines, could result in quicker and better outcomes and limit the deleterious effects of these disorders on health and functioning. While this evidence is not without its limitations, it provides a compelling case for trialling early intervention approaches in EDs. To date, only three streams of research have evaluated early intervention initiatives in EDs: (1) the *Psychenet* Healthcare Network Campaign in Germany; (2) the First Episode Rapid Early Intervention for Eating Disorders (FREED) service model in the UK; and (3) the Emerge-ED service model in Australia. Each of these are described in turn below.

1.2.4.1 Psychenet

Psychenet is a systemic public health intervention that was designed to facilitate the early recognition and treatment of AN in Hamburg, Germany. There were five components to the intervention. First, a health literacy campaign consisting of a brief

film portraying the personal experiences of an individual with AN and an accompanying poster campaign to increase awareness and reduce stigma in the Hamburg region. Second, an internet-based ED treatment guide for individuals with EDs, their relatives, and healthcare professionals. The guide provided information on AN, BN, and BED and contact details for local ED inpatient and outpatient services. Third, the establishment of a multi-disciplinary network to connect healthcare professionals working in EDs. The network provided a space for practitioners to share scientific knowledge and clinical experiences in EDs. Fourth, the implementation of a specialised AN outpatient clinic. Lastly, the development and implementation of a large dissonance-based prevention programme for school children. During the programme, all participating adolescents and their parents received a leaflet providing information on treatment options for adolescents with EDs. A pre-post study using cross-sectional samples of female patients with AN recruited before and after the intervention demonstrated that neither the duration of untreated AN (pre = 36.5 months vs post = 40.1 months) nor the duration until first contact with a health care professional (pre = 25.0 months vs post = 32.8 months) were significantly reduced by the *Psychenet* intervention. This either suggests that this type of intervention is ineffective in reducing DUED or that there were methodological flaws that impeded the study. Indeed, the authors listed several limitations including difficulties recruiting which resulted in small and unequal sample sizes (pre, n = 59; post, n = 18), no measure of implementation, exposure, or diffusion of the intervention, and cohort effects (Gumz et al., 2014; Gumz, Weigel, Wegscheider, Romer, & Löwe, 2018).

1.2.4.2 First Episode Rapid Early Intervention for Eating Disorders

First Episode Rapid Early Intervention for EDs (FREED) is an early intervention service designed to deliver rapid, person-centred, and evidence-based treatment to emerging adults (16-25 years old) with recent-onset EDs (illness duration <3 years) (Schmidt, Brown, McClelland, Glennon, & Mountford, 2016b). The service is specifically designed to focus on *both* early-stage illness (individuals within the first 3 years of illness) and emerging adults (individuals between 16 to 25 years old). The <3-year illness duration criterion was based on evidence suggesting that EDs may be more malleable during the first 3 years of illness (Eisler et al., 1997). Emerging adulthood was specifically targeted because it is a peak risk period for the onset of EDs (Davies et al., 2021; Solmi et al., 2021a) and emerging adults have, historically, been underserved in UK ED services (alongside other adults with EDs). In 2016, the UK government set

new wait time standards and provided investment for child and adolescent ED services. The aim of this investment was to improve rapid access to evidence-based ED treatments for individuals <18 years old (NHS England, 2015). Adult services did not receive comparable investment at the time and remain substantially under-funded relative to demand (Viljoen et al., 2022). The decision to limit FREED to the 16- to 25-year old age group (rather than all adults with early-stage EDs) was partially pragmatic, i.e., limited resources targeted at the peak age of onset within adult services (Brown et al., 2018). It also allowed the service to be tailored to the developmental needs of emerging adults. If early intervention services were to be developed for adults above the age of 25, the unique needs of this age group would need to be considered. Services are encouraged to use their clinical judgement when assessing eligibility for FREED. Specifically, if an individual is slightly above or below the criteria but would benefit from an early intervention approach then FREED should be considered.

First Episode Rapid Early Intervention for EDs was developed and piloted at the South London and Maudsley Hospital in 2014 and has since been scaled to over 60% of all eligible ED services in the National Health Service (NHS) in England. It is also running in an adapted form in Australia (see Emerge-ED section below). FREED drew on key ideas and principles from early intervention in psychosis (EIP) and the youth mental health reform in Australia (Brown et al., 2018; McGorry, Goldstone, Parker, Rickwood, & Hickie, 2014; Schmidt et al., 2016b). Specifically, FREED is based on a clinical staging framework, has the central aim of reducing DUED, and provides holistic, proactive, and optimistic evidence-based treatment (Brown et al., 2018).

First Episode Rapid Early Intervention for EDs operates as a dedicated early intervention service integrated into an existing evidence-based ED service (i.e., ‘service-within-a-service’ or ‘specialist-within-generalist’ model). A sub-group of ED clinicians within the service, referred to as the FREED mini team, allocate part of their case load/time to FREED. The mini team and FREED service are overseen and managed by a FREED Champion. FREED consists of a service model and care package, which are presented in Figure 1. The service model includes wait time targets of 2-weeks for assessment and 4-weeks for treatment, a 48-hour engagement call to triage and engage young people and their families as soon as possible, and a patient-tracker (an Excel spreadsheet) to monitor and manage patient throughput. Other core components of the service model include brief weekly FREED ‘huddle’ meetings and monthly FREED-specific clinical supervision. The care package involves adapting the

outreach/engagement, assessment, and evidence-based ED treatments to emerging adults in early-stage illness. The adaptations include active and flexible engagement, an emphasis on early change and the importance of early intervention, social media and health-related app use, age-appropriate family and significant other involvement, early psychoeducation on EDs, and attention to transitions and the developmental tasks of emerging adulthood (e.g., identity development, dealing with instability, focusing on broader life goals). Alongside these adaptations, clinicians are encouraged to adopt an optimistic, collaborative, and motivational stance, and where appropriate, to be flexible and creative in their work (Allen et al., 2020; Brown et al., 2018; Schmidt et al., 2016b).

There have been two key evaluations of FREED to date. A single-site pilot study to evaluate the feasibility, acceptability, and effectiveness of the model and a multi-site FREED-Upscaled (FREED-Up) study to evaluate the replication of effects at other sites and centres (Austin et al., 2021b; Brown et al., 2018; Flynn et al., 2020; McClelland et al., 2018). The pilot and multi-site studies were quasi-experimental pre-post designs comparing FREED patients (Pilot n = 56; FREED-Up n = 278) to a historical TAU control group (Pilot n = 86; FREED-Up n = 224). The TAU group were patients seen in the services in the 1.5-2 years before FREED was introduced. The FREED-Up study took place across four urban and rural ED services in England. Compared to TAU, FREED was associated with clinically and statistically significant reductions in the wait for assessment and treatment, DUED, and the need for more intensive treatment (in-patient/day patient), and improved treatment uptake. The reduced need for intensive treatment also resulted in considerable cost savings. There was no difference in the number of treatment sessions, treatment completion, and duration until first contact with services (Austin et al., 2021b; Brown et al., 2018; Flynn et al., 2020; McClelland et al., 2018). FREED patients experienced significant improvements in ED symptoms, BMI, general psychopathology (e.g., mood, distress), and psychosocial functioning over time. Substantially more FREED patients with AN (Pilot: 59%; FREED-Up: 53%) were weight recovered (BMI >18.5kg/m^2) at 12-months compared to TAU (Pilot: 17%; FREED-Up: 18%) (Austin et al., 2021b; McClelland et al., 2018). An electronic case record evaluation of FREED pilot study patients with AN found that the advantages in terms of less intensive treatment and higher BMI/weight recovery were maintained at a 24-month follow-up (Fukutomi et al., 2020). The degree of improvement in wait times, DUED, uptake, and clinical outcomes were comparable in the pilot and FREED-Up studies. Qualitative data collected during the FREED-Up study support the quantitative

results. Most participants receiving FREED treatment reported positive psychological and behavioural changes and found the following features of FREED treatment beneficial: rapid access to treatment, knowledgeable and skilled clinicians, and the focus on life beyond the ED, building support networks, and becoming their own therapist (Potterton et al., 2021).

Altogether, these findings demonstrate that FREED is feasible (reduces waits and DUED), acceptable (increases treatment uptake), and effective (improves outcomes) and can be successfully scaled to different sites and settings. Given these positive findings, FREED has since moved into its next phase of implementation, referred to as FREED-4-All. The aim of this phase is to continue to scale FREED nationally and internationally to reach as many young people as possible, and for FREED to become standard practice in ED services. Evaluation remains central to this scaling, especially research focusing on implementation processes and factors that may facilitate or hinder its use, and examining whether FREED continues to be feasible and effective as it is scaled to more diverse settings (Allen et al., 2020). The continued evaluation of FREED during the initial and national scaling is the central focus of this thesis.

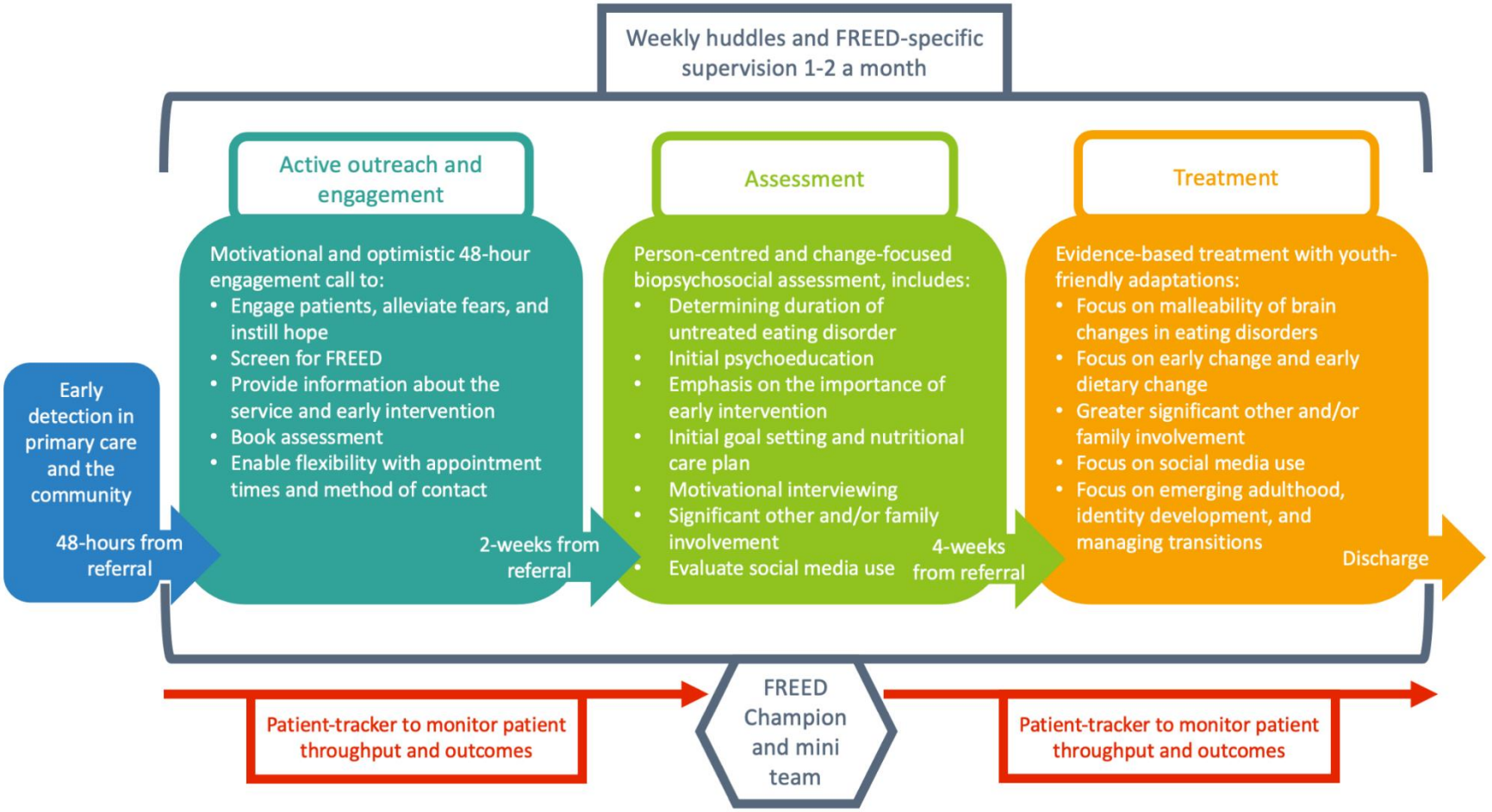

Figure 1. First Episode Rapid Early Intervention for Eating Disorders service model and care package. FREED = First Episode Rapid Early Intervention for Eating Disorders.

1.2.4.3 Emerge-ED

Emerge-ED is a primary care based early intervention service informed by the FREED model. The service currently operates in two headspace centres (youth primary mental health services) in South Australia. The Emerge-ED service focuses on rapid engagement (assessment in approximately 3-weeks) and person-centred treatment tailored to the illness stage with an emphasis on family and social support, psychoeducation, and nutrition management. Inclusion criteria for the service are being aged 16–25 with a DUED of less than 3 years, a BMI >14.5, and no previous evidence-based ED treatment. A case series of Emerge-ED found significant reductions in self-reported ED symptoms, depression, anxiety, stress, and psychosocial impairment over time. The effect size for the reduction of ED symptoms over time (*Cohen*'s $d = 2.05$) was comparable to other ED effectiveness studies and the UK Improving Access to Psychological Therapies (IAPT) programme. However, caution is needed when extrapolating these results as there was a high degree of missing data at the end of treatment (~30% completed) (Radunz, Pritchard, Steen, Williamson, & Wade, 2021). Following this initial positive evaluation, there are now ambitions to further scale the model to more headspace centres across Australia (Allison et al., 2021).

1.3 Implementation: Translating evidence into clinical practice

The phrase that business challenges are 5% strategy and 95% execution (implementation) is also highly applicable to healthcare (De Silva & Ryan, 2016). Determining the effectiveness of a new intervention is typically not sufficient to ensure widespread uptake and use in routine practice. Active dissemination and implementation efforts are needed (Bauer & Kirchner, 2020). Dissemination involves actively promoting research findings and knowledge amongst relevant stakeholders, and implementation involves mobilising human, material, and contextual resources to use and integrate a new practice (Clarke et al., 2013; Nilsen, 2015). Successfully implementing and scaling healthcare innovations and consequently enabling real improvements in population health is a lengthy and complicated process (Greenhalgh & Papoutsi, 2019). Healthcare systems are a mass of siloed and interdependent ecosystems, each with their own climate, infrastructure, and bureaucracy. Insufficient resources, competing priorities, and external social and political pressures further complicate the process and create tensions within and between these systems. Healthcare is a complex social system characterised by embedded uncertainty and unpredictability (Braithwaite, Churruca, Long, Ellis, & Herkes, 2018). Given these

challenges, interventions that demonstrate robust effects in clinical trials consistently fail to replicate outcomes or achieve widespread use within healthcare (Greenhalgh & Papoutsi, 2019; Horton, Illingworth, & Warburton, 2018).

The chasm between what we know is effective in research and what is implemented in clinical practice has long been recognised as an issue in EDs (Kazdin, Fitzsimmons-Craft, & Wilfley, 2017; Lilienfeld et al., 2013; Mussell et al., 2000). Surveys indicate that between 6 to 60% of ED clinicians routinely use evidence-based treatments or manuals, and even when clinicians claim to be delivering evidence-based treatments, adherence to core components of these treatments can be low to moderate (Kosmerly, Waller, & Robinson, 2015; Mulkens, de Vos, de Graaff, & Waller, 2018; Tobin, Banker, Weisberg, & Bowers, 2007; Wallace & von Ranson, 2011; Waller, Stringer, & Meyer, 2012; Wisniewski, Hernandez Hernandez, & Waller, 2018). For example, only 10% of clinicians reported using four key features of CBT for EDs (CBT-ED) with 90-100% of their patients (i.e., food diaries, cognitive restructuring, exposure, and structured eating) (Mulkens et al., 2018). Encouragingly, more recent studies demonstrate higher estimates of evidence-based treatment and manual use, possibly due to increased training and focus on evidence-based practice in recent years.

A variety of modifiable factors, including beliefs, knowledge, and emotions, have been implicated in the uptake and successful implementation of evidence-based practice in EDs (Waller & Turner, 2016). Training, or lack thereof, is frequently cited as a reason for using or not using evidence-based ED treatments. However, even with training, use and adherence can be low, suggesting that training in isolation does not guarantee optimal use (Couturier et al., 2013; Mussell et al., 2000; Simmons, Milnes, & Anderson, 2008; von Ranson & Robinson, 2006; von Ranson, Wallace, & Stevenson, 2013). Clinician anxiety can also hinder the use of evidence-based practices due to low confidence, intimidation, or concerns about negatively impacting the therapeutic alliance (Couturier et al., 2013; Mulkens et al., 2018; Turner, Tatham, Lant, Mountford, & Waller, 2014; Waller et al., 2012; Waller & Turner, 2016). Clinician beliefs and attitudes are a key driver in the use of evidence-based treatments (Waller & Turner, 2016). When belief in the importance of evidence-based ED treatment manuals is low, so too is the use of the manuals (Tobin et al., 2007). Perceiving a practice as evidence-based can also increase its use, sometimes to a lesser extent than other beliefs, such as, beliefs about effectiveness from clinical experience and perceived compatibility with theoretical orientation and style (Mussell et al., 2000; Simmons et al., 2008; von Ranson

& Robinson, 2006; von Ranson et al., 2013; Wallace & von Ranson, 2012). Concerns about the rigidity and generalisability of evidence-based treatments to the complexities of routine clinical practice is another widely endorsed reason for not or sub-optimally using evidence-based approaches in EDs (Haas & Clopton, 2003; Simmons et al., 2008; von Ranson et al., 2013). This is by no means an exhaustive list of all factors that can facilitate or hinder the use of evidence-based practices in EDs, but it highlights the importance of evaluating implementation to effectively translate clinical research into routine practice. Much of this research has also progressed without reference to the field of implementation science or formal theory (however, there are notable exceptions, e.g., Couturier et al., 2013; Oswald, Boswell, Smith, Thompson-Brenner, & Brooks, 2019). FREED is at a critical stage in its implementation as it moves from the confines of a limited number of innovator sites to widespread whole system adoption and scaling. Evaluating the implementation of FREED is therefore of paramount importance.

1.3.1 Implementation science and theories

Implementation science is a relatively new field that emerged out of the need for a systematic and evidence-based approach for navigating the complexities of healthcare delivery and understanding how and why implementation succeeds or fails. The core aim of implementation science is to maximise the successful translation of clinical research into routine practice and therefore improve quality and outcomes in healthcare (Bauer & Kirchner, 2020; Eccles & Mittman, 2006; Nilsen, 2015). Implementation science is less concerned with the health impact of an intervention and more focused on identifying implementation barriers and facilitators, as well as strategies to maximise successful implementation (Bauer & Kirchner, 2020). While the problems of implementation are not new, the recent unification of approaches under the umbrella of implementation science is an important step towards enabling a comprehensive, consistent, and rigorous evidence-base to guide implementation projects and evaluation. To date, there has been limited use of implementation science in EDs.

Central to implementation science are implementation theories, models, and frameworks (TMFs). TMFs provide a robust set of evidence-based and generalisable tools to structure, prompt, and frame implementation research (Damschroder, 2020). Implementation research without reference to formal theory has been described as “an expensive version of trial-and-error” (Eccles, Grimshaw, Walker, Johnston, & Pitts, 2005). The complexity and transdisciplinary nature of implementation science has led to an extensive catalogue of TMFs (Birken et al., 2018; Nilsen, 2015). Selecting the

appropriate TMF has almost become as complex as the process of implementation itself. Typically, there is no single "correct" or "right" TMF, and researchers and practitioners must carefully assess the fit of the TMF to the implementation project and aims. TMFs often overlap but provide different lenses through which to plan, understand, and evaluate implementation (Birken et al., 2018). Three key TMFs were chosen to guide the focus, design, and analysis of the studies in this thesis: (1) RE-AIM (Reach, Effectiveness/Efficacy, Adoption, Implementation, and Maintenance), (2) Theory of Planned Behaviour (TPB), and (3) Normalisation Process Theory (NPT). These TMFs were selected because of their analytical level and aim (i.e., evaluating population impact and individual attitudes and agency), widespread use, and empirical support. Each are described in turn in the next section.

1.3.1.1 Impact: RE-AIM framework

The RE-AIM (Reach, Efficacy/Effectiveness, Adoption, Implementation, and Maintenance) framework is one of the most widely used frameworks for planning and evaluating implementation across a range of clinical, community, and corporate settings (Glasgow et al., 2019). The framework was borne out of the desire to address the disproportionate focus on internal relative to external validity and to increase the translatability and population-based impact of scientific findings. The framework outlines five dimensions that dynamically interact to determine the broad and equitable population-based impact of a new evidence-based initiative, program, or policy. The initial aim of the framework was to increase the assessment and reporting of these dimensions (Glasgow, Vogt, & Boles, 1999; Glasgow et al., 2019). The five dimensions and their accompanying implementation strategy for FREED are outlined in Table 1. Specific implementation strategies, such as building adopter commitment and capability, are required to support the successful uptake and spread of new interventions (Horton et al., 2018). The implementation strategies for FREED were developed using the RE-AIM framework (Allen et al., 2020). Numerous studies demonstrate the usefulness of RE-AIM in supporting implementation endeavours and encouraging implementers to consider equitable reach to the target population, establishing effectiveness on important outcomes (e.g., quality of life, economic), wide adoption in diverse settings, consistent implementation at an appropriate cost, and sustained use across different settings (Balis, Strayer, Ramalingam, & Harden, 2018; Gaglio, Shoup, & Glasgow, 2013; Gaglio, Phillips, Heurtin-Roberts, Sanchez, & Glasgow, 2014;

Glasgow & Estabrooks, 2018; Glasgow et al., 2019). The RE-AIM framework is used in Chapters 2, 3, and 4 of this thesis.

Table 1. RE-AIM dimensions and the corresponding FREED implementation strategies (adapted from Allen et al., 2020).

RE-AIM dimension	FREED implementation strategy
Reach: The absolute number, proportion, and representativeness of the individuals willing to engage with and targeted by the service, i.e., who is the target audience and how are we reaching them?	- Key target audiences were identified (e.g., patients, families, GPs, commissioners) and materials, such as summaries of evidence and impact, were developed and tailored to each target audience, including both quantitative data and real-life stories. - Information on the FREED website (www.freedfromed.co.uk), including freely available online training modules and psychoeducation materials. - Traditional publications (e.g., blogs, news articles) and social media (e.g., Facebook, Twitter, and Instagram) used to disseminate key messages and engage stakeholders. - Establishing a "FREED Network" to facilitate communication and collaboration between all services using the FREED model, and scaling across regions. - Lived experience involvement via co-creation, and input on FREED initiatives, implementation, materials and resources, social media, and real-life stories ("FREEDom Finders"). - FREED-specific events and presentations at professional conferences, events, and seminars. - Publication of research articles and inclusion in position statements and clinical guidelines.

Effectiveness: The impact of the service on important outcomes, i.e., how do we know that FREED is effective?	- Formal effectiveness studies incorporating quantitative and qualitative data have been conducted from the outset. - Ongoing evaluation was built into the operational processes of the model. FREED sites share a core set of de-identified data every quarter that contributes to a national FREED data set.
Adoption: The absolute number, proportion, and representativeness of the settings and intervention agents (clinicians delivering the service) willing to adopt the service, i.e., how do we develop intervention agent and organisational support to deliver FREED?	- FREED readiness and equivalence assessments: an evaluation of pre-existing service characteristics and compatibility with FREED service model (e.g., evidence-based, existing service processes, enthusiasm for change), additional preparation may be needed for some sites. - Extensive stakeholder engagement and relationship building activities to develop buy-in at all levels, including service users, providers, commissioners, community stakeholders, and senior executives. Including specific efforts to develop a sense of ownership, service user involvement at all stages, and involving all stakeholders in strategic decisions. - FREED-specific implementation materials, such as a FREED business case, data collection templates and agreements, and a Champion Pack. - One-to-one implementation support from SLaM and AHSNs. - Shared regional learning and local peer leadership, e.g., FREED Champion regional leads supporting neighbouring ED services.

Implementation: The implementation fidelity, adaptations, and time and cost of delivery, i.e., how do we ensure that FREED is delivered properly?	- A clear training package: (1) Online training platform: initial orientation to the FREED service model, evidence, and principles. (2) Single-day in-person/virtual training delivered by the FREED team at SLaM. The training consists of presentations, concrete examples of how to apply FREED principles and processes, interactive polls/activities, role-playing, and group discussions. (3) Train-the-trainer approach, whereby trained FREED Champions and leads continue ongoing training and support locally. - Ongoing implementation support and monthly peer implementation supervision for FREED Champions. - Enthusiastic FREED Champion responsible for managing and championing the pathway. - Internal FREED-specific supervision. - FREED-specific guides, materials, resources, and videos to support implementation. - The FREED Network and regional peer support networks and collaboratives to facilitate communication, collaboration, and shared learning. - A ‘hard core, soft periphery’ approach: adherence to the core components of the model while also enabling a degree of adaptability to local pressures and needs to maximise the acceptability and fit of the model locally. - Quarterly data summary reports regarding individual site and entire Network performance.

Maintenance: The extent to which an intervention is sustained and/or becomes institutionalised and part of routine practice, i.e., how can FREED become standard practice and for it to be delivered in the long-term?	- Buy-in at all levels and the whole team supporting FREED. - Enthusiastic FREED Champion with "can do" attitude. - Continued engagement, cross-site learning, and collaboration through the FREED Network, FREED events and media, supervision, and data sharing and feedback. - Developing a shared sense of ownership through collaboration, shared learning, involvement in decisions, and capacity to adapt FREED. Train-the-trainer model and FREED Champion role also contribute towards model ownership.

Note. FREED = First Episode Rapid Early Intervention for Eating Disorders; ED = eating disorder; SLaM = South London and Maudsley; AHSN = Academic Health Science Network.

1.3.1.2 Attitudes: Theory of Planned Behaviour

Psychological theories of human behaviour place beliefs and attitudes at the heart of why people act the way they do. Attitudes refer to the degree to which a person holds negative and/or positive evaluations of an object, concept, or behaviour (Ajzen, Fishbein, Lohmann, & Albarracín, 2018). In implementation science specifically, attitudes have been defined as a favourable or unfavourable pre-disposition towards an evidence-based practice due to beliefs about the advantages and disadvantages of implementing it (Fishman, Yang, & Mandell, 2021). The pioneering and widely tested Theory of Planned Behaviour (TPB) hypothesised that beliefs about the consequences of behaviour, perceived social norms, and beliefs about capabilities to perform the behaviour predicts behaviours through the mediating role of intentions. Intentions represent the subjective likelihood that the person will perform the behaviour (Ajzen et al., 2018). Substantial evidence indicates that these beliefs and behavioural intentions can account for approximately 14-35% of the variance in behaviour across a wide range of different behaviours and contexts. The relative influence of different types of beliefs and predictiveness varies by behaviour and context (Armitage & Conner, 2001; Godin, Bélanger-Gravel, Eccles, & Grimshaw, 2008; McEachan, Conner, Taylor, & Lawton,

2011). It is evident from these findings and other research from implementation science that beliefs and attitudes have a considerable and decisive impact on one's actions (Fishman et al., 2021). It is consequently important to have a good grounding on what people think about early intervention for EDs and FREED, especially the opinions of those that are required to change their behaviours to deliver the intervention. Opposition to an evidence-based practice is a widely recognised barrier to implementation, which requires specific intervention (e.g., Case 1 in Braithwaite et al., 2018). Therefore, attitudes and other beliefs towards early intervention for EDs and FREED were investigated in Chapters 5 and 6 of this thesis.

1.3.1.3 Agency: Normalisation Process Theory

Implementing, embedding, and integrating a new evidence-based practice requires people to work individually and collectively to operationalise and enact them. 'Work' here is defined as goal-directed social actions that involve the investment of individual and group resources. The Normalisation Process Theory (NPT) is primarily concerned with this 'work' and expressions of agency, i.e., focusing on what people must do to embed and integrate (i.e., normalise) a new intervention into the everyday routines of clinical practice. NPT operationalises this work through four generative mechanisms: coherence, cognitive participation, collective action, and reflexive monitoring (May & Finch, 2009). These mechanisms are defined in Table 2, alongside example questions that were used to facilitate the application of the NPT in Chapter 5 of this thesis. The content of the table was drafted with reference to the NPT website (www.normalizationprocess.org) and key NPT publications (Bracher & May, 2019; Clarke et al., 2013; Finch et al., 2018; May & Finch, 2009; Murray et al., 2010; Rapley et al., 2018). These underlying mechanisms interact with each other and the context in a non-linear and dynamic way to support or hinder the integration of a new practice into clinical settings (May, 2013; May, Johnson, & Finch, 2016). In the NPT, implementation is understood as an emergent process where continuous individual and collective investment is required to sustain the integration of the practice in the social context (Bracher & May, 2019; May & Finch, 2009). NPT was developed iteratively over nine years using empirical generalisations, formal theory-building, "road-testing", and discussions and seminars. Compared to other TMFs, NPT has the added advantage of being derived specifically from implementation studies (May et al., 2009). A large and growing body of literature demonstrates NPT's utility as an analytical tool to identify mechanisms that shape the delivery of complex health interventions as well as

selecting interventions to address barriers (May et al., 2009; May et al., 2018; McEvoy et al., 2014). Interestingly, a systematic review of professional behaviour change interventions in healthcare (e.g., audit/feedback, reminders, educational materials) found that more effective interventions tended to address a greater number of NPT constructs, especially collective action and reflexive monitoring. Less effective interventions tended to emphasise only coherence or early cognitive participation (Johnson & May, 2015). The NPT was used to structure the study design and data analysis in Chapter 5.

Table 2. Definitions and example questions for the Normalisation Process Theory generative mechanisms.

Construct	Definition	Example Questions
Coherence	The sense-making work that people do individually and collectively when defining and operationalising a set of practices. Specifically, ideas about the meaning, uses, and utility of the practice which hold it together.	- How does the practice compare to what already happens? How is it different? - Is there a shared understanding of the aims, purpose, and benefits of the practice? - How is the practice and the specific tasks and responsibilities for the practice understood by individuals? - How is the value, benefits, and importance of the practice understood?
Cognitive Participation	The relational work that people do to create and sustain engagement and a community of practice	- Are there people working to drive the practice forward? - How do people come to take part or become

	around new intervention or way of working.	enrolled in the practice? - What work is done to ensure people believe that it is right for them to be involved? - What work keeps people motivated to continue taking part?
Collective Action	The mental and material work that people do to enact a set of practices, involves individual and collective purposive action, allocation of resources and training, and reshaping and reorganising behaviours, relationships, and contexts.	- How compatible is it with existing practices and context? - Does it disrupt existing relations and practices? - How do people work with each other and elements of the practice to make it work? - How is confidence and accountability developed and maintained around the practice? - Is work assigned to those that have the training and skills to implement it? - How will the work, responsibilities, and resources around a set of practices be divided amongst the team?

		- Are sufficient resources allocated and protocols and procedures developed to enact the set of practices?
Reflexive Monitoring	The individual and communal appraisal work that people do to assess and understand the impact, utility, and effectiveness of the new set of practices.	- How do people systematically gather evidence to appraise the practice? - How do people formally or informally evaluate a practice? - Do people reconfigure the practice in light of this appraisal?

1.4 Overview of thesis

In summary, eating disorders are serious psychiatric illnesses that typically emerge in adolescence and young adulthood with long term implications for health, psychosocial functioning, and quality of life. Even with significant progress in ED treatments over the last few decades, outcomes for many remain poor. As outlined in Section 1.2, there is a strong rationale and preliminary evidence suggesting that early intervention could potentially increase the effectiveness of evidence-based treatments and improve outcomes in EDs. However, much of the evidence to date has been generated during funded research studies at a small number of innovator sites and with limited attention towards implementation, including key factors that can facilitate or hinder implementation and effectiveness in routine clinical practice. Importantly, routine clinical practice is where an intervention has its true impact on population health. As outlined in Section 1.3, interventions are not always implemented as intended and/or can fail to replicate desired effects when they move from funded research studies into everyday use in clinical practice. The continued evaluation of an intervention over time as it evolves and is implemented in different and more diverse clinical settings is therefore of paramount importance. The effective translation and scalability of an

intervention can also critically depend upon its feasibility and fidelity (how easy and well it is implemented), provider and recipient attitudes and acceptability, and other key contextual factors that can enable or impede its implementation (Klaic et al., 2022). The overarching aim of this thesis was to continue to evaluate early intervention in EDs and FREED as it transitions from small scale piloting into widespread use in routine clinical practice, with particular attention to implementation and key factors impacting implementation. The specific aims of this thesis were to: (1) evaluate the implementation (e.g., fidelity, processes and feasibility) and effectiveness of FREED during initial and national scaling in England, and (2) evaluate barriers and facilitators to this implementation, scaling, and effectiveness, especially attitudes towards early intervention and FREED. The focus was on developing pragmatic knowledge to inform implementation and scaling. Implementation theories, model, and frameworks (TMF) were drawn upon to inform and frame this research.

This thesis consists of eight chapters, including the current chapter. The current chapter (Chapter 1) provides a general introduction to EDs and their treatment, the rationale for early intervention in EDs, and an overview of implementation science, and TMFs used throughout this thesis. Chapter 8 provides an overview of the main findings of this thesis in relation to the thesis aims, clinical implications and future research directions, and overall conclusions. Below, I provide a brief overview of the rationale and content of each results chapter (i.e., Chapter 2-7) and how they link together.

In the first section of this thesis (i.e., Chapters 2 and 3), a scoping review of the literature on early intervention services for non-psychotic mental health disorders (including EDs) was conducted. Despite the intuitive appeal of early intervention, the evidence in non-psychotic disorders is limited, although growing, and segregated into disciplinary silos. Drawing this research field together and providing a baseline characterisation of the structure, implementation, and effectiveness of early intervention services may facilitate cross-disciplinary learning, identify gaps in the literature, and inform future evaluations and directions. A scoping review was therefore conducted to map the extent, range, and nature of the literature on early intervention services in non-psychotic mental health disorders as well as the structure, implementation and effectiveness of these services. This baseline characterisation provided foundational knowledge of the structure and implementation of early intervention services, which informed thinking in subsequent chapters of this thesis. The protocol for this review is outlined in Chapter 2. The protocol was published to enhance the transparency of the

research process, prevent any unnecessary duplication, and to obtain peer feedback on the proposed method. The review itself is presented in Chapter 3. The RE-AIM implementation framework was used to evaluate the external validity of the studies included in the review.

Investigations of implementation alongside comparative effectiveness and effectiveness in different centres are central for understanding whether, how, why and under what conditions early intervention services work. Consequently, in subsequent chapters of this thesis, some of the implementation-based knowledge gaps identified in the scoping review were addressed. This type of implementation research is particularly important for FREED given where it is in its implementation journey (i.e., that it has undergone pilot and initial scaling evaluations and the next phase of implementation [FREED-4-All] is focused on continuing to scale the model nationally and internationally (Allen et al., 2020)). As outlined in Section 1.3, making the leap from small scale piloting to widespread uptake and use is notoriously difficult. A recent review of reviews found that only 9% of healthcare interventions were successfully scaled to other populations or settings and 4% resulted in sustained changes in practice (Klaic et al., 2022). An important starting point in evaluating and/or supporting the implementation and scalability of FREED is to know how well the model was implemented (implementation fidelity) during the initial scaling.

In Chapter 4, implementation fidelity to core components of the FREED model during the initial scaling (i.e., across four sites in the FREED-Up study) was therefore evaluated. Specifically, adherence to the FREED wait time targets and the use of the FREED care package were examined. This chapter builds upon the already published work from the multi-site FREED-Up study by assessing model *fidelity* in this study. The impact of FREED on DUED, wait times, and clinical outcomes during FREED-Up have been reported elsewhere (Austin et al., 2021b; Flynn et al., 2020). Assessing implementation fidelity and adherence during this initial scaling is important to ensure that the model is implemented as intended at the outset and is feasible at sites beyond the originating centre. From this study, we can begin to understand what features of FREED were implemented well, what may need to be modified, and/or where more attention is needed in terms of training and support. It also provides some insights into the importance (or not) of these core model components, i.e., if adherence and/or use is high then these components may be contributing to the positive outcomes reported in Austin et al., (2021b) and Flynn et al., (2020).

As outlined in Section 1.3, several potentially modifiable facilitative and hindering factors, such as provider and recipient attitudes, can have a large impact on how well an intervention is implemented and replicated in routine clinical practice (e.g., Damschroder et al., 2009a; Fishman et al., 2021; Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou, 2004; Klaic et al., 2022). Chapter 5 builds upon Chapter 4 by providing much greater depth to our understanding on how FREED is implemented and factors that may facilitate or hinder this implementation in routine settings. An understanding of these facilitative or hindering factors can support the development of implementation strategies aimed at addressing barriers and maximising the reach and effectiveness of the intervention (Powell et al., 2017). Moreover, evaluating the attitudes of ED clinicians and individuals with lived experience of an ED is important to ensure that the intervention and how it is being implemented aligns with the values and preferences of those most directly affected by it. The individual attitudes and experiences of patients receiving FREED treatment have been evaluated and reported previously and were therefore not explored in this thesis (Potterton et al., 2021). Chapter 5 involves an in-depth evaluation of the attitudes towards and experiences of clinicians working directly with and implementing FREED with a particular focus on implementation processes and barriers and facilitators to implementation. The study used semi-structured interviews to investigate individual attitudes and experiences of early adopters using the model across eight diverse FREED sites (e.g., rural and city-based ED services, all-age and adult services). This study was conducted after the FREED-Up research study had finished. During this phase, new teams were adopting FREED and existing teams were trying to embed FREED as part of routine clinical practice. Given the analytical level of the study (i.e., at the individual clinician level), the Normalisation Process Theory was used as a sensitising and analytical theory to examine the ‘work’ people engaged in to enact, integrate, and embed FREED.

Given the prominent role of clinician attitudes and enthusiasm in the implementation of FREED in Chapter 5, in the next chapter (Chapter 6) I further extended this work by evaluating the broader collective attitudes on the relative importance of early intervention compared to other prioritisation factors (e.g., age, diagnosis, medical risk) in ED services. Participants in Chapter 5 were all early adopters of FREED and directly involved in delivering the service, which could have positively biased attitudes in the study. Chapter 6 builds on Chapter 5 by including the opinions of clinicians and individuals with lived experience of an ED who may or may not have had

direct experience of early intervention or FREED, so therefore provide a wider perspective on attitudes towards early intervention. Chapter 6 also quantitatively evaluated the relative importance of factors used to prioritise patients in ED services, including early intervention. Evaluating the opinions of the broader community (i.e., those not directly involved in delivering and receiving FREED) and the relative importance of early intervention compared to other prioritisation factors is particularly important given the limited resources available to ED services. Those not directly involved in delivering and receiving FREED could be impacted by and/or impact the implementation of the model. Indeed, many implementation TMFs, including the Consolidated Framework for Implementation Research (Damschroder et al., 2009a) and the Non-adoption, Abandonment, Scale-up, Spread, and Sustainability framework (Greenhalgh et al., 2017), highlight the role of the social context both within and outside of the implementing organisation for implementation success (Klaic et al., 2022). A Delphi method was used in Chapter 6 to evaluate the broader collective attitudes and degree of consensus (agreement/disagreement) among clinicians and individuals with lived experience of an ED towards priority setting factors in ED services, including the importance of early intervention relative to other prioritisation factors. Chapters 4-6 provide important contextual information (e.g., acceptability, challenges and facilitators for implementation) for the final results chapter of this thesis, which evaluated the implementation and effectiveness of FREED at national scale.

The primary aim of Chapter 7 was to evaluate whether the implementation and effectiveness of FREED in the earlier FREED-Up study (including the results in Chapter 4) were replicating in different and diverse ED services (n = 30) across England during national scaling (FREED-4-All). It is critical to evaluate whether findings of earlier research studies are indeed replicating in routine and diverse clinical settings, otherwise valuable and limited healthcare resources, time and efforts could be wasted. Many interventions and new evidence-based practices can fail to replicate at scale. Unfortunately, due to data quality issues with the FREED national data set (e.g., limited data for these items), it was not possible to include the standard treatment comparator ("non-FREED") group or evaluate the use of the care package in Chapter 7. Given issues with data quality, especially with clinical outcomes, the findings of Chapter 7 should be treated as preliminary and used alongside other evidence and information on the scaling and implementation of FREED.

Chapter 2. Early intervention service for non-psychotic disorders: A scoping review protocol

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A copy of the article is provided in Appendix A. The formatting of this article has been amended here for stylistic consistency. The body of the text remains largely unchanged, except further details on the definition of early intervention used within the review have been added to the chapter.

Author contributions: The candidate (Katie Richards) was responsible for the conception and design of the study and drafted the manuscript. Amelia Austin, Dr Karina Allen, and Professor Ulrike Schmidt contributed towards the conception and design of the study and read and substantially revised the manuscript. Constructive feedback was received from peer reviewers at *BMJ Open* and the manuscript altered accordingly.

2.1 Abstract

Introduction: Worldwide mental health disorders are associated with a considerable amount of human suffering, disability, and mortality. Yet, the provision of rapid evidence-based care to mitigate the human and economic costs of these disorders is limited. The greatest progress in developing and delivering early intervention services has occurred within psychosis. There is now growing support for and calls to extend such approaches to other diagnostic groups. The aim of this scoping review is to systematically map the emerging literature on early intervention services for non-psychotic mental health disorders, with a focus on outlining how services are structured, implemented and scaled.

Methods and analysis: The protocol was developed using the guidance for scoping reviews in the Joanna Briggs Institute manual and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews checklist. A systematic search for published and unpublished literature will be conducted using the following databases: (1) MEDLINE, (2) PsycINFO, (3) HMIC, (4) EMBASE and (5) ProQuest. To be included, documents must describe and/or evaluate an early intervention service for adolescents or adults with a non-psychotic mental health disorder. There will be no restrictions on publication type, study design and date. Title and abstract, and full-text screening will be completed by one reviewer, with a proportion of articles screened in duplicate. Data analysis will primarily involve a qualitatively summary of the early intervention literature, the characteristics of early intervention services and key findings relating to their evaluation and implementation.

Ethics and dissemination: The synthesis of published and unpublished articles will not require ethical approval. The results of this scoping review will be published in a peer-reviewed journal and disseminated via social media, conference presentations and other knowledge translation activities.

2.2 Article summary

Strengths and limitations of this study:

- This scoping review will provide a comprehensive overview of both published and unpublished literature for the emerging research field of early intervention services for non-psychotic mental health disorders.
- The review will be conducted according to the standardised methodology outlined in the Joanna Briggs Institute manual and using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses checklist for scoping reviews.
- Part of the screening and charting process will be completed in duplicate to ensure reliability of these methods.
- Only articles written in English, German, French and Spanish will be included, the review may, therefore, be biased.

2.3 Introduction

Early intervention is widely perceived as beneficial in medicine and typically refers to the early detection and initiation of stage-specific treatment (McGorry, 2008). As outlined in Chapter 1 (section 1.2.1), in this thesis early intervention is defined as providing treatment as early as possible for individuals with recent-onset subthreshold or threshold disorders. Pro-active early treatments matched to the stage of illness can limit or even avert unfavourable outcomes, reducing the need for costly and more invasive treatments in the future (Gillies et al., 2007; Shah et al., 2016). Despite such promise, early intervention approaches have been slow to gain momentum in mental health (McGorry & Mei, 2018; McGorry, Ratheesh, & O'Donoghue, 2018b). Mental illnesses are a major contributor to mortality and disability worldwide, particularly for young people (Patel, Flisher, Hetrick, & McGorry, 2007; Rehm & Shield, 2019; Vigo, Thornicroft, & Atun, 2016). The typical age of onset for mental disorders is adolescence and early adulthood (12-30 years old), a period of marked social, psychological, and biological change (de Girolamo, McGorry, & Sartorius, 2019; Kessler et al., 2007). A delay in or lack of access to effective treatments during this time could disrupt key developmental milestones and have long-lasting effects on health, social, and occupational trajectories (Malla et al., 2018).

Service provision does not match the topography of onset or burden of disease associated with mental disorders, even in relatively well-developed health systems (Vigo, Kestel, Pendakur, Thornicroft, & Atun, 2019). Globally, access to evidence-based care is poor, and even for those that do access it, this is often after lengthy delays (de Girolamo, Dagani, Purcell, Cocchi, & McGorry, 2012; McGorry, 2015; Patel et al., 2018). The duration of untreated illness (DUI), defined as the period between the onset of psychiatric disorder and the initiation of treatment, ranges from 1-2 years for psychosis to 10 years for obsessive-compulsive disorder (OCD) (Albert et al., 2019; Altamura, Buoli, Albano, & Dell'Osso, 2010a; Dagani et al., 2016; Marshall et al., 2005). Over time, mental disorders can become more entrenched through functional deterioration, neuroadaptation, and habitual behaviour patterns (Anderson, Voineskos, Mulsant, George, & McKenzie, 2014; Currin & Schmidt, 2005; Fineberg et al., 2019; Schaffalitzky et al., 2015). Indeed, a longer DUI is associated with worse symptomatic and functional outcomes, and a lower treatment response across diagnostic groups (Altamura et al., 2008; Altamura et al., 2010b; Drancourt et al., 2013; Ghio et al., 2015a Marshall et al., 2005). More worryingly, young people, the group at highest risk for

psychiatric difficulties, tend to have the worst access to timely care (Burgess et al., 2009; Cleary, Nixon, & Fitzgerald, 2007; Dagani et al., 2016; de Girolamo et al., 2012; Weigel et al., 2014).

Together, such findings provide a compelling case for establishing early intervention services that match the developmental needs and symptomatic profile of individuals with recent-onset mental disorders (McGorry, 2015; McGorry & Mei, 2018). The greatest strides in early intervention have been made within psychosis. Over the past 30 years, early intervention in psychosis (EIP) has gained tremendous support from researchers and healthcare professionals worldwide (McGorry, 2015). EIP services have two fundamental aims: to reduce the duration of untreated psychosis, and to provide evidence-based, stage-specific treatment (McGorry et al., 1996). EIP services use a clinical staging approach to map the extent of illness progression from early pre-symptomatic risk to severe and enduring, enabling a prevention orientated framework that matches the intensity of treatment to the level of need (Cross & Hickie, 2017; McGorry, Hickie, Yung, Pantelis, & Jackson, 2006). A comprehensive body of high-quality research now shows that compared to standard care, multi-component EIP services are associated with a reduction in symptom severity, relapse rates and hospitalisation risk, as well as improved global functioning and quality of life (Correll et al., 2018). Moreover, consistent evidence suggests that EIP services are a cost-effective alternative to standard care (Aceituno et al., 2019). There has been a recent surge in papers calling for early intervention approaches to be broadened to other diagnostic groups, including major depression (Davey & McGorry, 2019), OCD (Fineberg et al., 2019), eating disorders (Schmidt et al., 2016b), and bipolar disorder (Vieta et al., 2018). Preliminary evidence from services for recent-onset eating and mood disorders demonstrate significant improvements in symptoms, reduced hospital (re)admissions, and most importantly, high levels of patient satisfaction (Brown et al., 2018; Kessing et al., 2013; McClelland et al., 2018; Osuch et al., 2019).

The utility of focusing exclusively on discrete diagnostic categories in the delivery of early intervention specifically, and mental health care more generally has, however, been questioned (Cross & Hickie, 2017; McGorry et al., 2018b). The early stages of mental disorder are often characterised by fluctuating patterns of specific and non-specific subthreshold symptoms, diagnostic instability, and comorbidity (Iorfino et al., 2019; McGorry, Hartmann, Spooner, & Nelson, 2018a). A single-disorder focus could result in these earlier presentations of illness being excluded (Cross et al., 2014).

A transdiagnostic approach, consistent with evidence for pluripotent models of clinical staging, has been put forward as a necessary solution to address this problem (Cross & Hickie, 2017; Scott et al., 2013; McGorry & Nelson, 2016; McGorry et al., 2018b). The recognition of the need to broaden the early intervention paradigm has led to the development of several integrated youth mental health hubs (Hetrick et al., 2017; Lee & Murphy, 2013). These hubs act as entry-level services for young people irrespective of diagnosis, and typically provide a comprehensive package of low-intensity mental, physical, and social care support in community settings. Young people tend to rate these services positively and between 52-68% of young people experience improvements in symptoms and functioning. However, a proportion of individuals with more severe symptoms do not seem to benefit from these services and rigorous outcome research for youth hubs is limited (Hetrick et al., 2017; Settipani et al., 2019).

Although the role of early intervention in reducing distress and functional impairment seems obvious, the evidence-base for these services is incomplete and much more work needs to be done (Fineberg et al., 2019; McGorry, 2015). There is limited prospective evidence evaluating the utility of these services for non-psychotic disorders, it is unclear to what extent the findings from psychosis would translate to other diagnostic groups. There is also a lack of research evaluating the feasibility or the implementation of services in clinical settings (Settipani et al., 2019). Moreover, even within psychosis, further research is needed to determine how long EIP services should be provided, whether it is the reduction in DUI or other components of EIP services that account for the improved outcomes, and whether outcomes would be similar with other service structures and models (Behan, Masterson, & Clarke, 2017; Fusar-Poli, McGorry, & Kane, 2017). An ever-growing population accompanied by reducing health budgets, creates an environment where only services that demonstrate effectiveness, economic viability and sustainability receive funding (Stuckler, Reeves, Loopstra, Karanikolos, & McKee, 2017). It is therefore imperative to develop a rigorous evidence-base to refine, adapt and evaluate early intervention services for non-psychotic disorders, with a particular focus on identifying the “active ingredients” of such services and the most effective methods for widespread scaling and implementation.

The primary objective of this review is to provide a baseline characterisation of the differing ways in which early intervention services are structured and implemented for non-psychotic mental health disorders. The emerging literature for non-psychotic disorders are heterogenous and dispersed, with distinct streams of research developing

in disciplinary silos. The aim of this review is to draw together these streams to facilitate collaboration and cross-disciplinary learning and discourse. By synthesising the field and highlighting commonalities and differences, we hope that a broad set of common principles for early intervention services will emerge. This review, in conjunction with reviews in psychosis, will help set the stage for a more unified approach to expanding and refining early intervention services for psychiatric disorders. Here, we focus exclusively on disorders that tend to emerge in adolescence and adulthood rather than in childhood. Neurodevelopmental disorders typically use a very different approach to early intervention than adolescent- and adult-onset disorders (e.g. intervening in infancy) (Cioni, Inguaggiato, & Sgandurra, 2016). A scoping review methodology was selected for this review as early intervention is an emerging, dispersed and heterogenous research area and is therefore not amenable to the narrower aims of a traditional systematic review (Peters et al., 2015; Tricco et al., 2018a). Given that this is a relatively new research area, we sought to map all the available evidence within this field rather than only the best available evidence (e.g. randomised controlled trials) (Murray et al., 2016).

2.4 Research questions

1. What is the extent, range, and nature of the literature on early intervention services for adolescents and adults with non-psychotic mental health disorders?
2. What are the characteristics of early intervention services and care pathways?
    a. Are there any similarities and/or differences across early intervention services provided for each diagnosis and transdiagnostically?
3. Are there any factors that influence the implementation of early intervention services (i.e., implementation processes, and barriers and facilitators to implementation)?
4. Do early intervention services reduce DUI, improve the course and outcome of mental disorders, or minimise the disruption to psychosocial development and function?

2.5 Methods and analysis

The Preferred Reporting Items for Systematic Reviews and Meta-analyses extension for Scoping Reviews (PRISMA-ScR) checklist (Tricco et al., 2018a), and the scoping review framework outlined in the Joanna Briggs Institute (JBI) Reviewer's Manual (Peters et al., 2017) were used to guide the development of this protocol. A copy of the PRISMA-ScR checklist can be seen in Table 3.

Table 3. PRISMA extension for scoping reviews checklist.

Section	Item	PRISMA-ScR Checklist Item
Title		
Title	1	Identify the report as a scoping review.
Abstract		
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.
Introduction		
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.
Methods		
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.

Section	Item	PRISMA-ScR Checklist Item
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.
Results		
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).

Section	Item	PRISMA-ScR Checklist Item
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.
Discussion		
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.
Limitations	20	Discuss the limitations of the scoping review process.
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.
Funding		
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.

Note. JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be

used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

2.5.1 Eligibility criteria

Documents will be included if they: (1) describe and/or evaluate an early intervention service for non-psychotic mental health disorders (*concept*) based in any type of healthcare facility (i.e., hospitals, day services, and community settings) and in any geographic area (*context*). Here, early intervention refers to a structured programme of care delivered by a stand-alone team or teams integrated into mental health services that provide treatment for individuals with recent-onset subthreshold or threshold disorders. The service will be required to target recent-onset subthreshold or threshold disorders. The level of care can vary from low-intensity techniques of signposting, psychoeducation, and self-help resources all the way through to specialised multi-disciplinary teams and complex high intensity interventions; (2) describe and/or evaluate an early intervention service for adolescents (≥10-17 years) or adults (≥18 years) with a recent-onset subthreshold or threshold mood disorder, anxiety disorder, eating disorder, personality disorder, impulse control or substance use disorder, and/or somatoform disorder (*types of participants*). Transdiagnostic early intervention services and early intervention services for comorbid/concurrent disorders will be included provided that at least one of the diagnoses is listed in the previous sentence; (3) mixed child and adolescent services will be included, where feasible, only information relevant for the adolescent portion of the services will be charted, and (4) all document types and study designs are eligible for inclusion: randomised controlled trials, non-randomised studies, observational studies, qualitative studies, reviews, ongoing trials, protocols, theoretical papers, grey literature, editorials, opinions pieces, and expert consensus statements (*types of studies*).

Documents will be excluded if they: (1) Describe a primary prevention programme based in educational establishments, high-risk groups (e.g. athletes), or in the general population; (2) Describe a parent only intervention; (3) Describe a specific intervention (e.g. type of CBT) that is not attached to a service; (4) Primarily or only focus on early intervention for a physiological or medical condition, schizophrenia spectrum and other psychotic disorders, and/or neurodevelopmental disorders; and (5) services that merely label themselves as early intervention or refer to themselves as early intervention because they target children and young people but are, in practice, not specifically for individuals with recent-onset mental health disorders will not be included.

2.5.2 Search strategy

A comprehensive literature search will be conducted from inception on PsycINFO, MEDLINE, EMBASE, and HMIC. ProQuest databases will also be searched for grey literature (i.e., conference papers and proceedings, theses, government publications). The search will be completed in three stages. First, an initial limited search was conducted in MEDLINE using the terms "early intervention" and "mood disorder" or "anxiety disorder" or "eating disorder" or "personality disorder" or "impulse control disorder" or "substance use disorder" or "somatoform disorder". The initial limited search was conducted by KR in April 2019 to identify keywords and subject headings to generate a search strategy. Different combinations of keywords and subject headings were trialled in MEDLINE, and key papers from the early intervention field were used as indicators for the sensitivity of the search strategy. The preliminary search strategy was developed by KR and reviewed by AA, KA, and US. An iterative process was used to balance the sensitivity and specificity. The MEDLINE-specific search strategy returns 3,545 documents before de-duplication and is outlined in Table 4.

In the second stage, all databases will be searched using the MEDLINE search strategy. The search strategy will be tailored to each database. The search for scoping reviews are more iterative than systematic reviews, it is therefore feasible that as the reviewers become more familiar with the literature that additional search terms and sources may be identified. The final stage involves identifying additional articles by searching the reference lists of included articles. Studies not reported in English, German, French, and Spanish will be excluded from the review during the screening and eligibility assessment. No date limits will be applied to the search. References will be imported to the EndNote x8 reference manager.

Table 4. MEDLINE search strategy.

	Query	Results
#1	exp Early Medical Intervention [MeSH term]/ or (early intervention* or early-intervention*).tw	19623
#2	exp Mood Disorders [MeSH term]/ or Bipolar Disorders [MeSH term]/ or (mood disorder* or affective disorder* or depressi* or dysthymi* or bipolar*).tw	453041
#3	#1 AND #2	1616

#4	exp Anxiety Disorders [MeSH term]/ or (anxiety disorder* or neurotic disorder* or agoraphobi* or obsessive-compulsive disorder* or OCD or panic disorder* or phobic disorder* or post-traumatic stress disorder* or post traumatic stress disorder* or PTSD or generalised anxiety disorder* or social phobia).tw	119604
#5	#1 AND #4	560
#6	exp "Feeding and Eating Disorders" [MeSH term]/ or (eating disorder* or anorexi* or bulimi* or binge-eating* or binge eating* or (eating disorder not otherwise specified) or EDNOS or (other specified feeding or eating disorder) or OSFED).tw	56480
#7	#1 AND #6	199
#8	exp Substance-Related Disorders [MeSH term]/ or exp "Disruptive, Impulse Control, and Conduct Disorders" [MeSH term]/ or (((substance-related or alcohol or opioid or morphine or marijuana or heroin or cocaine or amphetamine or cannabis) adj1 (disorder* or illness* or dependence or abuse or misuse)) or (impulse control disorder*) or conduct disorder* or fire setting behaviour* or gambling or trichotillomania).tw	295108
#9	#1 AND #8	924
#10	exp Somatoform Disorders [MeSH term]/ or (somatoform or somatoform disorder* or somati#ation or body dysmorphi* or conversion disorder* or hypochondri*).tw	25487
#11	#1 AND #10	38
#12	exp Personality Disorders [MeSH terms]/ or (personality disorder* or antisocial personality disorder* or anti-social personality disorder* or borderline personality disorder* or emotionally unstable personality disorder* or obsessive-compulsive personality disorder* or dependent personality disorder* or histrionic personality disorder* or narcissistic personality disorder* or avoidant personality disorder* or paranoid personality disorder* or schizoid personality disorder* OR schizotypal personality disorder*).tw	47019
#13	#1 AND #12	208

2.5.3 Study selection process

The title and abstract screening in the second stage of the search will be completed by one reviewer with a portion of the articles being screened in duplicate to ensure reliability (25%). Retrieved full-texts will also be screened by one reviewer with a sample of full-text documents (25%) being screened in duplicate for reliability. The eligibility criteria will be applied to each document on a case-by-case basis to determine eligibility for inclusion. Discrepancies between reviewers will be resolved by discussion, and if necessary, other members of the review team will be consulted.

2.5.4 Data items and charting

A standardised data charting form developed by the study team will be used to chart the data from eligible studies (see Table 5 for a description of each data item). The data charting form was developed using the template from the JBI manual and by drawing on recent reviews of youth service models (Hetrick et al., 2017; Settipani et al., 2019). Each section of the data charting form was developed to address one of the four research questions. The 'Document Details' section which provides descriptive information on document type, author(s), publication date, title and aim/purpose of document will be used to evaluate the extent, nature, and range of the literature on early intervention services (question 1). The second section 'Characteristics of Early Intervention Service' will address the second question as key characteristics of the services, namely the population, setting, structure, and interventions used in early intervention services will be charted (question 2). The 'Outcome Research' section will be used to answer questions 3 and 4 as any data related to implementation, effectiveness, or efficacy will be charted (question 3 & 4). Similar to the full-text screening, one reviewer will chart the majority of the documents with only a portion (25%) of the documents being charted in duplicate to ensure reliability. A small selection of documents will be charted by both reviewers at the outset to ensure that there is clarity and consistency in the use of the data charting form. Where there is more than one paper on the same service model, information will be pooled across the papers to provide the most detailed description of the model and any available evidence.

Table 5. Draft data charting form.

Data Item	Description of Item
Document Details	

Type of document	The type of document can include but will not be limited to published or unpublish primary research, any type of review, protocols, theoretical paper, guidelines, opinion pieces, editorials, and expert consensus papers.
Author(s)	List of authors
Year of publication	Year of publication
Title	Title of document
Journal	The title of the scientific journal (for published documents only)
Country of origin	Country where the document originates
Aim/purpose of document	Summary of the aim/purpose of the document
Study design	For published or unpublished research papers, the design of the study as reported in the paper. Includes but is not limited to randomised controlled trials, pre-post design, historical controlled trial, prospective or retrospective cohort studies, cross-sectional, and case series/study.
Study methodology	The methodological framework: qualitative, quantitative, or mixed methods.
Characteristics of Early Intervention Service	
Name of service	The name of the early intervention service/program.

Year established	The year the early intervention service was established.
Location	The country and region in which the early intervention service was implemented.
Population	The population for which the service was designed for. This item will include details such as age, diagnosis, duration of illness, and illness severity.
Setting	The physical setting in which the early intervention service is based. This includes but is not limited to community centres, primary care, outpatient clinics, and inpatient wards. Early intervention services can occupy more than one of these settings.
Service providers	A description of who provides the service and their role, includes but is not limited to social workers, youth workers, peer support workers, nurses, clinical or counselling psychologists, and psychiatrists.
Service structure/process	A description of the service structure and administrative processes includes but is not limited to ‘service within a service’ models, stand-alone multi-disciplinary team models, ‘hub’ and ‘spoke’ models, and process variables such as specific wait time targets.

Access to service	Methods for accessing the early intervention service, includes but is not limited to active engagement and outreach through schools, colleges and youth clubs, referral from primary care, self-referral, and drop-in.
Services and interventions	A description of the types of services and interventions provided, includes but is not limited to psychoeducation, online self-help and self-management support, psychological therapies (e.g., CBT, brief therapy), sexual health and family planning, health promotion, social services, peer support, and crisis intervention and management.
Clinical staging	Whether a clinical staging approach was used to inform the design, evaluation, or implementation of the service.
Outcome Research	
Participants	Details related to the participants included in the study. This will include information related to sample size, diagnosis, age, sex, and inclusion/exclusion criteria.
Comparator data or standard care	Description of comparator data or the care provided to a control group.

Outcomes and time-points	Description of the qualitative and quantitative outcomes and the time points of data collection. This will include standardised clinical assessments, and self-report measures as well as implementation outcomes, such as measures of acceptability, feasibility, adoption, fidelity, and sustainment.
Key results/findings	An outline of the key results and findings reported in the document. This includes quantitative outcomes such as changes in symptoms, engagement, and patient satisfaction, as well as qualitative outcomes, such as, descriptions of barriers and facilitators to implementation.

2.5.5 Critical appraisal

The lack of critical appraisal tools in scoping reviews has been highlighted as one of the primary limitations of this knowledge synthesis method (Pham et al., 2014). Critical appraisal can facilitate the interpretation of reviews by identifying the relative strengths and weaknesses of the included articles and identifying gaps in the research field. However, formal evaluations of methodological quality for scoping reviews can be challenging given the diversity of study designs and the volume of included literature (Levac, Colquhoun, & O'Brien, 2010). Given the range of study designs, a two-stage assessment of methodological quality will be conducted for this review. First, each study will be ranked using the JBI Levels of Evidence for Effectiveness from high (Level 1) to low (Level 5) (Level 1 – Experimental Designs; Level 2 – Quasi-experimental Designs; Level 3 – Observational - Analytical; Level 4 – Observational - Descriptive; Level 5 – Expert Opinion and Bench Research) (Jordan, Lockwood, Munn,

& Aromataris, 2019). Once stratified according to the level of evidence, the quality of the studies within each stratum will be evaluated using the JBI Critical Appraisal tools (Joanna Briggs Institute, 2017). Additionally, the generalisability and real-world applicability (external validity) of the included studies will be evaluated against the domains of the RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance) framework. A modified version of a RE-AIM framework rating system developed by Gaglio and colleagues will be used in the current study (Gaglio et al., 2014). The modified rating system can be seen in Table 6. Each document will be given a rating ranging from 1 (limited generalisability or no information) to 3 (generalisable/pragmatic or information to enable generalisation) on six key domains: Participant Representativeness, Setting Representativeness, Outcome Representativeness, Fidelity/Adaptation, Cost/Feasibility of Intervention, and Sustainment. A narrative summary of the methodological quality will be provided alongside quantitative values for each domain of the RE-AIM framework. A portion of the included articles will be appraised in duplicate.

2.5.6 Synthesis of results

The search results will be reported using a flow diagram to clearly detail the review decision process, indicating the number of citations screened, duplicates removed, study selection, and full texts retrieved. The characteristics of the included studies will be presented in an informative table with a narrative and quantitative (e.g., frequencies) summary in text. Figures will be used to display the distribution of documents over time and across diagnoses. Descriptions of the early intervention services will be reported for each diagnostic group and transdiagnostically along with any evidence supporting the services and barriers and facilitators to implementation. An aggregated summary of early intervention services with descriptions of common themes and differences across the services will be provided. An effort will be made to identify gaps in knowledge to inform the direction of future research.

2.5.7 Patient and public involvement

No patients or public were involved in the development of this protocol.

2.6 Ethics and dissemination

This review contributes to the growing body of research for early intervention initiatives in mental health by mapping the existing literature on early intervention services for non-psychotic mental health disorders. Through the publication of the results and dissemination via social media and conference presentations, the results will hopefully

provide a timely foundation for cross-disciplinary discourse and early intervention service development and research. The results of this review may inform the design of new services and policies to support them. The synthesis of existing knowledge will not require ethical approval.

Table 6. Summary of Reach, Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) framework criteria.

Reach (Participant Representativeness)	The representativeness of individuals enrolled in the study to the characteristics of the intended population. 1 = Limited generalisability: highly selected subsample that is not typical of the intended population, high number of exclusionary criteria, and/or a recruitment strategy that is likely to result in a biased sample. 2 = Moderately generalisable: participants match intended population on key characteristics (e.g., sex/gender, diagnosis, age), but are still a selected subsample due to exclusion criteria and recruitment strategies. 3 = Generalisable: participants are typical of the intended population, limited or no exclusion criteria, and/or recruitment strategies is not selective and are unlikely to result in a biased sample.
Effectiveness (Outcome Representativeness)	Measured outcomes are important and meaningful to all stakeholders involved, including potential negative effects, quality of life, and economic outcomes. 1 = Limited generalisability: primary outcomes restricted to an estimate of the overall effect of the intervention on a single metric of health, limited attention to process outcomes, quality of life, patient and staff satisfaction, patient engagement, unintended harms, or functional rehabilitation. 2 = Moderate generalisability: primary outcomes focus on overall effect of intervention on health, some inclusion of measures that are meaningful to stakeholders or process outcomes. 3 = Generalisable outcomes: primary outcomes include mix of impact of intervention on health and outcomes that are meaningful to patients and other stakeholders (including qualitative evaluations), explicit discussion around prevention of harms to participants, process outcomes, patient engagement, acceptability, and satisfaction.

Adoption (Setting Representativeness)	The representativeness of settings and the individuals within those settings who deliver the program. 1 = Limited generalisability: highly selected settings and staff and/or only includes 'best' sites and staff, i.e., well-resourced, credentialed, or seasoned interventionists, many exclusion criteria; or limited information to determine context of study or intervention. 2 = Moderate generalisability: intervention tested in contexts outside of 'best' sites and staff, but adoption is still limited to selected settings that are well-resourced with some expertise in intervention trials. 3 = Generalisable: sites and staff are randomly selected, few or no exclusion criteria, and/or trialled in diverse settings.
Implementation (Fidelity/Adaptation, & Cost/Feasibility)	Fidelity to the intervention and adaptations made to intervention during study/program. 1 = Limited information on the implementation: no details on adaptation to local context, no details related to core element of interventions, or an evaluation of the consistency of implementation across settings, staff, and patients. 2 = Moderate reporting of fidelity/adaptations: core elements described but details missing, or fidelity was monitored but no details on measurement tools. 3 = Detailed report of modifications made, adaptations to local context, and rationale for modification, an outline of core elements and evaluation of the fidelity to core elements of the model.
	The cost of the intervention in terms of time and money. 1 = No details on time, cost, and resources, no efforts to contain costs, and use of state-of-the-art resources and procedures such that costs of intervention are likely to be high.

	2 = Details on time, cost, and resources is still limited but more than for a rating of 1. The intervention has minimal impact on time, cost, and resources. 3 = Explicit efforts to contain costs and to make the intervention feasible in low resource settings.
Maintenance (Sustainment)	The extent to which an intervention becomes institutionalized or part of the routine organizational practices and policies and the extent to which behaviour is sustained for more than 6 months. 1 = Limited sustainability efforts or details of such efforts: no report of efforts to continue an intervention after the completion of study, or no reports of continued use. 2 = Moderate sustainment: limited discussion regarding the sustainability of an intervention, some evidence of continued use. 3 = Sustainment: long-term outcomes reported, explicit plans for handing off intervention to setting/sites, details of methods to encourage sustainable implementation or embedding within routine organisational practices and policies, or evidence of sustained use for 6 months or more.

Chapter 3. Early intervention service for non-psychotic disorders: A scoping review

Author contributions: The candidate (Katie Richards), Amelia Austin, Dr Karina Allen, and Professor Ulrike Schmidt were responsible for the conception and design of the study. The candidate conducted the systematic literature search, the de-duplication, and title and abstract and full-text screening. Amelia Austin and Luiza Grycuk screened 25% of the titles and abstracts and full-text documents in duplicate. The candidate charted and critically appraised all included documents. Amelia Austin critically appraised 25% of the articles in duplicate. The chapter was drafted by the candidate. The chapter was reviewed by Amelia Austin, Dr Karina Allen, and Professor Ulrike Schmidt who provided constructive feedback and suggested amendments.

3.1 Abstract

Background: Rapid access to evidence-based treatment can minimise the adverse effects of mental health disorders on health, well-being, and psychosocial functioning. However, until relatively recently the development and delivery of early intervention services in mental health was largely confined to psychosis. There is now an emerging but fragmented literature extending and adapting such approaches to other diagnostic groups. The aim of this scoping review was to bring together the literature on early intervention services for non-psychotic mental health disorders and examine the characteristics, implementation, and effectiveness of these services.

Method: This review was conducted in accordance with the guidance for scoping reviews in the Joanna Briggs Institute (JBI) manual and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR) checklist. A systematic search for published and grey literature was conducted using MEDLINE, EMBASE, PsychInfo, HMIC, CENTRAL, ProQuest, and Web of Science databases. Included documents described and/or evaluated an early intervention service for adolescents or adults with non-psychotic mental health disorders. There were no restrictions on publication type, study design, geographic location, and date. Title and abstract, and full-text screening, data charting, and critical appraisal were completed by one reviewer, with 25% of articles screened, verified, and appraised in duplicate.

Results: The search and screening yielded 66 eligible documents. The documents described and/or evaluated 22 different early intervention services for trauma and stress-related (n = 5), mood (n = 3), personality (n = 3), perinatal (n = 3), substance use (n = 2), eating (n = 2), and anxiety (n = 1) disorders. The remaining three services were transdiagnostic. Most services targeted peak risk periods for the onset of mental health disorders, actively increased treatment accessibility and engagement, and were multidisciplinary teams (MDTs) providing pharmacological and psychosocial interventions. The services were associated with significant improvements over time, but comparative data and information on implementation fidelity and cost were limited.

Conclusion: Commonalities in the structure, implementation, and effectiveness of early intervention services for non-psychotic disorders were identified. However, there was variation in precisely how these commonalities were operationalised for each service.

Future efforts should focus on rigorous evaluations of effectiveness, implementation, and cost with comparative data and in a range of different contexts and settings.

3.2 Introduction

Mental health disorders are typically understood as maladaptive patterns of thinking, coping, and behaviours that commonly emerge in early life (most before 35 years old) and have long-lasting effects on health and psychosocial functioning (American Psychiatric Association, 2013; Solmi et al., 2021a). Mental health disorders exceed many communicable and non-communicable diseases in terms of burden and disability, especially for young people, and carry enormous economic and social costs (GBD 2019 Mental Disorders Collaborators, 2022; Trautmann, Rehm, & Wittchen, 2016). Despite the development of effective evidence-based interventions, the burden and disability associated with mental health disorders has remained relatively stable, if not, increased, since 1990, suggesting limited population-level impact of interventions (GBD 2019 Mental Disorders Collaborators, 2022; Jorm, Patten, Brugha, & Mojtabai, 2017).

While access to mental health treatment varies across countries, many with diagnosable disorders do not receive adequate treatment or do so only after years of symptoms and distress (Jorm et al., 2017). For example, the duration of an untreated illness (DUI) for binge eating disorder (BED), obsessive-compulsive disorder (OCD), and bipolar disorder range between 6-9 years (Austin et al., 2020; Albert et al., 2019; Brakoulias, Pineda, & Fimmano, 2021; Dagani et al., 2016). By the time treatment is received, maladaptive thinking and behaviours are already neuro-behaviourally entrenched, which may reduce the overall effectiveness of treatments and the likelihood of long-term remission and recovery (Andrés-Pepiñá et al., 2019; Fico et al., 2021; Ghio, Gotelli, Marcenaro, Amore, & Natta, 2014; Howes et al., 2021; Perris et al., 2021). Moreover, the longer someone experiences symptoms the higher the disruption to everyday life, developmental trajectories, and personally meaningful endeavours. There is consequently a pressing need to develop, co-ordinate, and implement more effective methods of distributing evidence-based treatments earlier.

In the field of psychosis, there have been huge efforts to implement and evaluate early intervention services to rapidly deliver evidence-based treatment to individuals with early-stage psychosis. Early intervention in psychosis (EIP) is based on a clinical staging framework, where the symptoms and dysfunction of patients with early presentations are differentiated from individuals with longer term more chronic illnesses. EIP services typically operate as stand-alone MDTs providing case management and interventions addressing psychiatric symptoms, functional recovery,

and physical health. Family member involvement is also encouraged. Assertive outreach in the community and the patient's home and actively promoting engagement are core features of EIP services. Another characteristic element of EIP is community awareness raising and education of stakeholders in the healthcare system and other relevant organisations and services. The services are usually targeted at individuals with an illness duration of less than 3 years and between 12-35 years old, which is a peak risk period for the onset of psychosis. However, recently some services have expanded their age range all the way to 65 years old (Csillag et al., 2018).

Consistent evidence demonstrates that in the short and medium term EIP services are superior to treatment as usual (TAU) at improving access and engagement, symptom severity, psychosocial functioning, quality of life, and relapse (Bird et al., 2010; Correll et al., 2018). Despite the initial up-front costs of developing EIP, evidence shows that EIP services are cost-effective relative to standard treatment (Aceituno et al., 2019). These findings have led to the widespread proliferation of EIP services internationally. However, some uncertainties remain. Evidence of the long-term benefits are inconsistent; some studies show that prior gains can be lost at 5 and 10 years (Bertelsen et al., 2008; Gafoor et al., 2010; Secher et al., 2014). Many EIP services provide treatment for 2-3 years but there is still uncertainty regarding the optimal duration and intensity of treatment (Albert et al., 2017 Malla et al., 2017). Moreover, most of the efficacy and cost-effectiveness evidence are based on the stand-alone MDT model, which may not be appropriate or feasible in low resource or rural and remote contexts. Alternative service models include 'hub and spoke' and 'specialist-within-generalist' or integrated EIP services. Some preliminary evidence suggests that these models are superior to TAU but inferior to the stand-alone MDT model (Behan et al., 2017).

The success in psychosis has led to tremendous interest in establishing specialised early intervention services in other areas of mental health. There is a growing and promising literature on early intervention services in non-psychotic mental health disorders, including eating (Schmidt et al., 2016b), mood (Osuch et al., 2019), and personality disorders (Chanen et al., 2009b). While many of these services have drawn on the work in psychosis, others have not (e.g., Zatzick et al., 2011). The unique characteristics of each diagnostic group and the clinical context in which treatment is provided may lead to different variants of early intervention, and alternative service

formats and structures. It is also unclear whether the benefits of early intervention are universally applicable, especially given that the pathophysiology and prognosis for many mental health disorders are somewhat uncertain (Fusar-Poli et al., 2021; Malhi et al., 2021). Research in trauma and stress-related disorders suggests that providing something early is not always better than nothing. Certain types of single-session interventions provided immediately following traumatic event are at best ineffective and at worst harmful (Bisson, 2014; Rose, Bisson, Churchill, & Wessely, 2002). The effectiveness, feasibility, and costs need to be carefully considered before scarce and limited resources can be re-orientated towards early intervention. Many questions remain on the best way to implement and integrate early intervention services in mental health, even within the well-developed field of psychosis.

The primary goal of this review was to provide a comprehensive characterisation of the differing ways in which early intervention services have been structured, implemented, and evaluated in non-psychotic mental health disorders. Currently, these parallel streams of research are fragmented and dispersed into diagnostic silos. Synthesising this research can facilitate cross-disciplinary learning and discourse and, alongside reviews in psychosis, can enable a more unified approach to specialist early intervention services. Innovations in transdiagnostic youth mental health services have emerged across the world. While these services are an important component of early intervention, their aims are much broader and evidence suggests that they lack the capacity and skillset to treat individuals with more complex presentations (McGorry et al., 2022; Settipani et al., 2019). Higher-level specialised early intervention services are therefore needed. By distilling the commonalities and differences in structure, implementation, and effectiveness of these services, we can evaluate the feasibility of developing closely networked and/or transdiagnostic services. A scoping review methodology was adopted for this study because the aim was to identify all available literature in an emerging and heterogeneous research area. The objectives of this review were broad and therefore not amenable to the narrower focus of traditional systematic reviews (Peters et al., 2020).

3.3 Research questions

The following questions were addressed in the review:

1. What is the extent, range, and nature of the literature on early intervention services for adolescents and adults with non-psychotic mental health disorders?
2. What are the characteristics of early intervention services and care pathways?
    a. Are there any similarities and/or differences across early intervention services provided for each diagnosis and transdiagnostically?
3. Are there any factors that influence the implementation of early intervention services (i.e., implementation processes, and barriers and facilitators to implementation)?
4. Do early intervention services reduce DUI, improve the course and outcome of mental disorders, or minimise the disruption to psychosocial development and function?

3.4 Methods

This review was designed and conducted in accordance with the standardised methodology in the JBI manual and PRISMA-ScR checklist (Peters et al., 2017; Tricco et al., 2018a). Since the methods for this review are outlined in the previous chapter, they are only described briefly below alongside any protocol deviations. Deviations, modifications, and additions to the review method since the protocol was published are highlighted in bold. It is important to note that in the most recent iteration of the JBI manual (Peters et al., 2020), it states that if authors are addressing single or precise questions regarding the feasibility, appropriateness, meaningfulness, or effectiveness of certain interventions, then systematic reviews are likely the most valid approach. While questions related to effectiveness have been addressed in previous scoping reviews (e.g., Aceituno et al., 2021; Settipani et al., 2019; Tricco et al., 2018b), questions of effectiveness are generally more appropriately addressed using systematic reviews. However, given the emerging and heterogeneous nature of this evidence and the broader scope of inclusion criteria for question 4 (e.g., the "open" population, intervention, and types of outcomes measured), this question should be considered as providing a preliminary overview of the evidence from which more precise systematic review questions can be developed. Systematic reviews typically answer specific effectiveness questions based on precise PICO (Population, Intervention, Comparator, and Outcomes) inclusion criteria (Peters et al., 2017; Peters et al., 2020).

3.4.1 Eligibility criteria

The eligibility criteria were modified and expanded upon during the screening process. Modifications/additions were agreed upon through consensus discussions with the review authors. The following inclusion and exclusion criteria were used, and any modifications/additions are highlighted in bold:

Inclusion criteria:

1. *Concept*: Describe and/or evaluate an early intervention service for non-psychotic mental health disorders. Here, an early intervention service refers to a structured programme of care delivered by a stand-alone team or teams integrated into **another** service that provide treatment for individuals with recent-onset subthreshold or threshold disorders. **The service was required to target recent-onset subthreshold or threshold disorders**. The level of care can vary from low-intensity techniques of signposting, psychoeducation, and self-help resources all the way through to specialised multi-disciplinary teams and complex high intensity interventions.
2. *Context*: The early intervention service can be based in any type of healthcare facility (i.e., hospitals, day services, and community settings) and in any geographic area.
3. *Types of participants*: Describe and/or evaluate an early intervention service for adolescents (≥10-17 years) or adults (≥18 years) with a recent-onset subthreshold or threshold mood disorders, anxiety disorders, eating disorders, personality disorders, impulse control or substance use disorders, somatoform disorders, **trauma and stress-related disorders** and/or **perinatal mental health disorders**. Transdiagnostic early intervention services and early intervention services for comorbid/concurrent disorders were included provided that at least one of the diagnoses is listed in the previous sentence. Mixed child and adolescent services were included, where feasible, only information relevant for the adolescent portion of the services were charted.
4. Types of studies: All document types and study designs were eligible for inclusion: randomised controlled trials, non-randomised studies, observational studies, qualitative studies, reviews, ongoing trials, protocols, theoretical papers, grey literature, editorials, opinions pieces, and expert consensus statements.

Exclusion criteria:

1. Describe a primary prevention programme based in educational establishments, high-risk groups (e.g., athletes), or in the general population.
2. Describe a parent only intervention **not attached to an early intervention service.**
3. Describe a specific intervention (e.g., type of cognitive behavioural therapy) that is not attached to an early intervention service.
4. Primarily or only focus on early intervention for a physiological or medical condition, schizophrenia spectrum and other psychotic disorders, neurodevelopmental disorders, **neurological or neurodegenerative disorders, crime/delinquency/violent behaviours, suicidal behaviours (not associated with a specific mental health disorder), and smoking/tobacco consumption**.
5. **Describe an intervention/service for mental health symptoms associated with a physiological or medical condition, neurodevelopmental disorders, and neurological or neurodegenerative disorders.**
6. **Describe an internet-based only intervention.**
7. **Services labelled as early intervention solely because they target children and young people, but, in practice, are not specifically for recent-onset mental health disorders.**

3.4.2 Search strategy

The search strategy was consistent with the protocol, except that two additional databases were included in the search (CENTRAL and Web of Science). A comprehensive systematic search for published and unpublished literature was conducted from inception to November 2019 using the following databases: MEDLINE, EMBASE, PsychInfo, HMIC, CENTRAL, ProQuest for theses & dissertation, and Web of Science for conference proceedings. Additional articles were identified by searching the reference lists of included documents. Other key documents that the authors became aware of during the screening and charting process were also included in the review. No date or language limits were applied to the initial search. Only documents reported in English, German, French, or Spanish were included in this review.

3.4.3 Study selection process

The study selection process did not deviate from the protocol. The lead author (KR) de-duplicated records in EndNote x8. The references were then transferred to Rayyan for title and abstract and full-text screening (Ouzzani, Hammady, Fedorowicz, & Elmagarmid, 2016). All titles and abstracts and full-text articles were screened by the lead author. Two authors (AA and LG) independently screened approximately 25% (*n* = 2102) of the titles and abstracts and 25% (*n* = 162) of the full-text articles in duplicate. The concordance rates for the title and abstract and full-text screening were 92% and 88%, respectively. Disagreements were resolved by discussion, and if necessary, a third reviewer conducted an independent screening. Additional internet searches were conducted, and document authors were contacted if it was difficult to determine whether the document/service were eligible.

3.4.4 Data items and charting

The standardised data charting form was updated early during the data charting process to include additional data items in the *Document Details*, and *Outcome Research* sections. Data items related to the RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance) framework were also added to facilitate the evaluation of implementation and critical appraisal. The data charting form is outlined in Table 7 with new items in bold. All data were charted by the lead author with 30% (*n* = 20 articles) of the data verified by two authors (AA and LG). Verification was used instead of duplicate charting due to the volume of articles and time constraints. Since the data were verified rather than charted in duplicate, the data charting form was not piloted by two authors at the outset.

Table 7. Data charting form.

Data Item	Description of Item
Document Details	
Type of document	The type of document can include but will not be limited to published or unpublish primary research, any type of review, protocols, theoretical paper, guidelines, opinion pieces, editorials, and expert consensus papers.

Author(s)	List of authors
Year of publication	Year of publication
Title	Title of document
Journal	The title of the scientific journal (for published documents only)
Conference	**The title of the conference (for conference abstracts and proceedings)**
Publisher	**The name of the publisher (for books and book chapters)**
Country of origin	Country where the document originates
Aim/purpose of document	Summary of the aim/purpose of the document
Study design	For published or unpublished research papers, the design of the study as reported in the paper. Includes but is not limited to randomised controlled trials, pre-post design, historical controlled trial, prospective or retrospective cohort studies, cross-sectional, and case series/study.
Study methodology	The methodological framework: qualitative, quantitative, or mixed methods.
Characteristics of Early Intervention Service	
Name of service	The name of the early intervention service/program.
Year established	The year the early intervention service was established.
Location	The country and region in which the early intervention service was implemented.
Population	The population for which the service was designed for. This item will include details such

	as age, diagnosis, duration of illness, and illness severity.
Setting	The physical setting in which the early intervention service is based. This includes but is not limited to community centres, primary care, outpatient clinics, and inpatient wards. Early intervention services can occupy more than one of these settings.
Service providers	A description of who provides the service and their role, includes but is not limited to social workers, youth workers, peer support workers, nurses, clinical or counselling psychologists, and psychiatrists.
Service structure/process	A description of the service structure and administrative processes includes but is not limited to ‘service within a service’ models, stand-alone multi-disciplinary team models, ‘hub’ and ‘spoke’ models, and process variables such as specific wait time targets.
Access to service	Methods for accessing the early intervention service, includes but is not limited to active engagement and outreach through schools, colleges and youth clubs, referral from primary care, self-referral, and drop-in.
Services and interventions	A description of the types of services and interventions provided, includes but is not limited to psychoeducation, online self-help and self-management support, psychological therapies (e.g., CBT, brief therapy), sexual health and family planning, health promotion, social services, peer support, and crisis intervention and management.

Clinical staging	Whether a clinical staging approach was used to inform the design, evaluation, or implementation of the service.
Outcome Research	
Participants	Details related to the participants included in the study. This will include information related to sample size, diagnosis, age, sex, and inclusion/exclusion criteria.
Comparator data or standard care	Description of comparator data or the care provided to a control group.
Outcomes and time-points	Description of the qualitative and quantitative outcomes and the time points of data collection. This will include standardised clinical assessments, and self-report measures as well as implementation outcomes, such as measures of acceptability, feasibility, adoption, fidelity, and sustainment.
Types of included/excluded studies	**Types of studies included/excluded from narrative and systematic reviews.**
Critical appraisal	**For systematic reviews, were studies critically appraised, and if so, did this determine eligibility.**
Qualitative data collection method	**Method used to collect qualitative data, includes but is not limited to one-to-one interviews, focus groups, and questionnaires.**
Ontology, epistemology, and analytical method	**For qualitative studies, the ontological, epistemology (e.g., critical realism) and analytical method (e.g., reflexive thematic analysis) used in the document.**

Reach	**Whether there was any discussion of the reach of the service and the representativeness of the study participants.**
Adoption	**The degree of adoption in terms of number of sites, types of sites and contexts, and the representativeness of the sites included in the study.**
Implementation	**Whether there was a detailed description of key service components, adherence/fidelity to the key components, and any discussion of flexibility/adaptations.**
Funding/Cost	**Descriptions of funding for the service, the cost, and whether the service was cost-effective or containing and/or could be implemented in low resource settings.**
Maintenance	**Whether there was any discussion of sustainability or a long-term implementation plan, and/or evidence of sustained use and normalisation in routine practice.**
Key results/findings	An outline of the key results and findings reported in the document. This includes quantitative outcomes such as changes in symptoms, engagement, and patient satisfaction, as well as qualitative outcomes, such as, descriptions of barriers and facilitators to implementation.

Note. CBT = cognitive behaviour therapy.

3.4.5 Critical appraisal

The critical appraisal was largely consistent with the protocol, except for the addition of a "low, medium, or high quality" rating system for the JBI Critical Appraisal Tools. The critical appraisal was used to facilitate the interpretation of the results, rather than to exclude articles. Only articles providing data on implementation and effectiveness were critically appraised, i.e., articles that only described a service were not appraised. A

two-stage critical appraisal was conducted. First, documents were assigned to one of the JBI Levels of Evidence (e.g., Level 1—Experimental Designs through to Level 5—Expert Opinion and Bench Research) and assessed with the corresponding JBI Critical Appraisal Tool (Joanna Briggs Institute, 2017; Jordan et al., 2019). Items on each JBI Critical Appraisal Tool were rated "yes", "no", "unclear", or "not applicable". To aid the interpretation of methodological quality, studies were assigned a label of low (0-33% of criteria met), medium (34-66% of criteria met), or high (>67% of criteria met) quality depending upon the percentage of criteria rated "yes". Items rated as "not applicable" were not included in the percentage calculation (Fernandez et al., 2021). Mixed methods and narrative reviews were not appraised at this stage as there was no Level of Evidence or JBI Critical Appraisal Tool for these study designs. When more than one type of design was included in a single document, the highest Level of Evidence was selected and critically appraised.

In the second stage, each document was assessed according to a modified version of the RE-AIM framework rating system developed by Galgio and colleagues (2014). This rating system is outlined in Table 6 in the previous chapter. In brief, studies are assigned a value of 1 (limited generalisability or no information) to 3 (generalisable/pragmatic or information to enable generalisation) for participant representativeness, setting representativeness, outcome representativeness, fidelity/adaptation, cost/feasibility, and sustainment. Twenty-five percent of the articles (n = 14) were appraised in duplicate.

3.4.6 Synthesis

The data synthesis was conducted as per protocol with some minor deviations. A narrative and quantitative summary of the extent, range, and nature of the literature for early intervention services in non-psychotic mental health disorder is provided in text, including a figure displaying the distribution of documents over time for each diagnostic group. The following characteristics of early intervention services are presented in a table and in text: the name of the service, the year the service was established (or the date of the earliest recorded document), the primary target population, the setting, structure, and service provider(s), outreach activities and methods of accessing the service (e.g., referral pathways, screening, wait times), and the treatments and supporting interventions. The study designs, Levels of Evidence, and critical appraisal of documents evaluating the implementation (including reach, fidelity,

and barriers/facilitators) and effectiveness of services are presented in tables and summarised in text. A detailed overview of the studies evaluating implementation and effectiveness is provided in Table 24 in Appendix G Section 10.7.1.1. The key findings of these studies were divided into the following categories and summarised in text: *reach and engagement*; *implementation, process, and resources*; and *outcomes: clinical, functional, and satisfaction*. Finally, an aggregated summary of the early intervention services, commonalities and differences across the services, and gaps in the evidence-base and future directions are provided.

3.5 Results

3.5.1 Search and screening

The results of the search, screening, and selection process are outline in the flow diagram in Figure 2. The initial search yielded 16556 records. After de-duplication, 8407 articles remained. An additional 100 articles were identified through reference list searches. The full texts of 771 articles were assessed for eligibility. However, 101 (13%) of the full-text articles could not be accessed for screening. Over half of the missing articles were books or book chapters (n = 61) and published before 2005 (i.e., before the widespread use of online journals and books) (n = 64). A proportion (n = 16) of articles could not be accessed as they were published in non-English language journals and 44 were available at the university libraries but could not be accessed during the screening process because the libraries were closed due to COVID-19. Overall, 66 articles were included in this review.

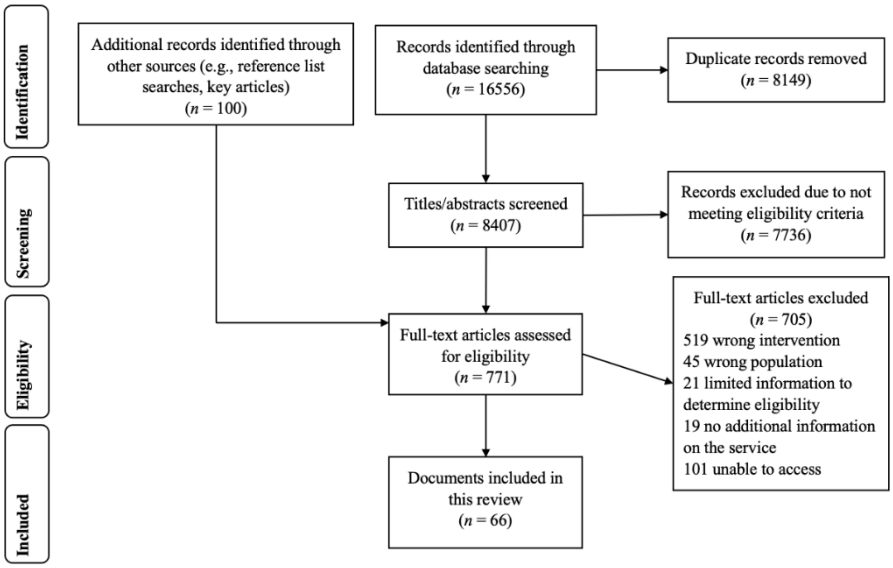

Figure 2. Flow diagram of search, screening, and study selection.

3.5.2 Question 1: What is the extent, range, and nature of the literature on early intervention services for adolescents and adults with non-psychotic mental health disorders?

Overall, 66 documents describing 22 different early intervention services were included in this review (Table 8). The documents were 60 journal articles, 5 conference abstracts, and 1 project report. The main purpose of the documents was to describe the service (*n* = 21), evaluate the impact of the service (*n* = 32), evaluate implementation, process, and cost (*n* = 10), and report protocols (*n* = 3). Figure 3 provides an overview of the number of documents published each year from 1980-2021. Most publications originate from Western, educated, industrialized, rich and democratic (WEIRD) countries, including Australia (*n* = 15), the United Kingdom (*n* = 14), Canada (*n* = 10), Germany (*n* = 8), Spain (*n* = 6), the United States of America (*n* = 5), Sweden (*n* = 3), Singapore (*n* = 3), France (*n* = 1), and Switzerland (*n* = 1). Of the 22 early intervention services, the primary target diagnoses were mood disorders (*n* = 3), anxiety disorders (*n* = 1), perinatal-related mental health disorders (*n* = 3), eating disorders (*n* = 2), trauma and stress-related disorders (*n* = 5), substance-related and addictive disorders (*n* = 2), personality disorders (*n* = 3), and the 3 remaining services were transdiagnostic. The number of publications per service varied from 1 to 9 (*Mdn* = 2). The main sources of funding for the documents were government agencies (*n* = 14), or a mix of government, health care, commercial, and/or research organisations (*n* = 14). A substantial number of documents did not provide any information on funding (*n* = 23). The remaining were

funded by independent charities (*n* = 7), private foundations (*n* = 3), research funding bodies (*n* = 2), healthcare organisations (*n* = 1), or had no funding (*n* = 2).

Table 8. Characteristics of early intervention services included in this review.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
Transdiagnostic					
EI Stream at the Youth Wellness Centre (YWC) [Ontario, Canada] (Wang et al., 2020)	2015	17-25 years at referral. Any untreated mental health or addiction concern that does not meet criteria for existing services.	EI service embedded in a larger centrally located community youth centre and co-located with a substance use and addiction service. MDT consisting of psychiatrists, psychologists, nurses, addiction and trauma specialists, clinical and occupational, therapists, family	Campaigns to promote awareness of the YWC using traditional and social media. Referrals are accepted from patients (via an online self-referral platform), family and friends, community agencies, and healthcare providers.	The EI stream offers assessments and structured treatment plan. Services include: an art drop-in, peer support, system navigation, counselling, psychiatric consultations, family counselling/support, group interventions, and brief individual therapy.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
			educators, LGBTQ+ workers, transition coaches, youth mentors, and indigenous youth wellness co-ordinator.		
First Episode Mood and Anxiety Program (FEMAP) [Ontario, Canada] (Anderson et al., 2019; Arcaro, Summerhurst, Vingilis,	2006	16-25 years old. Primary mood and/or anxiety disorder with or without substance use. Patients are excluded if they have extensive prior	Outpatient service located in a youth-friend community setting (renovated house). Stand-alone MDT consisting of psychiatrists, clinical social workers,	Education, outreach, and community engagement activities to increase awareness of the service (e.g., art competition in schools, presentations, Q&A sessions, community	Symptom, situational and functional assessment. Duration and type of treatment based on clinical need. Treatment is sensitive to the needs of emerging adulthood and person-centred, trauma-informed, strength-based, and collaboratively determined.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
Wammes, & Osuch, 2017; Arcaro et al., 2019; John-Baptiste, Li, Isaranuwatchai, Osuch, & Anderson, 2019; Osuch, Vingilis, Fisman, & Summerhurst, 2016; Osuch et al., 2019; Osuch et al., 2019; Ross, Vingilis, & Osuch, 2012;		psychiatric treatment.	addiction workers, family therapists, and psychologists.	partnerships, and FEMAP website). Referrals are accepted from the patient (self-referral), family or friends, educational institutions, and healthcare providers. Brief telephone screen at intake. Three attempts to engage youth that do not attend.	Multiple therapeutic modalities are offered (e.g., pharmacology, CBT, psychodynamic, addictions treatment, and group therapy).

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
Saunders et al., 2021)					
headspace Early Intervention Teams (hEITs) [Sydney, Australia] (Nash, Isobel, Thomas, Nguyen, & van der Pol, 2021; White et al., 2021)	2017	14-25 years old. Young people at risk of, or with an emerging early or untreated serious mental health disorder including mood, anxiety, psychotic, addiction, eating and personality disorders.	Integrated care co-ordination model co-located with youth primary mental health service (headspace). Team consists of mental health clinicians (not specified) and psychiatrists. Cross-service team model, enabling interagency collaboration and	Referrals accepted from headspace and other youth services, local mental health services, emergency departments, and GPs. Flexible, assertive, and community outreach and engagement.	Youth- and family-friendly service with expert, optimistic, and holistic person-centred and evidence-based care. A broad range of interventions and support are provided, including mental health, accommodation, family, employment/education, forensic, and physical health care. hEIT have access to services provided by headspace and specialist mental health services, including

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
			transitions between primary and specialist mental health services, includes close liaison, regular stakeholder meetings, and joint working.		psychologists, GPs, social supports, group programmes, specialists, hospital services, and after-hours acute care. Provides capacity building and upskilling of headspace staff. Time-limited service: 6- to 12-months of support.
Mood and Related Disorders					
Bipolar Stream of the Dresden Early Recognition Centre	2008	12-40 years old. Help-seeking youth at high-risk of bipolar disorder according to	Low threshold specialised early recognition centre based at a hospital.	Public relations work and promotion to increase awareness of service (e.g., lectures	Extensive assessment includes psychiatric and medical history, and structured clinical interviews.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
[Dresden, Germany] (Leopold, Pfeiffer, Correll, Bauer, & Pfennig, 2013; Leopold et al., 2014; Pfennig, Bauer, & Leopold, 2013)		Bipolar Prodrome Symptoms Scale (BPSS) and/or Early Phase Inventory for bipolar disorders (EPIbipolar).	Stand-alone MDT model consisting of psychiatrist, psychologist, child and youth psychiatrist, and social workers.	and information events, and media). Direct and low-threshold access via telephone, email, or at the centre. Referrals are accepted from patients and their social environment, and health services. First appointments offered within a week, and if desired, can be anonymous and with a third party.	Duration and type of treatment based upon clinical need. Treatment offered includes psychotherapy (CBT or CBT plus preventative intervention including mindfulness-based stress reduction and sleep hygiene), pharmacotherapy, addictions counselling, and psychoeducation.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
Bipolar Stream of the Zurich Early Recognition Program (ZInEP) [Zurich, Switzerland] (Theodoridou et al., 2014)	2014 (paper published)	13-35 years old. Patients at-risk of bipolar disorder according to standardised criteria.	Hospital-based early recognition units.	Referrals are accepted from health care services, outreach clinics, counselling services, teachers, and affected persons or family members.	Standardized criteria to identify persons at risk for bipolar disorder. Offers appropriate counselling to those at-risk.
Jano Program [Santander, Spain] (Gómez-Ruiz et al., 2010; González et al., 2012)	2005	16-55 years old. Bipolar disorder according to DSM-IV criteria with first manic episode within the last 5 years and first depressive episode	Based in a psychiatry service at a hospital MDT case management team consisting of psychiatrists, a clinical psychologist, a research	Referrals from in- and out-patient services.	Psychiatrist provides case management, medication, and follow-up consultations. Full psychological assessment and brief psychoeducation in three individual and family sessions.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
		within the last 10 years.	psychologist, a social worker, a nurse, and a nursing assistant.		Treatments offered include 18-session bipolar disorder psychoeducation group, 9-session family therapy group, and when necessary, individual CBT and/or family therapy. Nursing care, social work support, neuropsychological counselling, and occupational rehabilitation provided when needed.
Anxiety Disorders					
Panic Disorder Unit [Santander, Spain]	2001	Panic disorder of recent onset (seeking treatment for the first time)	Outpatient psychiatric service based in a hospital.	Referrals accepted from mental health centres or emergency department.	Specialised diagnostic interview. Treatment involves both pharmacotherapy (flexible-

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
(Biddle et al., 2008; Carrera et al., 2006; Herrán et al., 2005; Navarro, Sánchez, Herrán, & Sierra-Biddle, 2013)		with or without agoraphobia.	MDT including a psychiatrist specializing in anxiety disorders.		dose selective serotonin reuptake inhibitors (SSRIs)) and panic disorder specific psychotherapy (12-week Panic Management Program).
Perinatal-related Disorders					
Postnatal Depression Intervention Program [Kampong Java, Singapore] (Chen, 2011; Chen et al., 2011;	2008	Women at 2-24 weeks postpartum with an Edinburgh Postnatal Depression Scale (EPDS) score of 10-12 for counselling only or	Stepped care case management model embedded in obstetric outpatient clinics. MDT consisting of psychiatrists, perinatal mental	All patients 2-24 weeks postpartum at the obstetric clinics are screened using EPDS.	Patients scoring 10-12 on EPDS or those scoring >12 but refused psychiatric consultation were offered counselling and/or follow-up phone review by assigned case manager.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
Lee, Bautista, & Chen, 2016)		>12 (or answer yes to additional psychosis/infanticide questions) for the full intervention programme.	health case managers, social workers, an occupational therapist, and a psychologist.		Patients scoring >12 offered the full intervention programme which includes psychiatric assessment with supportive, psychoeducation, and problem-solving counselling (incorporating ITP and CBT), antidepressant medication, case management, peer support group, formal psychotherapy, and onward referrals for baby massage and for social problems (e.g., marital issues).
Eastern Sydney Perinatal Mental Health Service	1999 (paper published)	Women “at-risk” of developing perinatal mental	Stand-alone nurse-led case management model closely	Regular training seminars for health care professional from	Close liaison and joint management of patients with primary health care workers.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
[Sydney, Australia] (Austin, 2000; Austin, Dudley, Launders, Dixon, & Macartney-Bourne, 1999		health problems (i.e., history of psychiatric illness or presenting with risk factors) or experiencing acute episode.	affiliated with the Early Childhood Nursing and psychiatric services. Domiciliary service. Service providers included psychiatric nurses and adult and infant psychiatrists.	primary care, perinatal/obstetric services, and mental health services. Referrals accepted from primary care, Obstetric and Mothercraft Hospitals, psychiatrists, and patients and their family. At-home assessment offered within a week of referral.	Psychiatric assessment led by nurse (review by psychiatrist when safety concerns/medication needs). Nursing interventions include case management, psychoeducation for mother and family, mothercraft skills, supportive counselling, building support networks, brief CBT interventions, and onward referral when needed. Medication provided by psychiatrist or collaborating GP. Family member involvement is encouraged.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
The Early Motherhood Service [Victoria, Australia] (Judd, Stafford, Gibson, & Ahrens, 2011)	1997	Women ‘at-risk’ or who develop perinatal mental health problems.	Outpatient program co-located with maternity services. Assessment and treatment provided at the EMS clinic, the hospital, or in the patient’s home. Psychiatric nurses with specialist training in perinatal mental health, family therapy, CBT, and grief counselling. Supervision of staff through MDT	Community education activities to increase awareness of perinatal mental health problems (e.g., attendance to rural health days, and childbirth and parental education classes) as well as training, supervision, and capacity building for other health providers. Referrals accepted from patients (self-referral),	Information, advice, and secondary consultation provided to women, their social environment, and health providers. Joint assessments with community midwife, maternal child health nurses, and lactation consultant. Treatment and support provided to patient and family (duration varies, but generally 12-months). Group program designed as a preventive and EI for mothers at risk of or experiencing

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
			clinical review and a consultant psychiatrist.	maternity services, and GPs. 'No wrong door' approach, any woman that self-refers is assessed.	symptoms of anxiety, depression, and adjustment difficulties.
Feeding and Eating Disorders					
First Episode Rapid Early Intervention in Eating Disorders (FREED) [England, United Kingdom] (Austin et al., 2021b; Brown et	2014	16-25 years old. ED with an illness duration ≤3 years.	'Service-within-a-service': MDT embedded within a larger evidence-based outpatient ED service. ED clinician takes on the role of FREED Champion.	Outreach and close liaison with primary care and educational institutions to encourage early referrals. FREED website with information about the service and EDs.	Biopsychosocial, person-centred assessment, which is motivational and optimistic, and considers the person within their social context, focusing on needs and strengths plus an invitation for close others to join, and an exploration of social media use, initial goal

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
al., 2018; Flynn et al., 2020; Fukutomi et al., 2020; McClelland et al., 2018; Potterton et al., 2021; Richards et al., 2021; Schmidt et al., 2016b)				Referrals accepted from primary care and mental health services. Telephone call within 48 hours of referral to screen and engage patients. Active, person-centred, and flexible approach to initial and subsequent engagement with patient and family/carers. Assessment within 2-weeks and treatment	setting and a focus on early change, and psychoeducation. NICE-concordant evidence-based ED treatment tailored to the needs of emerging adults in early-stage illness (e.g., attention to transitions, early change, social media use). Pharmacotherapy is added as required.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
				within 4-weeks from referral.	
Emerge-ED [Adelaide, Australia] (Radunz et al., 2021)	2018	16-25 years old. Young people displaying ED symptoms for no longer than 3 years, BMI >14.5, and no previous evidence-based ED treatment.	Clinical psychologists embedded in youth primary mental health services (headspace).	Referrals accepted from the patient, family, or GP. A focus on rapid engagement of youth and their families/social support (assessments typically provided within 3 weeks).	Service focuses on an optimistic outlook, early full recovery, and psychoeducation and nutritional management throughout treatment. Treatment is tailored to need: (1) individuals presenting with disordered eating secondary to another diagnosis receive approximately five sessions focusing on psychoeducation and prevention; (2) individuals with a BMI >18.5 receive CBT-T; (3) individuals with a BMI

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
					<18.5 or who do not respond to CBT-T receive enhanced CBT.
Trauma and Stress-related Disorders					
Stepped Collaborative Care Intervention [Washington, United States] (Zatzick et al., 2013; Zatzick et al., 2015; Zatzick et al., 2011; Zatzick et al., 2004)	2001 (study start period)	≥14 years old. Patients admitted to a level 1 trauma centre surgical ward or emergency department for ≥24 hours with elevated PTSD risk according to medical records and/or PTSD Checklist Civilian	Stepped collaborative care case management model embedded within inpatient ward, emergency department and outpatient clinics in a level 1 trauma centre/hospital. Trauma-based mental health team included	Two phase screening for eligibility and access to the service: (1) all patients admitted to the trauma centre offered screening; (2) patients with elevated scores in the first screening are screened at a later time point (days and weeks later).	Care provided for 6-12 months post-injury. Measurement-based model (patients' symptoms were repeatedly measured, and higher intensity care provided for those with persistently high PTSD scores). Trauma-focused care management included collaboratively determined care plan, motivational interviewing

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
		Version (PCL-C) score ≥35.	case managers (nurse/social work/behaviour therapist), psychiatrists, and psychologist. Supervision provided by psychiatrist and motivational interviewing and CBT experts.	Computerised decision tool to facilitate real-time workflow integrated screening and intervention procedures.	to address treatment ambivalence and change high-risk behaviours (e.g., alcohol use, weapon carrying), behavioural activation and/or cognitive behavioural elements, assessment and amelioration of post-injury concerns, co-ordination across care providers, relapse prevention, and community integration. Evidence-based pharmacotherapy and trauma-informed CBT, or combined treatment delivered in a stepped care fashion.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
					Self-assessment and psychoeducational materials delivered via website and phone application (technology enhanced version only).
Paediatric Stepped Preventative Care Intervention [Philadelphia, United States] (Kassam-Adams et al., 2011)	2011 (study date)	8-17 years old. Admitted for unintentional injury with ≥4 items endorsed on the Screening Tool for Early Predictors of PTSD (STEPP) or a score ≥15 on Child PTSD Symptom Scale or a score of	Stepped preventative care model integrated within inpatient hospital for acutely injured children. Delivered by a nurse and social workers. Doctorate-level psychologists provide supervision, training,	All patients admitted to the hospital for unintentional injury were screened for eligibility for the service. Session 1 delivered during hospitalisation and session 2 delivered 2-weeks	Intervention consists of two standard sessions: Session 1 involved assessing the child's and parents' top concerns, distress, existing support system and medical treatment, and psychoeducation and information on postinjury care; Session 2 involved a brief interview to review progress

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
		≥24 on Center for Epidemiologic Studies Depression Scale (CES-D).	psychological assessment, and trauma focused psychotherapy. Child psychiatry service provide pharmacological treatment.	post-discharge by telephone. Decision rules guided the provision of additional treatment and increases in the intensity of care.	and arrange further contact/services if needed. Where indicated the following element were added: additional contact, care coordination, support with medical follow-up, brief parent–child intervention, psychological/psychiatric evaluation, and trauma-focused CBT.
German Trauma Outpatient Clinic [North Rhine-Westphalia, Germany]	2006	Children and adult victims of crime in need of psychological treatment.	Outpatient service located at psychiatric and psychosomatic psychotherapy clinics.	Quick and low-threshold access, initial consultation offered within days of referral.	Interventions/services vary but include consultant examination/diagnostics, psychoeducation, stabilization and crisis support, advice and

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
(Bollmann et al., 2012; Rassenhofer et al., 2016; Schürmann, 2010)			Treating doctors and psychologist at each trauma outpatient clinic.	Patients screened in first five sessions to determine need for treatment. Trauma outpatient clinics closely networked with victim protection police officers, self-help, advice, and domestic violence organizations.	mediation to suitable treatment, cognitive restructuring, EMDR, trauma-focused CBT, significant others involvement, exposure-based treatments, play therapy, and family therapy. Five sessions are offered in the first instance with 10 further sessions if needed.
Oral and Maxillofacial Trauma Psychological Services	2014	Facial injury patients who score above a cut-off criterion on screening tools for depression, anxiety,	Collaborative care team of clinical psychologists and a research assistant embedded within a	All outpatients attending the clinic screened for eligibility.	All screened patients provided with psychoeducation. Brief assessment to determine psychological need.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
[London, United Kingdom] (Choudhury-Peters & Dain, 2016; Price et al., 2015)		PTSD, substance use, risk to self and facial appearance distress.	maxillofacial trauma outpatient clinic.	Systematic liaison with reception and nursing staff to ensure all patients are screened. Direct liaison between surgeon and clinical psychologist in cases where there was risk. Assessment and intervention provided immediately in the clinic or within a few days.	Interventions included self-help leaflets and brief psychological treatment. Therapeutic models used included CBT, counselling skills, and affect-focused therapies. When indicated follow-up calls, emails, or appointments, signposting, or onward referrals were provided. Patients with more complex needs were provided with risk assessment, liaison with family members/carers, neuropsychological

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
					assessment, and co-ordination of mental health care.
Stepped Care Service Model [Australia] (O'Donnell, Bryant, Creamer, & Carty, 2008)	2008 (paper published)	Traumatic injury survivors with full syndrome or subsyndromal psychological symptoms that are sustained for at least a month post-trauma.	Stepped care model based within an acute hospital setting. Care co-ordinator to administer screening and liaise with psychological and psychiatric services.	Two-stage screening for eligibility: (1) screen all trauma injury survivors that present to hospital; (2) telephone follow-up with patients classified as at-risk 1-month postinjury.	Psychoeducation about mental health during screening. Care co-ordinator to liaise with mental health services when patients are at-risk. In-depth assessment with mental health practitioner. Care management including intensive in-person and telephone outreach, problem solving to address barriers to therapy, identification of patient concerns, and

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
					motivational interviewing to address poor engagement. Manualised evidence-based psychological treatment for PTSD adapted and applied flexibly to meet the needs of the individual patient.
Substance-related and Addictive Disorders					
The Karolinska Project for Early Treatment of Women with Alcohol Addiction (EWA)	1981	Female problem drinkers in early phase alcohol dependence that are socially well-functioning and	Female only outpatient clinic and 8-bed inpatient ward located within a general hospital.	Active outreach and promotion of service to women's organisations and spaces.	Biopsychosocial assessment. Detoxification in in- or out-patient setting. Treatment consists of an individualised treatment plan that focuses on the alcohol

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
[Stockholm, Sweden] (Dahlgren & Willander, 1989; Haver & Dahlgren, 1995; Haver & Franck, 1997)		with no previous history of adequate treatment for alcohol problems (outpatient treatment ≥6 months).	MDT model consisting of physicians, nurses, social worker, psychologist, and external supervisions by a psychotherapist.	Referrals accepted from patient (self-referral), significant others, physicians, employer, and social services. Initial contact typically over the phone for the patient or concerned person to get advice and information and, if desired, the call can be anonymous. Telephone contact repeated until the person feels safe enough to make the first appointment.	problem but also addresses the patient's whole life situation and is tailored to women. It includes psychotherapy, medical care, individual and group discussions, social-curative and occupational therapy, significant other involvement, and physiotherapy. Duration of treatment is at least 1-year.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
				First appointment offered within a few days up to a fortnight.	
Centres D'Hygiene Alimentaire (CHA) [Nationwide, France] (Babor, Treffardier, Weill, Fegueur, & Ferrant, 1983; Chick, 1984)	1972	Drinkers in the early or prodromal stages of alcohol dependence (non-dependent excessive drinkers) classed as "first-degree" drinkers on the Le Gô Grid (a method of assessing physical signs of drinking).	Outpatient MDT clinic based in health centres, hospitals, and downtown premises, such as, shopping areas. Typically staffed by at least a medical secretary/ receptionist, nurse, social worker and/or dietician, and physician.	Referrals accepted from patients (self-referral), family, healthcare professionals, social services, motor-vehicle violations and licence renewal services, and organisations supporting individuals with alcohol problems. Receptionist ensures that the initial contact	Consultations are almost exclusively focused with present medical and to some extent social and psychological problems and involves diagnostics, medical examination, setting drinking goals, and practical advice. Alcohol treatment encourages moderation rather than abstinences and involves insight development, attitude

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
			Home visit provided by social worker if needed.	is informal and friendly.	change, knowledge attainment, and behaviour modification. Treatments offered include pharmacotherapy, counselling, health education and dietary advice, goal-setting and self-monitoring, family counselling, medical treatment, and referrals to self-help groups. Patient progress is monitored and feedback during consultations according to the Le Gô Grid method. Social worker provides consultation to relatives, police, social-service agencies, self-help groups, industry, and

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
					unions to facilitate integration of patient into life.
Personality Disorders					
Helping Young People Early (HYPE) service at Orygen Youth Health (OYH) [Melbourne, Australia] (Betts et al., 2018; Chanen et al., 2015; Chanen et al., 2018; Chanen et al., 2009b; Chanen et al.,	1998	15-25 years old. Sub-threshold or full-syndrome borderline personality disorder (three or more DSM-IV criteria).	Integrated psychologically informed team-based model with assertive case management. Outpatient clinic, crisis care, and time-limited goal-directed inpatient care based at OYH. Team includes psychiatrists and psychologists.	Referrals made to OYH's single point of access are screened for eligibility for HYPE (referrals accepted from patient and social environment, healthcare organisations, emergency departments, and educational services).	Clinical assessment and rigorous diagnosis of personality pathology. Assertive 'psychologically-informed' case management (addresses housing, education or vocational issues, family matters, liaison and co-ordination with other services, and the management of crisis and deliberate self-injury) integrated with the delivery of psychotherapy.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
2008; Chanen et al., 2009a; Pearce et al., 2017; Sio, Chanen, Killackey, & Gleeson, 2011)				Strong emphasis on and a flexible and transparent approach to outreach and engagement, 6-week period of vigorous engagement and a focus on addressing barriers to care.	Explicit collaborative approach with the patient. CAT as core therapeutic model and common language used in HYPE, patients offered time-limited individual CAT sessions. Active involvement of families and carers with psychoeducation, family therapy, and carers group. Treatment of co-occurring psychiatric disorders including pharmacology. Crisis team and inpatient care that is brief and goal directed.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
					Activity groups programme at OYH.
The Outpatient Clinic for Adolescent Risk-taking and Self-harm Behaviours (AtR!Sk) [Heidelberg, Germany] (Ghinea, Edinger, & Kaess, 2018; Kaess, Ghinea, Fischer-Waldschmidt, & Resch, 2017)	2013	12-17 years old. Young people with risky and self-damaging behaviours (at-risk of borderline personality disorder).	Stepped care outpatient service based in a psychiatry service at a hospital. Short-term inpatient acute admissions for crisis intervention. Treating therapist and advice from social workers and specialists.	Quick and low-threshold access through 'open consultation hour', where a short screening is conducted.	Comprehensive diagnostic appointment to evaluate risk, personality pathology, and other psychiatric disorders using standardised interviews and questionnaires. Treatment is tailored to the problems of adolescents and offered in a stepped care fashion with brief CBT offered initially progressing to DBT for adolescents, and/or MBT for adolescents with social behavioural problems.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
					If necessary, short-term acute inpatient admission for crisis intervention. Psychosocial management and accompanying advice from social workers and specialists.
ICEBREAK [Plymouth, United Kingdom] (Farrand, Booth, Gilbert, & Lankshear, 2009; Gilbert, Farrand, & Lankshear, 2012; Marriott,	2003	16-25 years old. Young people with emerging personality disorders as evident from precursor signs and symptoms and no significant history	MDT model with assertive case management embedded in a holistic, 'street-level', open-access youth centre (The Zone) for young adults aged 16-25 years.	Advocates for a flexible working style that is non-stigmatising, non-labelling, and maximises the wellbeing of the young person. Open-door open-referral service, referrals can be taken	Case management includes non-judgemental individualised support, problem-solving, signposting, advocacy, engagement, normalisation, empowerment, social inclusion, assertive community outreach/treatment, and a focus on relationship-building.

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
Jones, & Martin, 2007)		of mental health service input.	Core team typically consists of a team leader, case managers, occupational therapist, administrator, GP, and clinical psychology lead. Extended team include psychotherapists, welfare rights worker, and mix of relevant staff from the Zone (youth and activity workers).	by phone or letter from any health, mental health, voluntary, or community agency and self-referrals are accepted. Collaborative working relationships with an array of relevant community and health organisations (e.g., police, housing, education/ employment, drug services, mental health services).	12-week assessment period to identify each person's difficulties, strengths, needs, and risks and protective factors and develop an open, trusting, and honest relationship. Case managers support access to a range of services and continues input even if an onward referral is made. Support is provided to family and dependants. Interventions include medical care, groups provided by the case managers (e.g., anger management, psychoeducation), and a range

Service name [Location]	Year service was established	Population	Setting, structure, and service provider(s)	Outreach and access	Treatment and supporting interventions
					of other therapeutic interventions/skills (e.g., CBT, DBT). Access to services provided by the Zone (e.g., counselling, sexual health services, accommodation support).

Note. AtR!Sk = The Outpatient Clinic for Adolescent Risk-taking and Self-harm behaviours; BMI = body mass index; BPSS = Bipolar Prodrome Symptoms Scale; CAT = cognitive analytical therapy; CBT = cognitive behavioural therapy; CBT-T = 10-session cognitive behavioural therapy for non-underweight eating disorders; CES-D = Center for Epidemiologic Studies Depression Scale; CHA = Centres D'Hygiene Alimentaire; DBT = dialectical behaviour therapy; DSM-IV = Diagnostic and Statistical Manual of Mental Disorders Fourth Edition; ED = eating disorder; EI = early intervention; EMDR = eye-movement desensitisation and reprocessing therapy; EPDS = Edinburgh Postnatal Depression Scale; EPIbipolar = Early Phase Inventory for bipolar disorder; EWA = Karolinska Project for Early Treatment of Women with Alcohol Addiction; FEMAP = First Episode Mood and Anxiety Disorder; FREED = First Episode Rapid Early Intervention for Eating Disorders; GP = General Practitioner; hEIT = headspace Early Intervention Team; HYPE = Helping Young People Early; ITP = interpersonal therapy; MBT = mentalization-base therapy; MDT = multidisciplinary team; NICE = National Institute of Care Excellence; OYH = Orygen Youth Health; PCL-C

= PTSD Checklist Civilian Version; PTSD = post-traumatic stress disorder; Q&A = question-and-answer; SSRI = selective seratonin re-uptake inhibitors; STEPP = Screening Tool for Early Predictors of PTSD; YWC = Youth Wellness Centre; ZInEP = Zurich Early Recognition Program.

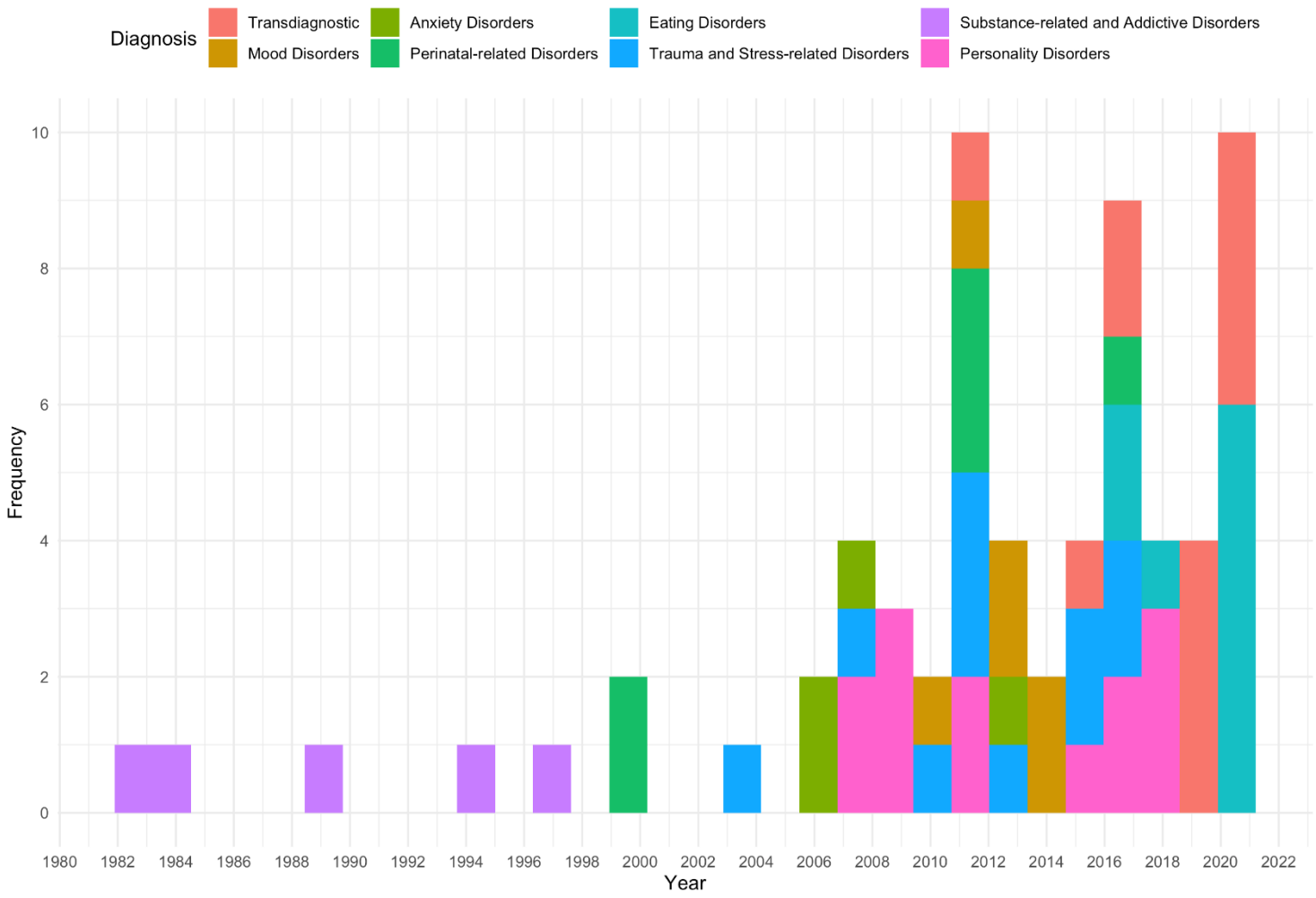

Figure 3. The number of early intervention publications over time for each diagnostic category

3.5.3 Question 2: What are the key characteristics of early intervention services and care pathways?

3.5.3.1 Summary of the models

Table 8 provides an overview of the early intervention services and their characteristics. Studies are organised by target diagnoses. Transdiagnostic services included the Youth Wellness Centre, First Episode Mood and Anxiety Program (FEMAP), and headspace Early Intervention Teams (hEITs). Mood and related disorders services included the Dresden Early Recognition Centre, Zurich Early Recognition Program (ZInEP), and Jano, all of which targeted at-risk or early-stage bipolar disorder. The Panic Disorder Unit was the only service identified specifically for anxiety disorders. Services for perinatal mental health disorders included the Postnatal Depression Intervention Program, Eastern Sydney Perinatal Mental Health Service, and the Early Motherhood Service. First Episode Rapid Early Intervention for Eating Disorders (FREED) and emerge-ED were the only services identified for feeding and eating disorders. Trauma and stress-related disorders included Stepped Collaborative Care Intervention, Paediatric Stepped Prevention Care Intervention, the German Trauma Outpatient Clinics, Oral and Maxillofacial Trauma Psychological Service, and Stepped Care Service Model. Substance-related and addictive disorder services were the Karolinska Project for Early Treatment of Women with Alcohol Addiction (EWA) and the Centres D'Hygiene Alimentaire (CHA), both of which targeted early-stage alcohol use disorders. Finally, personality disorder services included Helping Young People Early (HYPE), the Outpatient Clinic for Adolescent Risk-taking and Self-harm Behaviours (AtR!Sk), and ICEBREAK. The service characteristics outlined Table 8 include the year the service was established, the target population, the structure, setting, and service provider(s), the outreach and access to the service, and treatments and supporting interventions provided. These are summarised in detail below.

3.5.3.2 Population

Most of the early intervention services were targeted at peak risk periods for the onset of mental health disorders. Adolescence and emerging adulthood were prime target age groups for many services. Services for trauma and stress-related disorders tended to screen patients in hospital and emergency settings soon after a traumatic event and services for perinatal-related disorders screened or worked closely with maternity and obstetric services to identify at-risk patients. A range of criteria were used to determine

eligibility for early intervention, including standardised cut-off scores on screening/assessment tools, no or limited prior treatment, and evidence-informed duration of illness, symptom, and risk criteria. However, some services did not provide information for or justify their inclusion criteria (e.g., Jano, Early Motherhood Service).

3.5.3.3 Setting, structure, and service provider(s)

Many services (*n* = 15) were based within community or outpatient settings that were either youth-friendly or designed to try and minimise the stigma associated with traditional psychiatric and mental health settings, e.g., community centres, domiciliary services, and/or embedded with physical care settings. Close liaison, co-location and integration with other services and organisations were particularly important to quickly identify and reach target populations early, and address broader health and functional needs (e.g., work/education/social needs, and motherhood). Most services (*n* = 14) were MDTs, including psychiatrists, psychologists, nurses, and clinical social workers. The non-MDT services were nurse-led with support from other health professions (*n* = 3), a psychology team (*n* = 2) or it was unclear (*n* = 3). Eight services explicitly mentioned using a case management/care co-ordination model.

3.5.3.4 Outreach and access

Active outreach and awareness raising, and the service's access routes into care were identified as central for facilitating early identification and intervention. Community education and engagement and broad awareness raising activities (e.g., traditional and social media, seminars and lectures, service websites) were explicitly mentioned by seven services. Direct, open, and low-threshold access to the service was common. Twelve services allowed self- and family/friend referrals via open consultation clinics, and telephone, online, or email contact and for two this could be anonymous. Five services embedded within medical settings used standardised questionnaires to screen all potentially eligible patients. Advice/support was often provided immediately for these patients. There were reports of the need for rapid and timely access, but only five services provided timeframes for the start of assessment or treatment. One service used wait time targets of 2-weeks from referral to assessment and 4-weeks from referral to treatment, and four others aimed to offer the first appointment within a few days to a week, or a fortnight. The first contact for three services involved a brief triaging phone call or appointment to quickly screen for eligibility. Assertive outreach, motivation-building, and engagement activities were also integral to several services, including

motivational interviewing techniques and repeated initial engagement attempts. FREED, emerge-ED, hEIT, and HYPE services placed a strong emphasis on active and flexible engagement and addressing systemic and patient-related barriers to care. In HYPE, there was even an initial strategic collusion with dysfunctional relationship patterns to facilitate engagement and change. The CHAs used an ethically questionable method of "constructive coercion" to engage individuals with early-stage alcohol use disorders, i.e., threats of legal, economic, or employment sanctions to engage with the service (Babor et al., 1983).

3.5.3.5 Treatment and supporting interventions

Care typically began with an in-depth assessment of symptoms, diagnoses, functioning, and general health and concerns. Sometimes intervention components, such as family involvement and psychoeducation, were blended into the assessment, or assessment and treatment were provided simultaneous. Many services (n = 16) provided a combination of psychoeducation, psychological, and pharmacological treatments. A sizeable number of services also provided social and functional rehabilitation and support (e.g., housing, education/work) (n = 10), and carer/family involvement and/or interventions (n = 17). Most provided evidence-informed or based treatment packages, but six services did not provide information on evidence base. Seven services used a stepped care approach to determining treatment. FREED, hEIT, HYPE, and CHA were the only services that explicitly mentioned clinical staging models, and/or tailored treatment to illness stage. Other services were also tailored to developmental stage, need, female gender, and the tasks/skills/issues of motherhood.

3.5.4 Question 3 and 4: Are there any factors that influence the implementation of early intervention services (i.e., implementation processes and barriers and facilitators to implementation)? Do early intervention services reduce duration of illness, improve the course and outcome of mental disorders, or minimise the disruption to psychosocial development and function?

A detailed overview of the 58 studies investigating the implementation, and/or effectiveness of the early intervention services is provided in Appendix G Section 10.7.1.1. These findings are summarised in detail below under the headings of *reach and engagement, implementation, process, and resources,* and *outcomes: clinical, functional, and satisfaction*.

3.5.4.1 Study designs and methodological quality

The Levels of Evidence, study designs, and methodologically quality according to the JBI Critical Appraisal tools are outlined in Table 9. The overall ratings for the RE-AIM framework are provided in Table 10. A detailed per document summary of the JBI and RE-AIM critical appraisal is provided in Appendix G Section 10.7.1.2. Most studies were assigned to Level 2 (Quasi-experimental design; n = 20) or 4 (Observational – Descriptive; n = 11) and the quality of the studies was low (n = 11), medium (n = 15), and high (n = 24). Notable weaknesses across the studies included treatment concealment and blinding (in RCTs), appropriate statistical procedures (especially the use of power analysis), no control group (in non-RCTs), and inadequate information on loss to follow-up and data collection procedures. RE-AIM framework ratings varied substantially across the domains. Generalisability was higher for participants (reach), effectiveness, and maintenance, and low to medium for adoption, and implementation (fidelity/cost). In other words, most studies had limited or no exclusion criteria, a range of outcome measures, and evidence of sustained use (>6 months), but there was limited site representativeness (most studies were single site), evaluations of fidelity or adaptations, and explicit discussions of costs, resources, and time.

Table 9. Joanna Briggs Institute Levels of Evidence, study design, and methodological quality.

			Methodological Quality		
Levels of Evidence for Effectiveness		Number of papers per level (*n*, % of column total)	Low (*n*, % of row total)	Medium (*n*, % of row total)	High (*n*, % of row total)
Level 1: Experimental Design	1.c: Randomised controlled trial	5 (9%)	0 (0%)	1 (20%)	4 (80%)
	1.d: Pseudo-randomised controlled trial	1 (2%)	0 (0%)	1 (100 %)	0 (0%)
Level 2: Quasi-Experimental Design	2.c: Quasi-experimental prospectively controlled study	1 (2%)	1 (100%)	0 (0%)	0 (0%)
	2.d: Pre-test – post-test or historic control group study	20 (34%)	8 (40%)	8 (40%)	4 (20%)
Level 3: Observational – Analytical Design	3.c: Cohort study with control group	3 (5%)	0 (0%)	2 (67%)	1 (33%)
	3.e: Observational study without a control group	5 (9%)	1 (20%)	1 (20%)	3 (60%)

Level 4: Observational – Descriptive Studies	4.b: Cross-sectional study	11 (19%)	1 (9%)	1 (9%)	9 (81%)
Level of Evidence for Meaningfulness					
	3: Single qualitative Study	3 (5%)	0 (0%)	0 (0%)	3 (100%)
Levels of Evidence for Economic Evaluations					
	6: Single economic evaluation of moderate or poor quality	1 (2%)	0 (0%)	1 (100%)	0 (0%)
No Levels of Evidence Available					
	Single mixed method study	6 (10%)	NA	NA	NA
	Narrative review	2 (3%)	NA	NA	NA
		Total	11/50 (22%)	15/50 (30%)	24/50 (48%)

Notes. NA = not applicable.

Table 10. RE-AIM framework domain ratings for reach, implementation, and effectiveness studies.

	Reach	Effectiveness	Adoption	Implementation		Maintenance
	Participant representativeness	Outcome representativeness	Site representativeness	Fidelity/adaptations	Cost/resources	Evidence of sustainment
1: limited generalisability and/or no information (*n*, %)	10 (17.24%)	9 (15.52%)	43 (74.14%)	8 (13.79%)	38 (65.52%)	9 (15.52%)
2: moderate generalisability and/or some information (*n*, %)	23 (39.66%)	27 (46.55%)	15 (25.86%)	45 (77.59%)	16 (27.59%)	0 (0%)
3: generalisable/pragmatic or information to enable generalisation (*n*, %)	25 (43.10%)	22 (37.93%)	0 (0%)	5 (8.62%)	4 (6.90%)	49 (84.48%)

3.5.4.2 Reach and engagement

When available, non-medical/non-clinical referral routes (e.g., self- and family referral, educational institution) tended to be the most frequent method of accessing services, with estimates ranging from 10% (Austin et al., 1999) to 85% (Dahlgren & Willander, 1989). Data from FEMAP show that relative to individuals who accessed care through medical/clinical routes, individuals from non-medical/non-clinical routes were just as likely to be accepted and engage in the programme and had higher anxiety and risky drug and alcohol use, speaking to the equal severity of those accessing services without a medical/clinical referral. Those who self-referred to FEMAP were also more likely to be male (Arcaro et al., 2017; Osuch et al., 2015; Osuch et al., 2019). In the Dresden early recognition centre, self-referral was found to be higher amongst those with no prior contact with services (61% vs 43%) and individuals meeting at-risk criteria for bipolar disorder (45% vs 30%) (Leopold et al., 2013; Leopold et al., 2014).

The symptoms, distress, and functional impairment of patients presenting to these services was high with most patients previously seeking help (52-95%) and offered at least some treatment (60-95%). Services that screen all patients presenting to medical settings found that between 6 to 79% of patients were eligible, and a two-stage screening procedure was more effective at identifying individuals with high post-traumatic stress symptoms (Zatzick et al., 2011). While many services reached the intended population, there was some evidence of bias or under-representation of certain groups. For example, in the Youth Wellness Centre indigenous youth were under-represented (Wang et al., 2020). The average parental education of FEMAP patients was higher than the local population, and compared to non-users, FEMAP patients were younger, and less likely to be male, living in rural or deprived areas, have prior help-seeking, and diagnosed with an anxiety disorder (Anderson et al., 2019; Ross et al., 2012). Compared to base rate crime statistics, patients attending the German trauma outpatient clinics were more likely to be female and victims of sexual crimes or robbery/extortion and less likely to be victims of physical violence (Schürmann, 2010).

Overall, treatment initiation and engagement were high, ranging from 68% to 100%. The only exception was the Postnatal Depression Intervention Program in Singapore, where only 33% of eligible patients accepted treatment (Chen et al., 2011). Engagement was associated with higher symptoms/dysfunction (Arcaro et al., 2019; Chen et al., 2011; Farrand et al., 2009; Osuch et al., 2019; Saunders et al., 2021), lower

substance use (Farrand et al., 2009; Osuch et al., 2019), living in a deprived area, and being an early school leaver (Farrand et al., 2009). Specific barriers to help-seeking and engagement were stigma associated with mental illness (Arcaro et al., 2019; Chen et al., 2011; Leopold et al., 2013), under-recognition or limited perceived need for treatment (Arcaro et al., 2019; Chen et al., 2011; Leopold et al., 2014), a desire for self-management (Arcaro et al., 2019), limited time and cost concerns (Chen et al., 2011), and difficulties navigating services (Arcaro et al., 2019; Leopold et al., 2013). Qualitative feedback suggests that the name/location/timing of treatment, outreach and easy referral processes, and comprehensive, collaborative, and tailored care increased accessible and engagement (Arcaro et al., 2019; Chick, 1984; Haver & Franck, 1997; Marriott et al., 2007; Osuch et al., 2016). The immediate social environment, impacts on interpersonal and academic functioning, and reaching a crisis point were identified as drivers for help-seeking (Arcaro et al., 2017; Arcaro et al., 2019; Gilbert et al., 2012).

3.5.4.3 Implementation, process, and resources

Only three services evaluated fidelity or use of core components of the service model. Other services provided some indication of interventions provided. In HYPE, fidelity to cognitive analytical therapy (CAT; the core therapeutic model and lingua franca of HYPE) and standardised good clinical care (GCC) were satisfactory to excellent (Chanen et al., 2008; Chanen et al., 2009a). The use of core components of the FREED model (wait time targets and care package), and the Stepped Collaborative Care intervention for PTSD varied from low to high (Richards et al., 2021; Zatzick et al., 2004; Zatzick et al., 2013; Zatzick et al., 2015). Chick (1984) highlighted that some of the CHAs had moved away from their primary objective of addressing prodromal alcohol use disorders.

Numerous barriers and facilitators to implementation were identified across the studies. Barriers and/or challenges included limited staff resources, turnover, capacity, and physical space (Choudhury-Peters & Dain, 2016; Nash et al., 2021; Osuch et al., 2016; White et al., 2021), assuming care for inappropriate patient groups and patients needing longer term care (Osuch et al., 2016), time-limited treatment (Nash et al., 2021), disruptions to the flow of care (e.g., long wait times, transitions) (Arcaro et al., 2019; Osuch et al., 2016), incompatible information technology systems (Choudhury-Peters & Dain, 2016), different organisational cultures, and lack of clarity on the role of the service (Nash et al., 2021). For EDs specifically, gatekeeping/referral issues (Flynn

et al., 2020), a tendency to stop working towards full recovery once quality of life improved, and a lack of support networks, food availability, and transportation were identified as barriers to implementing early intervention (Radunz et al., 2021). Facilitators included quick triage and open referral processes (Judd et al., 2011; Osuch et al., 2016), addressing a "gap" in services (Nash et al., 2021), empathetic and skilled clinicians (Choudhury-Peters & Dain, 2016; Haver & Franck, 1997; Judd et al., 2011; Nash et al., 2021; Osuch et al., 2016), comprehensive, person-centred, and integrated treatment and consistent support within and between appointments (Arcaro et al., 2019; Nash et al., 2021), collaborative relationships, sharing expertise, and skill building for other services and health care professionals (Choudhury-Peters & Dain, 2016; Judd et al., 2011; Nash et al., 2021), less formal treatment settings (Marriott et al., 2007), relationships with other patients on inpatient wards (Haver & Franck, 1997), and evening/weekend appointments (Chick, 1984).

Seven services provided information on wait times and three for DUI. The average wait for the first clinical session was 25-45 days for FREED, 45 days for FEMAP, 47 days for the Youth Wellness Centre, 7 days for the Early Motherhood Service, 7 days for Stepped Collaborative Care, and 3 days for the Paediatric Stepped Prevention Care Intervention. Emerge-ED did not provide an exact estimate of wait times but stated that assessment appointments are typically provided within 3 weeks. Compared to treatment as usual (TAU), FREED patients waited significantly less time for assessment and treatment (Brown et al., 2018; Flynn et al., 2020) and FEMAP patients waited significantly less time to see a psychiatrist (Anderson et al., 2019). However, rapidly growing wait times were identified as a key challenge for FEMAP (Osuch et al., 2016). The wait for assessment at the Youth Wellness Centre was substantially longer than the provincial average (Wang et al., 2020). The average DUI for the Panic Disorder Unit, FREED, and EWA were 18-35 months, 13-18 months, and 6-7 years, respectively (Brown et al., 2018; Dahlgren & Willander, 1989; Flynn et al., 2020; Herrán et al., 2005). The DUI for FREED patients was substantially lower than TAU patients (Brown et al., 2018; Flynn et al., 2020). For the German trauma outpatient clinics, the time between the trauma and start of treatment was 46 days with 88% receiving treatment within 3 months (Bollmann et al., 2012). Male trauma outpatient clinic patients were seen significantly later than female (Schürmann, 2010). On average,

patients were referred at 5-month post-partum to the Eastern Sydney Perinatal Mental Health service (Austin et al., 1999).

The length and intensity of treatment varied widely across the services from two 17 to 30-minute low-intensity sessions offered by Paediatric Stepped Prevention Care intervention all the way through to over 12 months of treatment for EWA and FEMAP patients. Early intervention treatment tended to last slightly longer than TAU, and TAU patients tended to have higher use of other health care resources (e.g., inpatient admissions). A technology enhanced version of the Stepped Collaborative Care service was found to substantially reduce delivery time (10.7 hours vs 2.25 hours; Zatzick et al., 2015). Compared to non-users, FEMAP users incurred significantly lower costs for drug benefit claims and inpatient and ambulatory services, but significantly higher physician costs. The overall cost was not significantly different (John-Baptiste et al., 2019). The cost of 4-months of FEMAP treatment was also estimated to be considerably less than an emergency department evaluation and 4-months of disability support (Osuch et al., 2016). Compared to TAU, FREED was associated with substantially lower costs (Austin et al., 2021).

3.5.4.4 Outcomes: Clinical, functional, and satisfaction

Outcome data were available for 18 out of 22 services. Most studies were pre-test – post-test comparisons. Only eight services included some sort of comparative data or control group and three services provided qualitative outcome data. Generally, services demonstrated clinically and statistically significant improvements in symptomatic and functional outcomes over time (however Gómez-Ruiz et al., 2010; Sio et al., 2011). Much of this was supported by the qualitative data (Arcaro et al., 2019; Choudhury-Peters & Dain, 2016; Potterton et al., 2021). Three studies found that the early intervention service or an integrated component of the service led to significant improvements in symptoms, burden, disorder knowledge and accommodating behaviours for family/friends/carers (Haver & Franck, 1997; McClelland et al., 2018; Pearce et al., 2017).

Improvements were sometimes but not always superior to TAU or comparison data. FEMAP patients had significantly greater improvements than a wait list control group, but not when compared to patients that initially sought FEMAP treatment but were referred onwards or reassured no treatment was needed (Osuch et al., 2015; Osuch

et al., 2019). Postnatal Depression Intervention Program patients had significantly greater reductions in depression relative to patients who declined intervention (Chen et al., 2011). Compared to TAU, a substantially higher number of underweight FREED patients were weight recovered at 12-months and 24-months (Austin et al., 2021; Fukutomi et al., 2020; McClelland et al., 2018). Stepped Collaborative Care and trauma outpatient clinic patients demonstrated significantly greater improvements in PTSD symptoms relative to TAU, but did not consistently demonstrate better depression or alcohol consumption outcomes (Rassenhofer et al., 2016; Zatzick et al., 2013; Zatzick et al., 2015). Paediatric Stepped Prevention Care patients did not have significantly better post-traumatic stress outcomes than TAU (Kassam-Adams et al., 2011). EWA patients had substantially better drinking, mortality, and functional outcomes compared to TAU (Dahlgren & Willander, 1989). Difference between CAT (HYPE's main therapeutic model) and GCC delivered in the HYPE service were slight at best, and both were superior to a historical TAU group. However, there was no meaningful difference between HYPE treatment groups and TAU on borderline personality disorder dimension scores (Chanen et al., 2008; Chanen et al., 2009a).

Importantly, qualitative and quantitative data indicate that patients and health care professionals were satisfied or very satisfied with the early intervention services. Features of the services that were valued by patients and health care professionals included rapid access to treatment (Austin et al., 1999; Choudhury-Peters & Dain, 2016; Potterton et al., 2021), addressing a "gap" and building bridges between services (Nash et al., 2021), focusing on social networks and life beyond the disorder (Arcaro et al., 2019; Choudhury-Peters & Dain, 2016; Potterton et al., 2021), skilled, empathetic, and non-judgemental clinicians (Choudhury-Peters & Dain, 2016; Gilbert et al., 2012; Haver & Franck, 1997; Nash et al., 2021; Potterton et al., 2021), interactions with other patients (Haver and Franck, 1997), comprehensive and integrated care (Arcaro et al., 2019; Choudhury-Peters & Dain, 2016; Nash et al., 2021), personal choice, and patient empowerment and increased self-efficacy (Arcaro et al., 2019; Potterton et al., 2021). The central role of accessible, and non-judgemental care coordinators for a personality disorders service was highlighted by one study (Gilbert et al., 2012).

3.6 Discussion

This study reviewed the extent, range, and nature of the literature on early intervention services for non-psychotic mental health disorders. The characteristics, implementation,

and effectiveness of the services were also reviewed and provide a solid base upon which to create a unified cross-disciplinary approach to specialised early intervention services in mental health. However, data on the implementation, cost/resources, and the effectiveness of services relative to standard treatment were limited. All of these are important to facilitate the successful translation of research into routine clinical practice and different contexts and settings.

Almost all documents related to early intervention services for non-psychotic disorders were published from 2006 onwards. The exception to this were services for substance use disorders, which were published between 1980 and 2000. This evidence-base trails behind that of psychosis, where the first publications began to emerge in the late 1980s and 1990s, with widespread interest and proliferation of EIP services from 2000 onwards (Csillag et al., 2018; McGorry, 2015). The most widely researched non-psychotic disorders were trauma and stress-related disorders, followed by personality and mood disorders. There were fewer services for anxiety, substance-related, and eating disorders. While most services targeted specific diagnostic groups, comorbidity was widely recognised and treated in these services, suggesting that a transdiagnostic approach may be feasible for some disorders.

There were three common characteristics to the early intervention services but differences in precisely how these characteristics were operationalised and implemented. First, almost all services were targeted at a peak risk period and had eligibility criteria for early-stage illness. There were two distinct risk clusters, one focused on risk due to age and one focused on risk due to exposure to an event. Mood, eating, personality, and trans-diagnostic services were targeted at adolescents and emerging adults, a peak risk period for many mental health disorders (Solmi et al., 2021a). In contrast, services for trauma and stress-related and perinatal-related disorders were targeted at the time of the traumatic event or birth. Several different criteria were used to classify individuals as early-stage illness. These ranged from broad transdiagnostic criteria, such as, no prior treatment, all the way through to specialised disorder-specific assessments and procedures. For example, PTSD services advocated for a two-stage screening process, akin to a watchful waiting approach, because stress symptoms are common immediately following a traumatic event with only a sub-sample continuing to experience these symptoms and developing PTSD (O'Donnell et al., 2008; Zatzick et al., 2013). This is in direct opposition to other services, where watchful

waiting is perceived as detrimental and exacerbating an already lengthy delay to treatment (Schmidt et al., 2016b). Since these criteria determine access to services, it is important that the rationale for the chosen criteria is evidence-informed and clearly stated.

Second, almost all services had processes and procedures to make the service more accessible, engaging, and palatable to individuals with sub-threshold or early-stage symptomatology who may not identify as being unwell. The location and setting of the services were particularly important in this respect and should be a key consideration for early intervention services. Many services were based in youth-friendly, community or non-psychiatric settings. Some were co-located and/or closely networked with other services and relevant organisations to promote early identification, access, and integrated treatment. The precise setting varied depending upon the target population (e.g., perinatal services were co-located with obstetric services, whereas transdiagnostic, eating, and personality disorder services were co-located with youth services). Qualitative reports in some studies suggest that the location and co-location of services were indeed contributors to improved access and engagement (Arcaro et al., 2019; Judd et al., 2011; Marriott et al., 2007). In keeping with this, Settipani et al. (2019) found that integrated youth hubs typically emphasized the importance of making service settings accessible, non-stigmatising, and youth-friendly (e.g., community based, non-clinical spaces, and youth input on décor and design). Accessible, community and low-stigma settings are also recommended by the Global Framework for Youth Mental Health (https://www.orygen.org.au/About/Orygen-Global/Global-framework-for-youth-mental-health). While these youth services are not exclusively focused on early intervention, increased access and early treatment are core principles of many. Lessons learned from these services may therefore be applicable here, especially for youth-focused early intervention services.

Outreach and community awareness raising and education (e.g., seminars, campaigns, social media) for organisations and professionals relevant to the target population were also provided by some services. Additionally, many services either had direct, open, and/or low-threshold access (e.g., walk-ins and self-referral) or screened all potentially eligible individuals in medical settings to encourage quick and easy access to the service. When available, most patients tended to use non-physician routes to access services. Active engagement efforts and assertive outreach were also crucial features of

some services. Again, the engagement techniques varied by service. For example, in an alcohol use disorder service (EWA) repeated phone calls, where the patient could be anonymous, were used to gradually develop trust and a feeling of safety amongst potential patients (Haver & Franck, 1997). In contrast, for a personality disorder service (HYPE) the engagement approach was more assertive and included outreach to the patients' home (Chanen et al., 2009b). Despite the low threshold access, patients presenting to these services were distressed, impaired, and in need of clinical intervention. Indeed, services were largely reaching and engaging their intended population. However, formal evaluations of reach were lacking and there was some evidence that certain groups were under-represented (e.g., individuals from aboriginal, indigenous, rural, or deprived backgrounds, male patients). In future, it will be important to monitor reach and engagement to ensure that all eligible groups are gaining access to services.

Third, most services were MDTs offering a range of evidence-informed or -based pharmacological and psychosocial interventions with family/carer involvement. Non-MDTs tended to be closely networked with or supervised by other services and professions. The services were either stand-alone teams or teams integrated into other services. Some services used an explicit case management/care co-ordinator model. The primary role of the case manager/care co-ordinator was to enable more holistic, integrated, and individualised treatment, and to increase engagement and treatment adherence through assertive outreach and relationship building. Indeed, a qualitative study of ICEBREAK, an early intervention service for personality disorders, found that the care co-ordinator was a central and highly valued feature of the model (Gilbert et al., 2012). Only seven services mentioned using a stepped care approach, which matches treatment intensity to individual need. The main reason provided for adopting this approach was to maximise effectiveness while minimising cost. Systematic measurement-based procedures, and decisions tools and guides were used to facilitate the stepped care procedure in some but not all services (Kassam-Adams et al., 2011; Zatzick et al., 2015). Clinical staging models, which characterise illness progression from at-risk all the way through to severe and enduring illnesses and adapts treatment to match stage of illness, are a central feature of EIP, but were only reported in four services in this review. Services also adapted treatment to the social and developmental characteristics of the target population. Qualitative evaluations suggest that this tailoring

was valued by patients (Arcaro et al., 2019; Potterton et al., 2021). The intensity and duration of treatment varied widely across services (two 30-minute visits vs 13 months of treatment). Once more data accrues, it will be important to evaluate whether the duration and intensity has any bearing on outcomes and differs for each disorder. However, even the longest duration treatments were less than the 2-5 years recommended for EIP services.

There was a lack of information on implementation, key process variables, cost/resources, and effectiveness relative to standard treatment. Monitoring implementation fidelity is important because if the intervention is not implemented as intended then it is unlikely to produce the desired outcomes. The lack of fidelity monitoring for many services may be associated with the stage of implementation (i.e., services only operating at a single site). Fidelity monitoring has only recently received considerable attention in EIP services, where several countries have begun implementing national monitoring and feedback processes. Evidence suggests that many EIP services are not obtaining the minimally adequate standard of fidelity, but ongoing monitoring and feedback can substantial improve this over time (Addington et al., 2021). Very few studies provided information on barriers and facilitators to implementation. Limited resources were a key barrier underlying other challenges. Key facilitators included informal/non-psychiatric settings, open referral processes, empathetic and skilled clinicians, and collaborative relationships and skill development for other services and healthcare professionals. Alongside fidelity monitoring, information on barriers and facilitators to implementation are central for the successful widespread scaling of services.

While rapid treatment is recognised as a core feature of early intervention, only some services used specific timeframes for accessing care or reported on wait times and/or DUI. Wait time targets for accessing services ranged from a few days up to 4-weeks with some providing rapid triage phone calls or appointments. Access and wait time standards are also a relatively new addition to EIP services. In 2016, a 2-week wait time target for the initiation of NICE-concordant treatment was introduced in England, and a 1-month target for assessment was introduced in Denmark (Danske Regioner, 2016; NHS England, 2016). Wait time standards push teams towards evaluating and increasing efficiencies in services (e.g., Singh, Ghazi, White, Sarfo-Adu, & Carter, 2018). Indeed, the introduction of wait time standards in England have reduced the wait

for EIP services (Adamson et al., 2018; Kreutzberg & Jacobs, 2020; Singh et al., 2018). In terms of wait times, there were two distinct clusters. Services embedded or closely affiliated with physical health/medical services had very short waits for care (~5 days). In contrast, for all other services the wait was approximately 45 days. This is similar to EIP services in England, where the average wait for treatment was 50 days before the introduction of wait time standards (Reichert & Jacobs, 2018). DUI was 18 months for panic and eating disorder services, and 6-7 years for alcohol use disorder services. The DUI for EIP services is approximately 19 months (Correll et al., 2018). There were very limited comparison data, but the data available suggest that early intervention services reduce the wait for care and DUI relative to TAU.

Understanding the costs and effectiveness of early intervention services relative to standard treatment is essential for informing decisions on healthcare service provision. Only two services provided information on the relative cost of early intervention treatment, largely through service utilisation data. In accordance with work in psychosis, a pattern of resource utilisation was observed, where early intervention services were associated with less high intensity service use (e.g., inpatient, ambulatory care), but increased contacts with other staff members and initial up-front costs (Aceituno et al., 2019). While early intervention was cost saving in both studies, the difference only reached trend significance for FREED (Austin et al., 2021b). The lack of cost data is not unique to early intervention and has been identified as an issue in other areas of healthcare (Gaglio et al., 2013; Gaglio et al., 2014). Eighty percent of the studies provided at least some outcome data. Generally, outcomes were positive with significant improvements on most metrics over time, and patients and healthcare professionals were satisfied with or valued the services. However, rigorous comparative data (i.e., RCTs) to contextualise improvements and long-term outcomes were lacking. For studies that included comparative data, early intervention was not consistently better than TAU, highlighting the importance of including comparative data. Most studies at each JBI Level of Evidence were rated as moderate to high quality. The exception to this were studies at Level 2 (Quasi-experimental designs), where many were rated low quality. The main reasons for this were that studies did not include a control group or multiple pre- and post-treatment measures, there was inadequate details for evaluating loss to follow-up and data collection procedures, and very few studies used a power calculation.

3.6.1 Strengths and limitations

Substantial efforts were made to conduct a comprehensive and broad search across an array of databases including published and grey literature. However, there will inevitably be unidentified articles and documents. Greater use of search engines (e.g., Google) may have given a more comprehensive grey literature search. Several full-texts documents, largely books and book chapters, could not be accessed at the time of screening, which took place during the first year of the COVID-19 pandemic. Although English, German, French, and Spanish articles were included, articles in other languages may have been missed. The search itself was also conducted in English, which would have limited the number of non-English articles. Most documents originated from WEIRD countries and in selected locations within those countries. This is similar to EIP, where most research has been conducted in high income countries. There is work underway to adapt and integrate early intervention into low- and middle-income settings (Singh, Javed, & WPA Expert International Advisory Panel for Early Intervention in Psychosis, 2020). However, for now the generalisability of these results to low- and middle-income countries and contexts outside of the "best" available sites may be limited. Another limitation is that only a portion of the articles were screened, verified, and critically appraised in duplicate. While concordance was high, eligible articles and content may have been missed. A major strength of this study is the critical appraisal procedure, which evaluated both internal and external validity. Critical appraisals are not typically conducted for scoping reviews. However, this study demonstrated that this is not only feasible but desirable. The appraisal facilitated a deeper understanding of the documents and the identification of gaps in the literature. However, as anticipated, some articles (e.g., narrative reviews) could not be appraised and some of the items on the JBI tools were not applicable. More work is needed to develop a critical appraisal procedure suitable for the scoping review methodology.

3.6.2 Conclusions

This review brought together the fragmented literature on early intervention services for non-psychotic disorders to evaluate commonalities and differences in the structure, implementation, and evaluation of these services. Commonalities included targeting a peak risk period, efforts to enhance treatment accessibility and engagement, and multi-disciplinary and -faceted treatment. However, the precise procedures to obtain these objectives varied across the services with some overlapping more than others. Trauma

and perinatal services tended to overlap more, whereas mood, anxiety, personality, and eating disorders were more similar to each other. Findings are promising but more work is needed to develop an evidence-base that can support real world decision making (e.g., implementation fidelity and adaptations, evaluating benefits and costs relative to standard treatment, important contextual factors that can facilitate or hinder implementation and treatment effectiveness) across different areas of mental health.

Chapter 4. Assessing implementation fidelity in First Episode Rapid Early Intervention for Eating Disorder

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A copy of the article is provided in Appendix A. The formatting of this article has been amended here for stylistic consistency. The body of the text remains largely unchanged, except the following were added to this chapter: (1) the percentage adherence/use that would be considered as low, moderate, and high adherence/use; (2) effect sizes for the main contrasts of interest; (3) more details regarding the comparison displayed in Table 14; (4) a section to highlight that body image issues were not specifically addressed or evaluated in this study.

Author contributions: The FREED-Up study was conceptualised and designed by Professor Ulrike Schmidt, Dr Karina Allen, Dr Victoria Mountford, and Danielle Glennon. The authors Michaela Flynn, Amelia Austin, Dr Katie Lang, Dr Karina Allen, Ranjeet Bassi, Dr Gabrielle Brady, Dr Amy Brown, Dr Frances Connan, Mary Franklin-Smith, Danielle Glennon, Dr Nina Grant, Dr William Rhys Jones, Kuda Kali, Dr Antonia Koskina, Dr Kate Mahony, Dr Victoria Mountford, Nicole Nunes, Dr Monique Schelhase, Professor Lucy Serpell, and Professor Ulrike Schmidt conducted the study, and collected and managed the data. The candidate (Katie Richards) transferred the patient journey record data from paper into an electronic database, analysed the data, and drafted the manuscript with assistance from Professor Ulrike Schmidt and Dr Karina Allen. All authors reviewed and contributed towards the final version of the manuscript. Constructive feedback was received from peer-reviewers at *BJPsych Open* and the manuscript was altered accordingly.

4.1 Abstract

Background: First Episode Rapid Early Intervention for Eating Disorder (FREED) is associated with significant reductions in wait times and improved clinical outcomes for emerging adults with recent-onset eating disorders. An understanding of how FREED is implemented is a necessary precondition to enable an attribution of these findings to key components of the model, namely the wait time targets and care package.

Aims: This study evaluated fidelity to the FREED service model during the multi-centre FREED-Up study.

Method: Participants were 259 emerging adults (16-25 years) with an eating disorder of <3 years duration offered treatment through the FREED care pathway. Patient journey records documented patient care from screening to the end of treatment. Adherence to wait time targets (engagement call within 48-hours; assessment within 2 weeks; treatment within 4 weeks) and care package and differences in adherence across diagnosis and treatment group were examined.

Results: There were significant increases (16-40%) in adherence to the wait time targets following the introduction of FREED irrespective of diagnosis. Receiving FREED under optimal conditions also increased adherence to the targets. Care package use differed by component and diagnosis. The most highly used care package activities were psychoeducation and dietary change. Attention to transitions was less well-used.

Conclusion: This study provides an indication of adherence levels to key components of the FREED model during the FREED-Up study. These adherence rates can tentatively be considered as clinically meaningful thresholds. Results highlight aspects of the model and its implementation that warrant examination in the future.

4.2 Introduction

Rapid access to early intervention services in psychiatry can result in better outcomes and higher patient satisfaction compared to treatment-as-usual (TAU) approaches (Richards, Austin, Allen, & Schmidt, 2019). One such service is First Episode Rapid Early Intervention for Eating Disorders (FREED), designed for emerging adults (EAs; 16-25 years old) with recent-onset eating disorders (EDs) (Schmidt et al., 2016b). EDs are associated with substantial physical and psychosocial morbidity (van Hoeken & Hoek, 2020) and over time can become less amenable to change (Davis et al., 2020; Eisler et al., 1997; Steinglass & Walsh, 2016). EA is a peak risk period for ED onset, yet evidence suggests that help-seeking and treatment utilisation are particularly low within this group (Ali et al., 2020; Potterton, Austin, Allen, Lawrence, & Schmidt, 2020a; Weigel et al., 2014). FREED aims to deliver developmentally informed care for EAs that reduces service-related delays and barriers to treatment in order to maximise the likelihood of recovery and minimise the impact on psychosocial trajectories.

4.2.1 FREED service model

FREED operates as a service-within-a-service, overseen by a FREED Champion (typically a psychologist or nurse) who co-ordinates and leads a mini team of clinicians delivering FREED-adapted treatment. Procedurally, the model involves wait time targets of 2 weeks for assessment and 4 weeks for treatment, an electronic patient tracker to monitor and manage patient throughput, and weekly FREED ‘huddles’ and clinical supervision. Referrals to the service receive an engagement call within 48 hours of referral. This aims to engage patients by validating and praising help-seeking, emphasising the importance of early intervention, and alleviating concerns (e.g., practical concerns, confidentiality concerns, and fears about change and not being unwell enough to access treatment). Finally, the content of evidence-based treatment and style of working are adapted to meet the illness stage and developmental needs of EAs with recent-onset EDs. Treatment is delivered in a person-centred, motivational, and flexible style with a focus on transitions, ED-related brain changes, social media use, and significant other involvement (Allen et al., 2020).

4.2.2 FREED implementation and evidence base

The implementation and evaluation of FREED has been guided by the RE-AIM (Reach, Efficacy/Effectiveness, Adoption, Implementation, and Maintenance) framework (Allen et al., 2020; RE-AIM, 2020). This framework highlights five key dimensions that

facilitate or hinder the population-based impact of an intervention. These dimensions are (1) the *Reach* to the target population, (2) the *Effectiveness/Efficacy*, (3) the *Adoption* of the intervention by organisations or individuals that can deliver it, (4) the *Implementation* fidelity, time, and cost, and (5) the *Maintenance* of an intervention over time (Glasgow et al., 2019). An overview of the implementation of FREED to date with reference to the RE-AIM framework is provided by Allen et al. (2020). The *Effectiveness* of FREED has been demonstrated through a single-site pilot study (N = 142) and a larger multi-site study (FREED-Up study; N = 502). Specifically, FREED increases treatment uptake and reduces wait times and duration of untreated ED (DUED, i.e., time between the onset of an ED and the start of evidence-based treatment). It also improves ED symptoms and reduces the need for costly inpatient/day treatment, compared to TAU (Brown et al., 2018; Flynn et al., 2020; McClelland et al., 2018). The successful and ongoing scaling of FREED to ED services across England and internationally, alongside active outreach with community stakeholders and FREED's online presence, all continue to build towards the *Reach* and *Adoption* of FREED (Allen et al., 2020).

Once an effective intervention is adopted across a growing number of settings and organisations, it is important to ensure that it is delivered as intended, i.e., *Implementation* fidelity (RE-AIM, 2020). Fidelity can mediate treatment effects and explain why an intervention is more successful in one setting than another (Durlak & DuPre, 2008). Evaluations of fidelity also provide valuable information regarding the feasibility of an intervention and where additional training and support may be needed. To date, there has been limited evaluation of the *Implementation* dimension for FREED. Here, we focus on evaluating one component of this dimension, namely adherence to key aspects of the model during the multi-site FREED-Up study: the wait time targets and the FREED care package. The wait time targets for the engagement call (<48 hours), assessment (<2 weeks), and treatment (<4 weeks) are advisory and aspirational rather than obligatory. While wait time targets can reduce the wait for care (Kreutzberg & Jacobs, 2020; Willcox et al., 2007), they can have unintended consequences, such as tunnel vision (i.e., a focus on the target to such an extent that other important features of healthcare are neglected) (Mannion & Braithwaite, 2012). Target implementation requires careful consideration and ongoing evaluation to ensure that they are challenging and clinically meaningful but also achievable (Berry, Gardner, & Anderson,

2015). The FREED care package tailor's treatment to the needs of EAs with recent-onset EDs. In evaluations of FREED to date, it is unclear to what extent the care package adaptations were actually used and contribute towards the positive outcomes in the FREED-Up study. The care package adaptations measured in the FREED-Up study are outlined in Table 11.

The present study addressed three questions. First, how closely were the FREED wait-time targets for the engagement call, assessment and treatment adhered to, and did this vary across treatment group (FREED versus TAU) or diagnoses? Second, how frequently were the FREED care package adaptations used at assessment and during treatment and did this use vary across diagnoses? Third, did the use of the FREED care package adaptations change throughout treatment?

Table 11. FREED care package adaptations in the FREED-Up study.

Adaptation	Description
Biological malleability rationale for early intervention	A focus on the malleability of brain changes associated with eating disorders, emphasising the need for early intervention to restore brain changes and enhance the likelihood of recovery.
Psychoeducation on the impact of eating disorders on brain, body, and behaviour	Verbal and/or written psychoeducation materials on the impact of eating disorders on the brain, body, and behaviour initiated early at assessment and continued throughout treatment (e.g., the psychological effects of starvation, and the vicious cycle of dieting, bingeing, and purging) – even more than in treatment as usual with tailoring to developmental stage.
Dietary change	A focus on dietary change initiated early at assessment with initial goal setting and meal planning, and during treatment with nutritional information, meal planning, goal setting, and where possible, early dietetic involvement.
Family/significant other involvement	Active and ongoing encouragement for family or significant other involvement in care that is developmentally appropriate and collaboratively planned. Where possible, discussions around carer skills training and support should be provided.
Exploration of social media and health-related app use	An exploration of social media and health-related app use as a potential maintaining factor for the eating disorder at assessment and treatment. A ‘Social Media and Apps – Friends or Foes?’ booklet can be given to patients.

Exploration of transitions	Special attention is given to the experience and management of transitions in care and life. Structured University Preparation Groups covering topics such as social and sexual health, budgeting, time management, cooking, and developing independence can also be provided by teams.

4.3 Methods

4.3.1 Study design and sample

This study is an analysis of patient journey record (PJR) data collected during the FREED-Up study. In brief, FREED-Up was a multi-site quasi-experimental pre-post study evaluating the impact of FREED compared to TAU on wait times, DUED, and clinical outcomes (study findings are detailed elsewhere: Allen et al., 2020; Flynn et al., 2020). The study took place across four large specialist National Health Service (NHS) ED outpatient services in England. Ethical approval was granted by the Camberwell St Giles Research Ethics Committee (16/LO/1882) and NHS Health Research Authority. The study was conducted in accordance with the ethical standards of relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

FREED patients (*n* = 278) were aged 16-25 years, had a primary diagnosis of a DSM-5 ED, and an ED illness duration of <3 years. Diagnosis and illness duration were determined using a structured interview based upon the Eating Disorder Diagnostic Scale (Stice, Telch, & Rizvi, 2000) and the Eating Disorder Examination (Cooper & Fairburn, 1987). Illness duration was operationalised as the time since the onset of a diagnosable ED. Exclusion criteria were: (1) need for immediate inpatient admission; (2) a comorbid physical or mental disorder that should be the primary focus of treatment; (3) a severe learning disability or insufficient English language ability to complete study procedures. Written informed consent was obtained from all participants. The TAU comparison group (*n* = 224) were patients aged 16-25 years with an ED illness duration of <3 years who were referred to the ED services during the 1.5 to 2-year period before the implementation of FREED. Electronic patient records were screened to identify TAU patients that were of comparable age and illness duration to FREED patients. The present study largely focused on data from FREED patients with PJRs. However, wait time data for TAU were included for comparison purposes.

4.3.2 Outcomes

4.3.2.1 Sample characteristics

Sociodemographic and Eating Disorder Examination Questionnaire (EDE-Q) data were collected at baseline. The EDE-Q is a 28-item questionnaire measuring attitudinal and behavioural aspects of EDs in the past 28 days (Fairburn & Beglin, 1994). Only the EDE-Q global score is reported here. The global score consists of 22-items covering the

domains of dietary restraint, eating concerns, concerns about weight, and concerns about shape. Each item is rated on a 7-point scale for severity or frequency, with higher scores indicating greater ED psychopathology.

4.3.2.2 Wait times

Wait times for the engagement call, assessment, and treatment were defined as the time from when the referral was received by the service to when the patient received the engagement call, attended the assessment, or attended the first treatment session. Estimates of the average wait times are reported elsewhere (Flynn et al., 2020). Here, count data of the number of patients seen within the FREED timeframes were used: ≤2 working days for the engagement call (i.e., calculation excluded weekends), ≤14 days for assessment, and ≤28 days for treatment. Additionally, count data for the number of patients whose engagement call was initially attempted within 2 days (irrespective of whether it was successful or not), and the number of patients initially offered an assessment ≤14 days or treatment ≤28 days regardless of whether the patient accepted the appointment or not were included. Understanding waits that go beyond the initial timelines could prove informative for understanding any delays and for the development of the FREED model in the future. For this reason, count data for the number of patients seen within extended versions of the wait time targets were also included, in the form of participants seen within 4 weeks (28 days) for assessment and 8 weeks (56 days) treatment.

4.3.2.3 Patient journey records

Data from PJRs, developed for the study and completed by clinicians were used here. PJRs documented the care received by FREED patients from referral up to 1 year. The form records service process data such as date of referral, screening call, assessment, and treatment sessions. It also details (a) the type of evidence-based outpatient psychological intervention provided (i.e., cognitive behavioural therapy for eating disorders [CBT-ED], Maudsley Model of Anorexia Nervosa Treatment for Adults [MANTRA], guided self-help [GSH]), for how many sessions and (b) whether and when FREED-related care package adaptations were provided at assessment or treatment (see Table 11). The form also records any other additional outpatient appointments (e.g., dietician sessions, medical reviews). Only the frequency of these additional appointments was reported, but not their content, as these were assumed to

have a specific purpose, e.g., meal planning in dietician sessions or risk assessment in medical reviews.

4.3.3 Analysis

Statistical analyses were conducted using R programming software (R Core Team, 2020). The frequency (percentage) of adherence to the wait time targets and the overall use of care package components at assessment and treatment are reported. There are limited data on what should be considered as low, moderate, or high adherence/use of the FREED wait time targets and care package. For this reason, the criteria for low, moderate, and high adherence were created by dividing 100% into three equal parts. Specifically, low adherence/use was considered as <33%, moderate adherence/use as 33-66%, and high adherence/use as >66%. Changes in the use of care package adaptations over time were also evaluated by calculating the frequency of use at different stages of treatment. For this, treatment was categorised into five stages: (1) sessions 1 to 5; (2) sessions 6 to 10; (3) sessions 11 to 15; (4) sessions 16 to 25; (5) session 25 to end of treatment. For wait time targets, the key focus was on adherence to the set FREED timelines (i.e., 48 hours for engagement call, 2 weeks for assessment, 4 weeks for treatment) as well as adherence to an extended version of this timeline (i.e., 4 weeks for assessment and 8 weeks for treatment).

Chi-square or Fisher's exact tests were used as appropriate to evaluate whether there were any significant variations in wait time adherence and care package use across diagnostic groups, and treatment group. Moreover, an analysis of the differences in wait time adherence between patients who did and did not receive FREED under optimal condition was conducted. Patients with optimal conditions had minimal external delays (no gatekeeping or patient-related delays, such as patients taking a holiday before commencing treatment), no prior treatment, and/or no transitions from another service. Post-hoc analyses of the adjusted standardised residuals were used to determine which categories had substantially larger or smaller frequencies than expected in the context of a significant chi-square or Fisher's test. Residuals for each category (e.g., patients with AN that had any focus on dietary change) correspond to how much the observed frequency in each category deviates from the frequency we would expect by chance (i.e., null hypothesis). The residuals were then standardised to *z*-scores, which allow us to determine the significance of these deviations. In accordance with statistical conventions, standardised residuals equal to or greater than ±1.96 were considered as

significant at $p < .05$, standardised residuals equal to or greater than ±2.58 as significant at $p < .01$, and standardised residuals equal to or greater than ±3.29 as significant at $p < .001$ (Field, Miles, & Field, 2012). The asterisks in Table 13 and Table 14 relate to the significance level of the adjusted standardised residuals. Specifically, Table 13 compares differences in wait time target adherence across diagnostic groups and Table 14 compares difference in care package component use at assessment or treatment across diagnostic groups. It is important to note that the assessment and treatment contrasts in Table 14 were performed separately for each care package component but were included on the same line in Table 14. Cramér's *V* has been reported alongside the chi-squared tests as a standardised measure of effect with values of 0.1, 0.3, and 0.5 correspond to small, medium, and large effects, respectively. However, as suggest by Cohen these values for small, medium, and large should be used as a general frame of reference (Cohen, 2013). For continuous variables, a robust alternative to the t-test, the Yuen-Welch test *Ty*, based upon 10% trimmed means and Winsorized variances alongside percentile-t bootstrapping (2,000 bootstrap samples) was used (Ozdemir, Wilcox, & Yildiztepe, 2018).

4.4 Results

4.4.1 Sample characteristics

Patient journey records were available for 259/278 (93%) FREED patients in the FREED-Up study. The demographics and clinical characteristics of the patients with PJRs are presented in Table 12. Patients with PJRs did not significantly differ from those without in age, sex, ethnicity, baseline EDE-Q global score, and wait from referral to assessment or treatment (*p*-values varied between 0.16 to 1). Only data from patients with PJRs were included in subsequent analyses.

Table 12. Baseline characteristics of FREED patients with patient journey records.

	AN (n = 109)	BN/BED (n = 69)	OSFED (n = 81)	All (N = 259)
Age in years (*M, SD*)	19.88 (2.09)	20.62 (2.31)	20.22 (2.63)	20.19 (2.34)
Sex (F:M)	105:4	66:3	70:11	241:18
Ethnicity (*n*, %)				
White	75 (69)	36 (52)	59 (73)	170 (66)
Asian	10 (9)	8 (12)	7 (9)	25 (10)
Black	3 (3)	4 (6)	3 (4)	10 (4)
Mixed	6 (6)	10 (15)	3 (4)	19 (7)
Other/unknown	15 (14)	11 (16)	9 (11)	35 (14)
EDE-Q (*M, SD*)	3.69 (1.43)	4.38 (0.90)	4.28 (1.07)	4.06 (1.23)

Notes. FREED = First Episode Rapid Early Intervention for Eating Disorders; AN = anorexia nervosa; BN = bulimia nervosa; BED = binge eating disorder; OSFED = other specified feeding or eating disorder; EDE-Q = Eating Disorder Examination Questionnaire.

4.4.2 Wait-target adherence

Adherence to FREED wait time targets is shown in Table 13 along with the percentage of FREED patients who received an assessment and treatment according to extended (4 and 8 weeks) wait time targets. The engagement call was initially attempted within 48-hours for 89% of patients with approximately 50% actually receiving the call within this time, irrespective of diagnosis (attempted:$\chi^2(2) = 2.18$, $p = .34$, $V = 0.10$; received: $\chi^2(2) = 0.54$, $p = .76$, $V = 0.05$), or whether they received FREED under optimal conditions (attempt: $\chi^2(1) = 0.01$, $p = .90$, $V = 0.01$; received: $\chi^2(1) = 1.01$, $p = .31$, $V = 0.07$).

Overall, 51% of FREED patients were offered and 43% of FREED patients actually received their assessment within 2 weeks. This was substantially higher than TAU patients ($\chi^2(1) = 30.06$, $p < .001$, $V = 0.25$). Only 19% of TAU patients were seen for assessment within 2 weeks. Diagnostic group did not impact whether FREED patients were offered or seen within 2 weeks for assessment (offered: $\chi^2(2) = 1.70$, $p = .43$, $V = 0.08$; received:$\chi^2(2) = 1.52$, $p = .47$, $V = 0.08$). The number of patients waiting less than 2 weeks increased significantly for offered ($\chi^2(1) = 8.83$, $p < .01$, $V = 0.18$) and attended ($\chi^2(1) = 8.88$, $p < .01$, $V = 0.18$) assessments if patients were seen under optimal conditions.

Thirty-three percent of FREED patients were offered treatment and 22% started treatment within 4 weeks. Again, this was substantially higher than the TAU group with only 3% of this group starting treatment within 4 weeks ($\chi^2(1) = 30.10$, $p < .001$, $V = 0.26$). Slightly more FREED patients with anorexia nervosa (AN) were offered treatment within 4 weeks compared to bulimia nervosa (BN)/binge eating disorder (BED), and other specified feeding or eating disorder (OSFED), however, this difference did not reach statistical significance (offered: $\chi^2(2) = 5.26$, $p = .07$, $V = 0.15$). Diagnostic group did not impact the number of FREED patients attending treatment within 4 weeks (received: $\chi^2(2) = 0.65$, $p = .72$, $V = 0.05$). Receiving FREED under optimal conditions significantly increased the likelihood of being seen within 4 weeks (received: $\chi^2(1) = 4.08$, $p = .04$, $V = 0.12$) but did not significantly impact the number of patients offered treatment within this time frame (offered: $\chi^2(1) = 1.46$, $p = .29$, $V = 0.07$).

Extending the wait time targets for received assessment and treatment to 4 and 8 weeks resulted in a considerable increase in adherence rates, to 73% and 58% respectively. The increase in adherence was even more striking for offered assessment and treatment appointments (80% and 67%) or if patients with external delays were excluded (85% and 69%).

Table 13. Adherence to service wait time targets for all patients and patients with optimal conditions.

	FREED All patients				FREED Patients with optimal conditions			
	AN	BN/BED	OSFED	All	AN	BN/BED	OSFED	All
Engagement call								
Attempted ≤48 hours (*n*, %)	93/101 (92)	53/59 (90)	63/74 (85)	209/234 (89)	50/54 (93)	42/47 (89)	36/42 (86)	128/143 (90)
Received ≤48 hours (*n*, %)	53/100 (53)	32/66 (49)	36/75 (48)	121/241 (50)	26/55 (47)	24/50 (48)	20/42 (48)	70/147 (48)
Assessment								
Offered ≤2 weeks (*n*, %)	54/104 (52)	36/63 (57)	36/78 (46)	126/245 (51)	35/55 (64)	31/48 (65)	20/42 (48)	86/145 (59)
Received ≤2 weeks (*n*, %)	50/109 (46)	30/69 (44)	30/81 (37)	110/259 (43)	30/55 (55)	28/55 (55)	17/43 (40)	75/149 (50)
Received ≤4 weeks[a] (*n*, %)	78/109 (72)	49/69 (71)	61/81 (75)	188/259 (73)	45/55 (82)	43/51 (84)	38/43 (88)	126/149 (85)
Treatment								
Offered ≤4 weeks (*n*, %)	40/100 (40)	20/63 (32)	18/76 (24)	78/239 (33)	23/52 (44)	17/46 (37)	10/42 (24)	50/140 (36)

Received ≤4 weeks (*n*, %)	28/108 (26)	15/69 (22)	17/79 (22)	60/256 (23)	17/54 (32)	14/51 (28)	10/41 (24)	41/146 (28)
Received ≤8 weeks[a] (*n*, %)	64/108 (59)	41/69 (59)	42/79 (53)	147/256 (57)	40/54 (74)	35/51 (69)	26/41 (63)	101/146 (69)

Notes. All comparisons displayed in this table were evaluating differences in wait time target adherence across diagnosis for all FREED patients and FREED patients with optimal conditions, separately. The asterisks (i.e., significance levels) correspond to the post-hoc adjusted standardised residuals. AN = anorexia nervosa; BN = bulimia nervosa; BED = binge eating disorder; OSFED = other specified eating disorder.

[a]Extended wait time targets.

$^{***}p < .001$ $^{**}p < .01$ $^{*}p < .05$

4.4.3 Care package adherence

4.4.3.1 Assessment

Assessment data were available for 241/259 (93%) FREED patients with PJRs. As Table 14 shows, most domains of the FREED care package were well-used at assessment, with the exception of attention to transitions. Highly used adaptations included: a verbal discussion about the impact of EDs on brain, body, and behaviour, followed by a verbal discussion of social media use, any discussion of or actual involvement of family/significant others, and the biologically malleability rationale for early intervention. The accompanying online or print resources were less frequently used. Any focus on dietary change occurred in approximately half of all assessments. In accordance with the FREED model, the most widely used components of dietary change at assessment were early nutritional goal setting and meal planning. In relation to significant other involvement, a discussion about involvement was the most frequently reported adaptation, followed by a significant other actually attending the assessment. The significant other most frequently attending the assessment were mothers (57%), followed by romantic partners (11%), parents (9%), siblings (7%), friends (7%), and fathers (5%).

There were significant differences in assessment adaptation use across diagnoses as indicated by the asterisks in Table 14. The asterisks in Table 14 correspond to the post-hoc adjusted standardised residuals. Specifically, any focus on dietary change was less likely in BN/BED relative to AN and OSFED ($\chi^2(2) = 5.84$, $p < .05$, $V = 0.16$). Compared to patients with BN/BED or OSFED, patients with AN were substantially more likely to receive the nutritional booklet ($\chi^2(2) = 7.12$, $p < .05$, $V = 0.17$) and meal planning ($\chi^2(2) = 7.68$, $p < .05$, $V = 0.18$) at assessment. Patients with AN were also more likely to have a significant other attend the assessment than patients with BN/BED ($\chi^2(2) = 14.53$, $p < .001$, $V = 0.25$). Finally, social media use was more frequently explored in OSFED and less in AN ($\chi^2(2) = 7.07$, $p < .05$, $V = 0.17$).

Table 14. Percentage of patients receiving care package adaptations at assessment and treatment.

	AN		BN/BED		OSFED		All	
Adaptations	Ax (n = 102)	Tx (n = 106)	Ax (n = 64)	Tx (n = 68)	Ax (n = 75)	Tx (n =77)	Ax (N = 241)	Tx (N = 251)
Biological malleability rationale for early intervention	80%	49%**	67%	38%	83%	25%**	78%	39%
Psychoeducation on the impact of eating disorders								
Verbal discussion	88%	85%**	88%	96%	87%	96%	88%	91%
Leaflet or online resources given/reviewed	35%	28%	30%	35%	36%	35%	34%	32%
Dietary change								
Any focus on dietary change	58%	98%	41%*	100%	59%	99%	53%	99%
Nutrition booklet given/reviewed	25%**	40%	13%	38%	11%	52%	17%	43%
Meal plan given/reviewed	21%**	82%	6%	85%	11%	74%	14%	81%
Other nutrition information given/reviewed	11%	53%	6%	52%	8%	46%	9%	50%
Nutritional goal set/reviewed	23%	81%	9%	82%	23%	91%	19%	85%
Dietician appointment discussed/made	4%	45%**	2%	25%*	3%	29%	3%	35%
Dietician or dietetic group attended	NA	63%***	NA	25%**	NA	26%***	NA	41%
Family/carer/significant other involvement								
Any focus on significant other involvement	85%	90%***	72%	74%	78%	70%**	80%	79%
Discussed significant other involvement	63%	82%***	48%	63%	55%	56%**	56%	69%

Significant other attended assessment or treatment	40%**	55%***	13%***	25%*	33%	21%***	31%	36%
Discussed carer skills training	27%	39%***	16%	16%*	16%	14%**	20%	25%
Discussed carer support	33%	41%***	17%	21%	24%	12%***	26%	26%
Discussed family therapy	9%	23%	13%	18%	8%	13%	10%	18%
Family session attended	NA	16%	NA	9%	NA	7%	NA	11%
Discussed multi-family therapy	0%	1%	2%	3%	0%	1%	0.4%	2%
Exploration of social media and health-related app use								
Verbal discussion	78%*	53%	86%	62%	92%*	57%	84%	57%
Social media booklet/resources given/reviewed	35%	27%	31%	22%	28%	36%	32%	29%
Exploration of transitions								
Verbal discussion	27%	49%	34%	35%	36%	47%	32%	45%
University Preparation Group recommended	3%	22%	3%	10%	3%	12%	3%	16%
University Preparation Group attended	NA	6%	NA	0%	NA	4%	NA	4%

Note. All comparisons displayed in this table were evaluating differences in care package use across diagnosis at assessment and treatment, separately. The contrast for assessment and treatment were performed separately but included in the same line in this table. The asterisks (i.e., significance levels) correspond to the post-hoc adjusted standardised residuals. AN = anorexia nervosa; BN = bulimia nervosa; BED = binge eating disorder; OSFED = other specified eating disorder; Ax = assessment; Tx = treatment; NA = not applicable.

$^{***}p < .001$ $^{**}p < .01$ $^{*}p < .05$

4.4.3.2 Treatment

Treatment data were available for 251/259 (97%) FREED patients with PJRs. The average number of treatment sessions was 18.09 (*SD* = 11.70, range 0-57), with AN receiving more (*M* = 22.83, *SD* = 12.74) compared to BN/BED (*M* = 14.10, *SD* = 8.34), and OSFED (*M* = 15.03, *SD* = 10.44). Patients with AN received CBT-ED (49%), MANTRA (48%), cognitive analytical therapy ([CAT] 6%), or family-based therapy ([FBT] 1%). Patients with BN/BED received CBT-ED (83%), GSH (9%), or CAT (3%). Patients with OSFED received CBT-ED (90%), MANTRA (6%), FBT (3%), or CAT (2%).

Table 14 shows the overall use of care package adaptations during treatment, and Figure 4 depicts the change in adaptation use over time. Similar to assessment, psychoeducational discussions on the impact of EDs on brain, body, and behaviour remained high throughout treatment. In contrast, the biological malleability rationale was less frequently used during treatment relative to assessment. Social media and health-related app use was also less frequently explored in treatment relative to assessment with most discussions occurring within the first five sessions of treatment (stage 1 = 43% vs stage 5 = 21%). The use of accompanying online and print resources remained low during treatment, with the exception of the nutrition booklet which was used more during treatment relative to assessment. The most highly used domain of the care package during treatment was any focus on dietary change. Amongst the dietary change related activities, nutritional goal setting and meal planning were the most frequently used. Approximately 40% of patients saw a dietician individually or in a group setting at some point during treatment.

Overall, any type of significant other involvement remained high during treatment. Discussions about significant other involvement and actual attendance were the most frequently used carer-related activities. Carer support and skills training were less frequently used. Most carer-related activities occurred within the first five sessions of treatment with the exception of attendance which peaked at stage 5. There were limited discussions of family and multifamily therapy, and family sessions taking place. Similar to assessment, mothers tended to be the person who most frequently attended the treatment sessions (47%), followed by parents, families or fathers (37%) and others (16%). Attention to transitions increased during treatment relative to assessment,

however, discussions of or use of the University Preparation groups remained low. Unlike most adaptations, use of attention to transitions steadily increased over the course of treatment (22% at stage 1 vs 55% at stage 5).

As highlighted by the asterisks in Table 14, patients with AN were significantly more likely to have discussions around dietetic involvement ($\chi^2(2) = 9.34$, $p < .01$, $V = 0.19$), attendance to dietetic appointments or groups ($\chi^2(2) = 35.86$, $p < .001$, $V = 0.38$), any type of significant other involvement ($\chi^2(2) = 12.20$, $p < .01$, $V = 0.22$), discussions around significant other involvement ($\chi^2(2) = 15.74$, $p < .001$, $V = 0.25$), significant other attendance at treatment ($\chi^2(2) = 27.34$, $p < .001$, $V = 0.33$), and discussions around carer skills training ($\chi^2(2) = 18.07$, $p < .001$, $V = 0.27$) and support ($\chi^2(2) = 20.76$, $p < .001$, $V = 0.29$). Moreover, patients with AN were more likely to receive the biological malleability rationale for early intervention during treatment ($\chi^2(2) = 11.19$, $p < .01$, $V = 0.21$). In contrast, patients with BN/BED and OSFED were significantly more likely to receive psychoeducation on the impact of EDs than AN ($\chi^2(2) = 9.20$, $p < .01$, $V = 0.19$), but use was high across all groups.

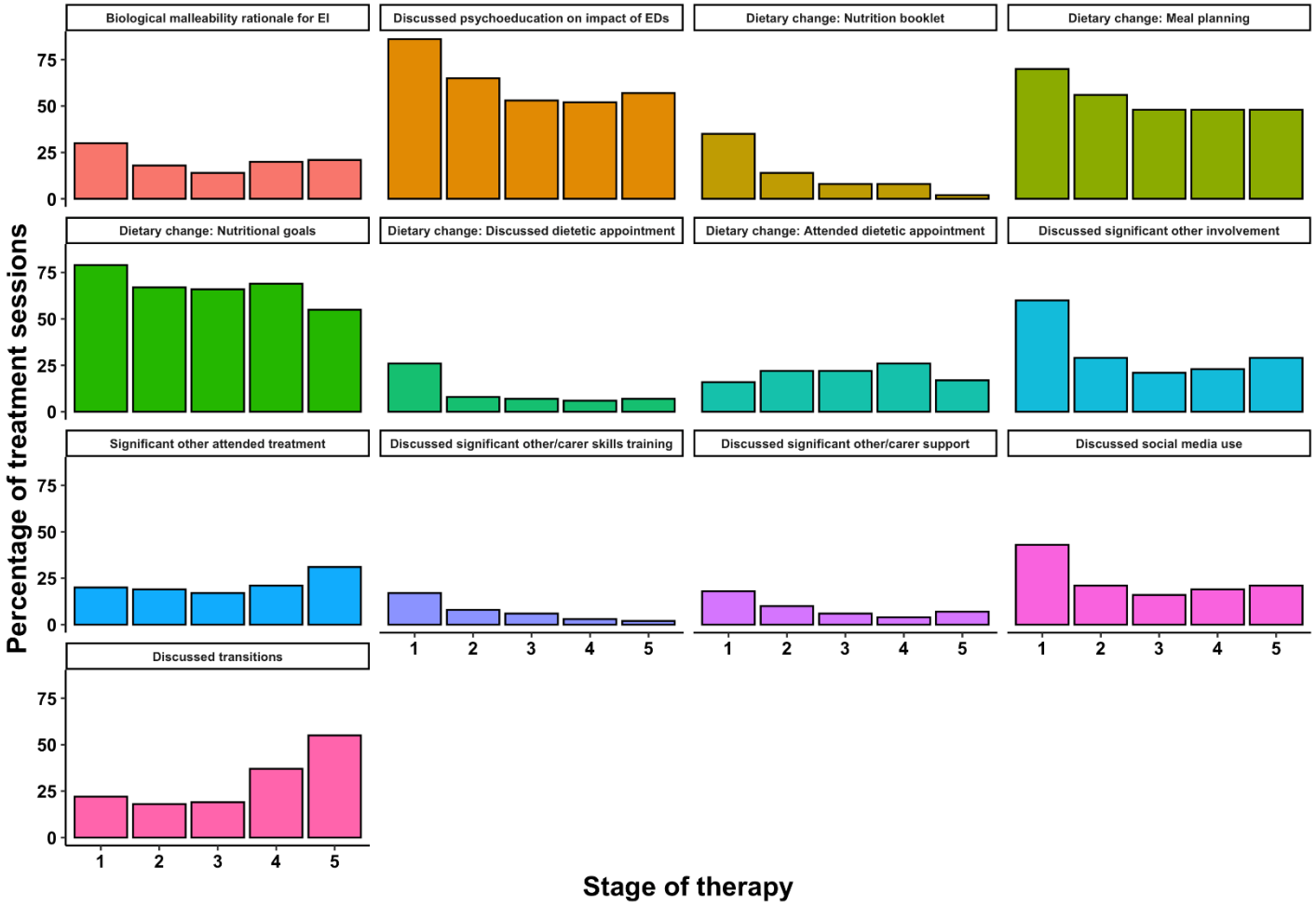

Figure 4. The frequency (percentage of sessions) of use of FREED treatment adaptations across stages of therapy. Stage 1: sessions 1 – 5; Stage 2: sessions 6 – 1; Stage 3: sessions 11 to 15; Stage 4: sessions 16 to 25; Stage 5: session > 25. EI = early intervention; ED = eating disorders.

4.5 Discussion

The process of translating new interventions into real-world clinical settings is complicated. The RE-AIM framework, a tool for enhancing the implementation and generalisability of interventions, was used to support the translation of FREED from a single-site research project to a wider initiative with the aim of reaching as many young people as possible (Allen et al., 2020). The purpose of this study was to evaluate the *Implementation* dimension of the RE-AIM framework in the multi-site FREED-Up study. Specifically, we evaluated adherence to two key components of the model during the study, the wait time targets and the care package, and whether adherence varied overtime, or across diagnostic and treatment groups.

4.5.1 Wait-time targets

Most patients, irrespective of diagnosis, had their engagement call attempted within 48 hours with approximately half receiving the call within this timeframe. This suggests that although the 48-hour target is a realistic goal for services, that actually getting the patient on the phone can be challenging. Patients frequently require multiple phone calls, may not feel comfortable talking over the phone, or may be ambivalent or refuse to engage with clinicians. Ambivalence can be particularly problematic in early-stage illness where the negative physiological and psychosocial consequences of EDs may not be as apparent to the young person (Potterton et al., 2020a). To overcome these barriers FREED advocates for a flexible and pro-active approach when engaging patients using their preferred method of contact (e.g., email, text). Specifically, if initial engagement attempts were unsuccessful, clinicians tried different methods of contact with a higher number of attempts over a longer period of time than traditionally used in services, i.e., did more ‘chasing’. Once contact was established, patients were also asked what method of contact they would prefer. This provides patients with a greater sense of autonomy in how they communicate with the service.

There was moderate adherence to the 2-week wait time target for assessment and low adherence to the 4-week wait time target for treatment. However, the introduction of FREED led to large increases in the number of patients seen within these timeframes. Double the number of patients were seen within 2 weeks for assessment and almost 10 times as many patients were seen within 4 weeks for treatment. Substantial differences were also evident between offered and attended appointments for those with and without external delays, suggesting that external and patient-related factors require

special attention when addressing delays to care. Patient-related delays could be addressed through evidence-based public awareness campaigns (Ali et al., 2020) and the development of tools, apps, and online resources to support EAs to seek help earlier. There was also a trend towards patients with AN being more likely to be offered treatment within 4 weeks.

This study provides an indication of the percentage of patients' that teams can expect to see within the wait time targets in real-world clinical settings: ~90% for attempted engagement calls <48 hours, ~60% offered an assessment <2 weeks, and ~30% offered treatment <4 weeks. This level of adherence was associated with significant reductions in wait times and DUEDs relative to TAU (Flynn et al., 2020), suggesting that these adherence rates are clinically meaningful irrespective of whether the targets were achieved or not. However, adherence to the assessment and treatment targets were low to moderate. Barriers to adherence need to be addressed in the future implementation of FREED. Targets should be challenging but also realistically achievable with the available skills and resources. Unattainable targets can motivate in the short-term, but eventually lead to frustration and stress (Locke & Latham, 2019; McCann, Granter, Hassard, & Hyde, 2015). Additional resources or an extension of the wait time targets may therefore be warranted for some teams using FREED. Extending targets for assessment and treatment to 4 and 8 weeks respectively led to vast improvements in adherence rates and may thus serve as achievable interim targets.

Our findings are timely given recent commitments by NHS England to introduce access and wait time standards for mental health services (Powis, 2019). Wait time standards of treatment within 4 weeks from referral for routine cases and 1 week for urgent cases have already been introduced in child and adolescent ED services (CAEDS) (NHS England, 2015). In the second quarter of 2020/21, 85% of referrals started urgent treatment within a week and 90% started routine treatment within 4 weeks. Approximately 65% were seen within these targets when they were first introduced in 2016 (NHS England, 2020a). Considerable and continued investment in CAEDS (an additional £30 million funding a year in the first instance and a further £11m in 2019/20 and 2020/21), rigorous performance monitoring, and a national program of training and support were vital to enable such vast improvements in target adherences. Our study provides the first evaluation of adherence to wait time targets in adult ED services but with very limited government investment to date (Academic

Health Science Network, 2020; NHS England, 2020b). Of note, the CAEDS waiting time targets use initial assessment as the start of treatment, which is more lenient than our separate assessment and treatment targets. If we apply this more lenient criterion here, around 70% of our FREED-Up patients would have been seen within the target period (Flynn et al., 2020). This findings must be seen against the wider backdrop of resource constraint within adult ED services in the NHS, something that is only likely to be exacerbated by the ongoing coronavirus pandemic (Charlesworth, Watt, & Gardner, 2020).

4.5.2 Care package

Overall, the care package adaptations were well-used during the FREED-Up study, increasing confidence in the extent to which this aspect of the model facilitates positive outcomes. The overarching domains were highly used at assessment or treatment with the exception of attention to transitions which was used in approximately half of all cases at either stage of care. This may be understandable given not all patients will experience transitions whilst in treatment, despite the relevance of transitions to the EA developmental stage. Attention to transitions did, however, increase over the course of treatment, probably owing to the increased likelihood of transitions in later stages of treatment. Most other adaptations had a pattern of decreasing use overtime, which is anticipated as once a topic is addressed it may not be necessary or appropriate to continue with it. Moreover, the therapeutic focus often becomes broader in the later stages of ED treatment (Couturier, Isserlin, & Lock, 2010; Dimitropoulos et al., 2020). However, attendance by significant others peak in the last stage of treatment. This could be due to the type of patients (mainly AN) receiving over 25 sessions of treatment or due to it taking time to persuade young people to involve significant others.

Any focus on dietary change and psychoeducation were the most used adaptations in treatment. This is reassuring given that nutritional rehabilitation is central to any evidence-based ED treatment. However, dietary change-related activities were only moderately used at assessment which is disappointing given that early nutritional change is one of the primary principles of FREED. Limited use of dietary change-related activities at assessment could be due to patient-related ambivalence, clinician reservations, and/or time constraints in the assessment session.

Some components of the care package had low to moderate use, specifically, accompanying print/online resources, discussions of family or multi-family therapy, carer skills training and support, and the University Preparation groups. These components may be considered as more supplementary than other aspects of the care package or may only have been discussed if the ED service could provide that facility. Increasingly, there is a trend towards not only online but app-based or interactive online materials and revising FREED care package components accordingly may be helpful.

The use of care package adaptations varied across the diagnostic groups. Patients with AN were more likely than other diagnoses to receive a focus on early dietary change at assessment and dietetic involvement during treatment, as well as significant other involvement, particularly significant other attendance, support, and skills training. Compared to BN/BED, patients with OSFED also received a higher focus on early dietary change, possibly due to AN-type presentations within this group. AN is typically (but not always) a more outwardly visible illness which may influence the perceived need for early nutritional change and signify to close others that the individual is unwell and requires support. In contrast, the shame and secrecy associated with other EDs may inhibit their disclosure and therefore require more effort to encourage significant other involvement. This imbalance in provision of nutritional advice and support, and significant other involvement needs to be considered further in the future implementation of FREED.

It is important to note that body image-related issues are not specifically addressed in the FREED care package. Body image-related issues are a well-established risk and maintenance factor for disordered eating and EDs (Fuller-Tyszkiewicz et al., 2022; McLean & Paxton, 2019; Vall & Wade, 2015). Body image-related issues have been described as a key therapeutic component and are addressed within many evidence-based ED treatments and manuals (e.g., CBT-E, “Getting Better Bite by Bite” self-help/guided self-help programme) (McLean & Paxton, 2019; Pennesi & Wade, 2016; Schmidt, Treasure, & Alexander, 2016d). The aim of the care package is to tailor, extend and adapt these evidence-based treatments to the needs of individuals in early-stage illness and emerging adults. While body image issues are important targets in ED prevention and treatment, they are already addressed within standard evidence-based treatments and are not specific to early-stage illness nor the emerging adulthood stage of life, although the nature of body image concerns may vary by age (Christian et al.,

2020; Christian et al., 2021; Matsumoto & Rodgers, 2020; McLean & Paxton, 2019; Peat, Peyerl, & Muehlenkamp, 2008). Therefore, body image-related issues, while important to address, were not included in the FREED care package. However, social media, a youth relevant maintenance factor for body image concerns, is specifically addressed in the FREED care package. Given the central role of body image in the aetiology and maintenance of EDs, it should be considered within standard evidence-based ED treatments and as a target for measurement within future studies of FREED.

4.5.3 Limitations

There are several limitations to the current study that require consideration when interpreting the results. First, care package adaptation use was only assessed using clinician self-report. While clinician-reported fidelity is efficient and non-intrusive, there are concerns regarding the accuracy of this method. Some studies find weak to moderate agreement between clinician and observer estimates (Hogue, Dauber, Lichvar, Bobek, & Henderson, 2015). Further validation of this mode of fidelity monitoring for FREED should be the focus of future research. Second, this study did not evaluate the way in which care package adaptations were used, i.e., the style and quality of delivery. Merely mentioning social media versus having an in-depth discussion about it as a maintaining factor are likely to have profoundly different effects on patient outcomes but would be noted down equally on the PJR. Limited information on the quality of delivery also prevented any meaningful evaluation of the impact of these adaptations on outcome. Thirdly, the non-randomised design limits the causal conclusions that can be drawn regarding the impact of FREED on wait times target adherence (Flynn et al., 2020). Finally, the data were collected within the context of a research study. It is unclear to what extent these adherence rates will generalise to settings outside of the study or when FREED becomes ‘business as usual’.

4.5.4 Conclusion

This study evaluated the *Implementation* of FREED, with attention to waiting time and care package adherence. To the best of our knowledge this is the first evaluation of adherence to wait time targets in adult ED services, providing a benchmark, not only for FREED, but for what might be possible in NHS ED services. Our findings suggest that adherence to the FREED wait time targets can be an achievable goal but require ongoing monitoring and refinement to ensure that the selected targets closely align with the baseline capacity of each team. This study also sheds light on how much and at what

point FREED care package adaptations were used. There was moderate to high use of the overall domains of the care package that varied over the stages of treatment and between diagnoses. This supports the applicability of FREED and suggests that care package adaptations are an important part of how FREED improves clinical outcomes. However, further validation of adherence, the quality of delivery, and its impact on outcomes is needed. A better understanding of adherence to key components of the FREED model (and evidence-based treatments more generally) is essential for conclusions regarding what is integral to its effectiveness and what aspects of the model may need to be adapted or refined.

Chapter 5. Early adopter perspectives of First Episode Rapid Early Intervention for Eating Disorders in England: A qualitative study

Author contributions: The study was conceptualised and designed by the candidate (Katie Richards), Professor Ulrike Schmidt, and Dr Karina Allen. The candidate recruited participants and conducted the qualitative interviews. The interviews were transcribed by the candidate and Luiza Grycuk with assistance from an automated transcription service. The interviews were coded and analysed by the candidate. Four interviews were independently coded by Mathew Phillips and compared to the candidate's codes to measure the trustworthiness of the analysis. Four study participants, Professor Ulrike Schmidt, and Dr Karina Allen provided constructive feedback on the results. The candidate drafted the chapter and Professor Ulrike Schmidt, Dr Karina Allen and Michaela Flynn reviewed and provided constructive feedback on the chapter.

5.1 Abstract

Background: Successfully scaling innovations in healthcare can be slow and bewilderingly complicated. The attitudes and experiences of clinicians from early adopter FREED sites were sought to understand barriers and facilitators to the implementation and scaling of this early intervention model.

Method: Semi-structured interviews were conducted with 21 clinicians involved in the implementation of FREED across eight rural and urban ED services. All included services were early adopters of FREED. The sample were largely female (90%), had a mean age 34.8 years (*SD* = 8.47), and consisted of 11 psychologists/psychotherapists, six nurses, and four other professions. An inductive thematic analysis was used to generate initial themes. The Normalisation Process Theory (NPT) was then applied to the themes to further evaluate underlying mechanisms and normalisation.

Results: The inductive coding generated six overarching themes consisting of 15 subthemes. These captured barriers and facilitators to implementation at the wider system, implementation strategy, service, model, clinician, and patient levels. Overall, clinicians' views about early intervention were positive, although reservations about capacity and the potential impact on patients not eligible for FREED were shared. The most prominent barriers were capacity and competing demands, and the most prominent facilitators were clinician enthusiasm and drive to implement FREED. FREED was largely normalising or normalised in many services with high levels of coherence, cognitive participation, collective action, and reflexive monitoring.

Conclusion: Interviewed clinicians were highly enthusiastic about early intervention in EDs and FREED, largely because of the prospect of improving patient outcomes. This was a considerable driver in the uptake and implementation of FREED. Features of the model and implementation strategy were effective at developing adopter enthusiasm, commitment, and capabilities. However, there were notable concerns about capacity, the impact on other patients, and aspects of the model and its implementation which require further development in the future.

5.2 Introduction

The FREED pilot and upscaled studies demonstrated that FREED is feasible, reduces wait times and DUED, and improves outcomes (Austin et al., 2021b; Brown et al., 2018; Flynn et al., 2020; McClelland et al., 2018). These positive findings led to additional funding and support to continue to scale and evaluate FREED. One of the main objectives of the next phase of implementation was to scale FREED to all ED services in NHS England (Allen et al., 2020). However, even with robust evidence of benefit, it can be difficult to achieve widespread use and replication of desired effects in new contexts and settings (Greenhalgh & Papoutsi, 2019; Horton et al., 2018). Healthcare systems are complex with many interacting parts, resource constraints, and entrenched ways of working. Prolonged periods of active change efforts and implementation are often needed to successfully scale interventions across healthcare systems (Damschroder et al., 2009a; Greenhalgh & Papoutsi, 2019; May & Finch, 2009). Understanding the most important barriers and facilitators to this implementation is central for developing effective change and implementation strategies, which can increase the likelihood of widespread adoption and maintenance in routine clinical practice (Skivington et al., 2021). To date, there has been no evaluation of implementation strategies or barriers and facilitators to implementing FREED (or any other early intervention programmes for EDs) across a range of settings.

The perceptions and experiences of frontline staff and clinicians (‘adopters’) are arguably one of the most fundamental units when trying to understand barriers and facilitators to implementation (Fishman et al., 2021; Godin et al., 2008; May & Finch, 2009). Adopter attitudes and therefore commitment and willingness to actively engage with and support a new practice (‘buy-in’), are cited as essential for successful implementation (Damschroder et al., 2009a; Greenhalgh et al., 2004; Greenhalgh et al., 2017; Mathews & Crocker, 2016). The perception of a practice as advantageous has been described as the *sine qua non* of adoption (Greenhalgh et al., 2004). However, the perception of a practice is by no means sufficient as additional social and contextual obstacles, such as lack of capacity and management support, can impede even the most enthusiastic clinician.

Limited data exist on clinician attitudes towards, and experiences with, implementing early intervention services in mental health generally and EDs specifically. Only 5/66 documents in the scoping review in Chapter 3 mentioned or

evaluated clinician opinions (Austin et al., 1999; Choudhury-Peters & Dain, 2016; Haver & Franck, 1997; Judd et al., 2011; Nash et al., 2021), and only an additional four studies not included in that review were identified as relevant to this topic (Ghio et al., 2015b; Gavin et al., 2008; Renwick et al., 2008; Rosen et al., 2012). Overall, data from these studies suggest that clinicians tend to hold positive attitudes towards early intervention with many perceiving it as useful, important, and beneficial for patients. For EDs specifically, a national survey of clinicians in Italy found that 71% of respondents considered early intervention for EDs to be "very important", second only to psychosis (Ghio et al., 2015b). Simultaneously, clinicians were concerned about insufficient resources, gaps in service provision, and the implications for other patients who are not eligible for early intervention. Other key barriers to the provision of early intervention included stigma, a lack of specific knowledge and training, doubts about the effectiveness of early intervention, poor patient insight and ambivalence, and poor inter-service communication and collaboration. Many of the abovementioned studies collected data using surveys, which can restrict or bias outcomes, and/or only included individuals not directly involved in the implementation itself (e.g., GPs). Moreover, apart from Ghio et al. (2015b), none evaluated attitudes or experiences towards early intervention for EDs. While some generic barriers and facilitators may impact different implementation projects, the relative important and constellation of these is unique for each type of intervention and implementation context.

The primary aim of this study was to evaluate the perceptions and experiences of clinicians implementing FREED, particularly attitudes towards early intervention for EDs and FREED, implementation processes, and perceived barriers and facilitators to implementation. All clinicians interviewed in this study were from early adopter sites (i.e., planned to or began implementing the model before national scaling). While only accounting for a small number of potential adopters (~15%), early adopters can "lead the way" and are important in the wider dissemination of new interventions and services (Dedehayir, Ortt, Riverola, & Miralles, 2017; Robert, Morrow, Maben, Griffiths, & Callard, 2011). Early adopters provide early and valuable insights into what does or does not work and decrease uncertainty for the later majority (Rogers, 2003). Early adopters can also hold more optimistic perceptions and a positive orientation towards innovations, which can facilitate their use (Dedehayir et al., 2017; Makam et al., 2014).

However, this positive orientation is important to bear in mind when considering the generalisability of the findings in this chapter.

As there is no existing literature on the topic, a qualitative approach was selected to enable an in-depth understanding of the attitudes and experiences of clinicians. Given the analytical level of this study (i.e., focused on the thoughts, feelings, and actions of clinicians), the Normalisation Process Theory (NPT) was used as an explicit conceptual lens through which to understand the implementation and embedding of FREED. The NPT outlines the individual and collective mental and material work needed to integrate and embed (i.e., normalise) a new intervention into routine clinical practice (May & Finch, 2009). This work is operationalised through four generative mechanisms which are outlined in Table 2 in Chapter 1. In brief, these four generative mechanisms are: (1) coherence: the individual and collective sense-making work people do around a set of practices, (2) cognitive participation: the work of enrolling and sustaining engagement in a set of practices, (3) collective action: the individual and collective work people must do to enact a set of practices (e.g., integration into context, developing accountability, allocating resources, and training), and (4) reflexive monitoring: the individual and collective appraisal work people engage in around a set of practices (May & Finch, 2009).

5.3 Methods

5.3.1 Study design and context

Semi-structured qualitative interviews were conducted with clinicians working in eight rural and urban specialised ED services in NHS England. All included services were early adopters of FREED. At the time of interview, the services had been implementing the model for a minimum of 5 months (range = 5 to 72 months). Data collection took place between February 2020 and April 2021. During this time, services faced the unprecedented challenge of implementing FREED during the coronavirus disease 2019 (COVID-19) pandemic. In April 2020, FREED was also selected for national adoption and scaling by the Academic Health Science Network (AHSN) (Academic Health Science Network, 2020). The FREED model is outline in Figure 1 in Chapter 1 and the FREED implementation strategies are provided in Table 1 in Chapter 1.

5.3.2 Procedure

Ethical approval was obtained from King's College London Psychiatry, Nursing and Midwifery Research Ethics Panel (LRS-18/19-13005) and the Health Research Authority for England and Wales (19/HRA/5347). Ethical approval documents are provided in Appendix B Section 10.2.1. Participants were purposefully sampled for diversity in career stage and experience with FREED. Key contacts at each site were approached for participation and to promote the study within their FREED team. Recruitment materials (poster and email) for the study are provided in Appendix E Section 10.5.1. Written informed consent was obtained from all participants. The participant information sheet and consent form are in Appendix C Section 10.3.1 and Appendix D Section 10.4.1. The interviews were conducted over the phone (n = 15), in-person (n = 2) or via video calls (n = 4). The average length of the interviews was 63 minutes (range = 32 to 118 minutes). A topic guide (in Appendix F Section 10.6.1) was flexibly used to guide the interviews. The topic guide was iteratively developed and included questions on attitudes towards, and experiences of, early intervention for EDs and FREED, barriers and facilitators to implementation, and NPT mechanisms. Additional questions on the impact of COVID-19 were also added during the study. Interviews were recorded and transcribed verbatim.

The researcher's role and biases were carefully considered throughout the study (i.e., a member of the FREED implementation team with a positive bias towards the model). The researcher explicitly pursued lines of negative enquiry and actively worked against positive biases to try and balance this. An emphasis was placed on confidentiality and anonymity, and the need to understand positive and negative views and experiences of early intervention and FREED. Reflective field notes were created immediately after each interview to further explore interview context and researcher bias. Moreover, the findings of the initial inductive thematic analysis were distributed to four participants for comments and feedback (i.e., member checking). All participants felt that the results were an accurate reflection of their experience.

5.3.3 Analysis

The analysis was conducted in NVivo 12 (QSR International Pty Ltd., 2020). A two-stage approach was used to analyse the data (Macfarlane & O'Reilly-de Brún, 2012). First, an inductive reflexive thematic analysis was conducted (Braun & Clarke, 2006, 2019). As much as possible, this analysis was data driven (MacFarlane & O'Reilly,

2012). However, the NPT was used as a sensitising framework for the topic guide, which influenced initial coding and emergent themes. The lead researcher (KR) initially immersed themselves in the data by transcribing, listening, and reading/re-reading the interviews. Interesting features of each transcript and all meaning units relevant to the study aims were coded. As the coding progressed, codes were grouped into larger themes and sub-themes based on recurring experiences across the data. Once initial coding was complete, the codes, sub-themes, and themes were re-organised/collapsed, defined, and described. In the second stage of the analysis, each NPT construct was applied to each subtheme to establish if any NPT mechanisms impacted the subtheme and to what extent, and to provide insights into if and how FREED becomes embedded and normalised.

A critical realist perspective was adopted throughout the study, i.e., there is a real, knowable world but our understanding of this world can only be gained through a filter of human experience and interpretation (Fletcher, 2017). The "findings" therefore reside within the intersection between the data and the researchers' contextual and theoretical interpretations (Braun & Clarke, 2019). Given this epistemic approach, data saturation was not used to determine sample size (Braun & Clarke, 2021b). Instead, the focus was on interviewing at least two clinicians from each early adopter FREED team. Unfortunately, this was not feasible in two teams due to limited capacity. Although data saturation was not sought, sub-theme saturation was obtained by interview six and 90% of the codes were created by interview 11 (100% of the most frequent codes were identified by interview 10).

While intercoder reliability (ICR) is not typically used as a measure of quality in reflexive thematic analysis (Braun & Clarke, 2021a), a portion (20% = 4 interview transcripts) of the data were independently coded and evaluated for similarity of outcome (i.e., ICR). This analysis was conducted to evaluate the trustworthiness and credibility of the results. Given the interpretative, situated (i.e., based in a specific context/time/place/situation), and organic nature of the analysis, a direct overlap in the codes was not anticipated. The aim of this analysis was not to control for or entirely remove researcher subjectivity from the analytical process, but to provide the reader with some reassurance that the researcher's role and biases have not impacted the analysis to such an extent that the findings are invalid. In addition to this, and as

outlined in the procedure section, member checking was also performed to evaluate the credibility and trustworthiness of the results.

Four transcripts were independently coded by an experienced qualitative researcher (MP/Coder 2) who was independent from the FREED clinical and research team. MP had some but limited knowledge of FREED and its implementation (i.e., MP was aware that FREED is an early intervention model for EDs but did not know what was included in the model or how the model has been/is implemented and used). The four transcripts were selected using a random number generator in R statistical programming software. Each transcript was divided into data units ("chunks"). Data units were typically responses to interview questions. However, lengthier answers were divided into smaller units. Changes in topic were used to decide where to "break" lengthier answers. The presence and absence of codes for each data unit were then determined. If a code was present in a data unit, then it was given a 1, and if it was absent, it was given a 0. Percentage agreement and Cohen's kappa ICR estimates were calculated for each code and overall (O'Connor & Joffe, 2020). Each ICR estimate has its relatively advantages and disadvantages, i.e., percentage agreement is easy to understand and interpret but does not take into account chance agreement, and Cohen's kappa takes into account chance agreement but assumes a fixed guess rate for each item, and symmetrical and asymmetrical imbalances in the prevalence of codes can drastically impact kappa values, resulting in difficulties with interpretation (Feinstein & Cicchetti, 1990; McHugh, 2012). Cohen's kappa tends to be interpreted as follows: $\kappa \leq 0$ as no agreement, $\kappa = 0.01$ to 0.20 as none or slight, $\kappa = 0.21$ to 0.40 as fair, $\kappa = 0.41$ to 0.60 as moderate, $\kappa = 0.61$ to 0.80 as substantial, and $\kappa = 0.81$ to 1.00 as almost perfect agreement. A value of 80% is recommended as the minimum acceptable level for percentage agreement (McHugh, 2012). Discrepancies in codes and codes with low ICR estimates were re-reviewed and discussed.

The second coder (MP) was not provided with the original codebook as to not unduly influence their coding. The focus of this ICR analysis was on shared and divergent meanings rather than an exact overlap in codes and terminology (Cofie, Braund, & Dalgarno, 2022). For example, the lead coder's (KR) code "*Ageless early intervention/Age criteria expansion desired"* was equated to MP's code "*Belief that FREED can work for any age with short illness duration"* as the sentiment underlying the codes was the same. In some instances, each coders raw codes were split or merged

to create overlapping or divergent codes. This would typically occur when one coder used multiple codes to code for a meaning/idea that the other coder only used one code for. For example, KR had separate codes for each part of the FREED model (e.g., engagement call, care package) when coding ease of use (e.g., "*48-hour engagement calls are easy*"), whereas MP had a single "*Ease of implementation*" code. In this situation, KR's separate ease of use codes were equated to MP's single code. It is important to note that MP's coding scheme was only based upon four interviews and without knowledge regarding the context of FREED and the teams the interviewees were situated in. Therefore, MP's coding scheme was largely focused on data-driven manifest codes rather than higher level meaning-laden latent codes derived from the entire data corpus.

The degree to which the coders varied in their propensity to code the data positively was also evaluated. The content of each code was categorised as positive, neutral or negative towards early intervention and FREED. It is important to highlight that this categorisation was specifically related to thoughts, feelings, and experiences towards the early intervention or FREED. Some codes were positive in their sentiment (e.g., "*The involvement of the wider team in FREED as facilitative*") but were not related to a specific feeling, thought, or experience towards early intervention or FREED so were therefore classed as neutral. Neutral codes were either codes that did not specifically related to an attitude/feeling/experience with early intervention or FREED or the code included both negative and positive experiences (e.g., "*Understanding early intervention and/or FREED*"). The frequency and proportion of each coder's codes classed as positive, neutral, or negative were then calculated. This analysis also provides some insights into the prevalence of positive, neutral or negative attitudes and/or experiences in the interviews.

5.4 Results

5.4.1 Participants

A total of 21 participants were recruited for the study. Nineteen were female and two were male. The age ranged from 20-55 years (M = 34.8, SD = 8.47). Participants included Clinical Psychologists (n = 6), Mental Health Nurses (n = 6), Counselling Psychologists (n = 3), Psychotherapists (n = 2), Assistant Psychologists (n = 2), an Occupational Therapist (n = 1), and a Drama Therapist (n = 1). Eight participants were FREED Champions, and the remaining 13 participants were involved in providing 48-

hour engagement calls, FREED-adapted assessments and treatment, data collection and management, and oversight of the pathway.

5.4.2 Stage 1: Inductive thematic analysis

The inductive thematic analysis resulted in six themes and 15 sub-themes (outlined in Table 15). The six themes are overarching organising concepts for the meaning-laden sub-themes. A table of example quotes for each theme/sub-theme is provided in Appendix G Section 10.7.2.1.

Table 15. Overarching themes and sub-themes.

Theme	**Sub-themes**
Patient	Patient engagement and a first positive experience of services
	Patient complexity and comorbidities
Clinician	Hope and enthusiasm: Making sense of early intervention and FREED
	Conflicting feelings: Eligibility and concerns about non-FREED patients
	Self-efficacy: Experience, stress, and resilience
The model	Flexibility within structure
	Champion as invaluable
	Meeting people where they are at: Care package, resources and going online
Implementation strategy	Practical and ongoing training
	Being part of something bigger: The FREED Network
Service/team	Capacity and competing demands
	Compatibility and integration
	An open dialogue: Sharing, participation, and involvement
Wider system	Broader system of care
	Coronavirus diseases 2019 (COVID-19)

5.4.2.1 Patient

5.4.2.1.1 Patient engagement and a first positive experience of services

Patient engagement was identified as a facilitator for FREED, whereas patient ambivalence was seen as a barrier. In addition, intervening very early, before someone was ready, was seen to result in early disengagement in some cases. FREED was perceived as providing a first positive experience with services (e.g., active engagement process, rapid access), which capitalises on the initial help-seeking motivation and counters early ambivalence. The 48-hour engagement call, a key part of the active engagement process, was a particularly valued and easy aspect of the model. The main barriers for the calls were getting the patient on the phone (which requires 'chasing') and missing information from referrers. The flexibility in the outreach process (e.g., emails, calls, texts) and active support during 'gaps' were highlighted as important for getting and keeping young people engaged. Cultivating hope for recovery and emphasising why intervening early is important were also a key part of the engagement process. Most interviewees reported improved engagement for FREED patients.

P005: "*To try and engage them with a phone call and get them into the service in that positive way, get them kind of knowing what like, I suppose, a friendly voice at the end of the phone*"

However, opinions were not unanimous, six clinicians experienced a notable level of early disengagement or did not feel that FREED improved engagement.

P020: "*I don't know sometimes just getting someone to engage is one of the most challenging things about FREED because they might come to the assessment and then I think what has happened fairly regularly is we'll have assessed and then offered treatment really quick and then we tend to get a bit of disengagement and that's been challenging because of the prolonged engagement process as well like there's quite a lot of steps to it, which is good because obviously it tries to pull people back as much as possible*"

5.4.2.1.2 Patient complexity and comorbidity

Ensuring patients were suitable for FREED was crucial for implementing the model. Clinicians spoke about patients feeling like a 'FREED patient', specifically that they were young and had limited experience and knowledge of mental health and ED services. However, where patients presented with comorbidities, questions around appropriateness of FREED vs other interventions arose. This issue arose specifically in

relation to young people with emerging personality disorders, where there might be a secondary gain from acquiring an ED diagnosis. A thorough evaluation of the function of the ED behaviours at the outset was important to ensure patients were given the right treatment.

P010: "*If you go in too quickly as a service […] they almost aspire to have an eating disorder, and that I'm speaking more of our, we've got some young people who were almost dual diagnosis, so an emerging personality disorder*"

5.4.2.2 Clinician

5.4.2.2.1 Hope and enthusiasm: Making sense of early intervention and FREED

Buy-in and enthusiasm amongst clinicians and senior management were high and identified as crucial for implementing FREED.

P005: "*The team were really really enthusiastic about it*"

Buy-in from senior staff was important as their influence supports wider buy-in and provides an additional level of oversight and support. FREED was perceived as important and needed across all EDs and services, and there was a high level of personal alignment with the model. However, there was variation in enthusiasm with some clinicians being cautious and sceptical about FREED, especially earlier in implementation.

P014: "*I think they know what FREED is and what sort of the concept is and the benefits that it can bring. I think they were a little bit worried at first that it would mean that the waiting list then got longer, but I think as that's clear that's not happened, they're a bit more relaxed*"

Buy-in was primarily driven by the expectation that FREED would improve outcomes and recovery, reduce the length and intensity of treatment, and reduce the impact on the person's life and development. These beliefs were a core part of how clinicians made sense of early intervention and FREED alongside intervening quickly and tailoring treatment to emerging adults with recent-onset EDs.

P010: "*It's being able to get in early when we can do the basics, before things are hardwired and set in and that for me is the most important bit of the work*"

Within all teams, there were key enthusiastic individuals (typically, but not always, the Champion) who were driving FREED forward and using a range of activities to get and maintain buy-in. These activities included training sessions, presentations and workshops, regular updates/reminders, sharing research findings and quarterly data reports, and bringing FREED into discussions with colleagues. The data and research evidence supporting FREED, and FREED being perceived as evidence-based was particularly important for developing buy-in and confidence in the model. The observed impact on patients (e.g., quick/easy change), and positive feedback from patients were also key contributors to the narrative and hope around the model and were highly rewarding for clinicians and boosted morale.

P004: "*The clinicians have really enjoyed working with it […] I guess seeing improved outcomes for FREED patients means that they have they've all got people on their caseload who are doing well and making changes*"

5.4.2.2.2 Conflicting feelings: Eligibility and concerns about non-FREED patients

Clinicians held mixed feelings towards the eligibility criteria and were uncomfortable knowing that some patients were not receiving early intervention. Clinicians were worried about negative effects of prioritising FREED patients on their standard waiting list and the message implied in FREED, i.e., that recovery will be more difficult in later stage illness. These concerns can create tensions within teams and two teams reported that FREED put pressure on their waiting list.

P003: "*Worries about impact on the rest of the waiting list and how it might negatively impact non-FREED patients can potentially put people off*"

Many expressed a desire to expand the age criteria for FREED but also recognised it as pragmatic (i.e., limited resources targeted at peak risk period) and allowed for tailoring to developmental stage. In contrast, the 3-year illness duration criterion was perceived as making sense due to research, but, at times, difficult to calculate. Three teams altered their eligibility criteria. One reduced the lower age limit to fit with their service and found that this worked well. One team expanded the upper limit of age and illness duration criteria but then decided to revise back down due to capacity. Finally, one team removed the upper age limit but, again, revised this back down because they felt that the over 25s did not engage with or benefit from FREED in the same way as younger patients.

P011: "*Our experience of people over 25 is that the uptake wasn't any better than what it was with FREED, if not worse […] we wondered whether at that point it's not a new eating disorder it's become a new behaviour that they've learned to manage a pre-existing mental health issue that they've been struggling with for quite some time*"

FREED was recognised as having a positive impact beyond FREED patients, and this helped counter some of the concerns about the impact on non-FREED patients. Specifically, the FREED principles/ethos/resources were applied to and found to be helpful for non-FREED patients and, in the long-term, FREED was perceived as freeing up resources for the entire service. FREED also enabled greater investment in and development of the service (e.g., an expansion of the team and their remit). Finally, FREED boosted clinician morale and resulted in a more pro-active, flexible, and early intervention-orientated culture within the team. While clinicians recognised that physical risk will always need to be a priority, they were advocates for prioritising on duration to prevent patients from getting to a medically risky state in the first place and valued the shift from solely focusing on physical parameters and chronicity to an early intervention-orientation.

5.4.2.2.3 Self-efficacy: Experience, stress, and resilience

The degree of clinical experience with EDs and FREED, people's belief and confidence in their (self-efficacy) and other's ability to implement the model, and stress and resilience were distinct but overlapping barriers and facilitators for FREED. Newer clinicians found adopting FREED easier as they had no set way of working but were "*still finding their feet*" and learning.

P005: "*Not very difficult but I think that's a little bit because I'm very new and it's the way that I started working and it's not hugely different to- I suppose because I'm very new, and new to the profession in general, I'm quite open to ideas because I haven't got a set way of working yet*"

Those with many years of experience and pre-existing caseloads understandably found the change more difficult. However, seeing the detrimental impact of EDs over many years increased their motivation to implement FREED. A mixture of experiences and skills within the FREED team was perceived as helpful. Regardless of ED experience, anxiety and apprehension were common at the outset. It takes time for

clinicians and the wider team to understand the model, gain confidence, and get used to working with and implementing FREED. Clinician stress on the one hand, and their resilience on the other, were also relevant to the implementation of FREED.

P015: "*Initially when I heard about it, I was a bit anxious about it, and thinking oh God what have I got to do, what is this now ((laugh))*"

5.4.2.3 The model

5.4.2.3.1 Flexibility within structure

FREED provided a clear structure and standardised model that enabled the implementation of early intervention, legitimising the work that clinicians either wanted to or were already engaging in. Clinicians valued the clear structure, they found that it kept them focused on early intervention and reduced the wait for care. Equally, if not more important to clinicians, was the adaptability and flexibility of the model. Awareness of and the ability to adapt parts of the model to fit the local context were a key driver in the adoption and implementation of FREED.

P011: "*We were always encouraged to be quite flexible with how we work as well, trying to understand that the model, you know, the service doesn't have to fit into the model, the model can fit into the service*"

Alongside the adaptability of the model, being flexible, open to change, creative, and/or holding a problem-solving orientated mindset (i.e., focusing on finding adaptive solutions to problems) were identified as significant and overlapping facilitators for FREED. The relationship between the FREED model and flexibility/creativity were reciprocal. FREED pushed and enabled teams and clinicians to be more flexible, which in turn facilitated the implementation of FREED. Not all clinicians valued the flexibility and at the outset some may need more structure and support to implement FREED.

P019: "*... people do want a bit more guidance or support and actually when would be the right time to be doing that so I think maybe the ah it is a structure it's there but it's not a specific structure is it and I think when people are quite new to working with something they like a structure, kind of feels a bit more containing it in that way*"

5.4.2.3.2 Champion as invaluable

P014: "*It's been essential really; I don't think you could do it without the FREED Champion*"

Having a dedicated FREED Champion within the team, was identified as crucial for getting FREED set up, integrated, and keeping it going. Key Champion responsibilities that facilitated the model were being a designated person for FREED-related questions and support, providing detailed management, leadership, and oversight of the pathway, and being an enthusiastic driver with a "*can-do*" attitude. The Champion role was described as busy, demanding, and requiring support from senior staff and the FREED mini team. In many teams, the Champion responsibilities, such as maintaining the tracker and the engagement calls were shared with others (via a rota), but with the Champion still holding oversight.

P009: "*I think FREED Champions work really hard and they do a lot of juggling actually. I think the engagement calls it's a bit different from you know, for example, when you're seeing someone for therapy you generally have a weekly session at a regular time with them. I think when a lot of your responsibility is doing these engagement calls you have to hold a lot more people in mind. There's a lot of it, feels like although it's still obviously very important work, it can feel a bit bitty*"

5.4.2.3.3 Meeting people where they are at: Care package, resources and going online

The care package and adapting treatment to meet the needs of emerging adults was valued by clinicians and perceived as beneficial for patients. FREED enabled greater awareness of the patients developmental and social context and how this might impact treatment. Clinicians found the care package easy to use because the topics were so relevant and/or were familiar from previous experience. However, family involvement was described as more challenging because it depends upon the family's willingness and ability to engage.

P011: "*I think for us it's not always been kind of easy to implement all of those core components of the model for us. I think surprisingly family involvement has always been quite a challenge for us […] because we have a lot of university students, a lot of families are not here in [Place 3]. So, a lot of families live far away, sometimes live abroad, we have a*

lot of students from overseas so actually just people don't know about their eating disorders"

Other barriers for using the care package were knowing how to integrate it into treatment and remembering to use it. Prompts and reminders, such as, altering paperwork and flash cards, and the psychoeducational materials supported clinicians in knowing how and when to use the care package. The FREED resources and materials and providing information online and in different formats (e.g., booklet vs video) were highly valued by clinicians. These resources increased awareness and made the model more accessible and easier to use, particularly when appealing to and engaging with young people.

P005: "*All of the materials that we get from that, I think that's kind of really really crucial in driving it, so that's absolutely, that's a facilitator*"

5.4.2.4 Implementation strategy

5.4.2.4.1 Practical and ongoing training

The FREED training was often described as helpful and inspiring, especially practical tasks, such as role playing and discussions within and between services. Nevertheless, more training was desired, particularly for calculating DUED, managing early disengagement, and integrating the care package.

P019: "*I guess it might be good going through some more examples of where DUED is quite hard to establish"*

The ongoing implementation support and supervision was highly valued and perceived as an essential part of the overall training package. The train-the-trainer model was utilised across sites, whereby the FREED Champion (or other senior clinicians) provided ongoing training and support at each site. The online training was also perceived as helpful and facilitated this internal and ongoing training. This ongoing training was vital to ensure the sustained use of the model.

P019: "*I found it really good actually, I really liked the fact that there was quite a lot of experiential exercises*"

5.4.2.4.2 Being part of something bigger: The FREED Network

The FREED Network, implementation support/supervision, and being part of a wider initiative were consistently described as facilitators and highly valued aspects of the

model. Being part of something bigger contributed towards how important the work felt and made it easier to "sell" to funders/commissioners. Clinicians described the Network and implementation supervision as a supportive space for information sharing, learning, and collective problem-solving. Hearing about the experience of other teams, what has/has not worked, and teething problems was also re-assuring for clinicians.

P014: "*It's nice to know that other people are experiencing the same things that you are and it's really easy to just drop an email to people and ask for advice*"

The Network's data collection and feedback was valued, created a sense of accountability, and enabled teams to stay on track, but was experienced as labour-intensive and challenging with limited resources.

P010: "*... for me is getting everyone to fill in the ROMs ((laugh)). I mean it's just getting those, but I think that's a challenge in any service at any level whether we're doing FREED or not, but just making sure they're on the system. We're not staffed at that level to do that bit…*"

The Network and continued evaluation were identified as important for sustainability, gaining buy-in (especially from commissioners), and for maintaining momentum (i.e., adherence and enthusiasm) with the model. FREED becoming a wider initiative, opportunities for local services to share their experiences with other services, and presentations at conferences and events were outlined as facilitating the spread of the model. These broader dissemination activities were important for "*taking FREED off the pedestal*", i.e., dismantling the notion that FREED is only feasible in some specialist ED services.

5.4.2.5 Service/team

5.4.2.5.1 Capacity and competing demands

P008: "*Because obviously it comes down to the capacity*"

Capacity, in terms of staff, resources, and time, was the most frequently mentioned barrier and facilitator to adopting and implementing FREED. Almost all interviewed clinicians expressed concerns about capacity and waiting lists regardless of whether they were facing current capacity issues or not. Five teams expressed difficulties implementing the model due to capacity. The wait time targets were perceived as

particularly challenging to implement, especially the treatment target. Some clinicians reported that an not being able to meet the wait time targets was difficult due to increased pressure and awareness that the quicker treatment may be beneficial for patients.

P005: "*I suppose, unfortunately at the moment we can't meet the kind of assessment and treatment deadlines, which is just really really unfortunate but we're kind of I suppose doing every aspect of FREED that we can do as a team at the moment*"

Due to limited capacity, competing demands, such as new initiatives and non-FREED work, were barriers to implementing FREED. Consequently, over time the model can drift and become less of a priority. An enthusiastic Champion, a designated mini team, and the FREED Network were identified as methods to work against the model drift and kept FREED as a priority. Existing teams linking in with interested/newer teams was also suggested as a way of addressing concerns about capacity. Despite capacity issues, interviewed clinicians still expressed a drive to use FREED. Several strategies were identified to manage capacity issues: (1) providing evidence-based individual treatments in group format; (2) flexibly altering and carefully balancing FREED and non-FREED caseloads; (3) low-level psychoeducational support/hubs; (4) extending the waiting time targets and (5) adopting a compassionate mindset that the team are doing the best they can.

P001: "*I just think that means we just adapt how we work and as rather than seeing it as "oh we can't do it" we just go okay so we have to do more group work*"

5.4.2.5.2 Compatibility and integration

Compatibility ('fit') between FREED and the clinician and service (e.g., self-referral, caseload allocation system), and the degree of integration with the service were facilitators for FREED because it made the model easier to use. High 'fit' or integration meant that clinicians did not need to effortfully think about using the model or alter ways of working.

P015: "*It's part and parcel of the fabric of what we do, so we use it, and we implement it, and I don't know how much we overly think about it. I don't*

mean that in a bad way in fact, that we just do it, but I think it's there, it's part of the process"

FREED was integrated into the staff induction, service processes, paperwork, meetings, ethos and culture, and resources of the teams. Streamlining the referral process was particularly important to ensure that the referrals were received by the FREED team as quickly as possible. Protected time for FREED (e.g., assessment and treatment slots) was also crucial for implementing the model. Protected time for Champions to set-up and embed FREED was viewed as essential. The weekly FREED huddles, and monthly supervision and dedicated time in the general team meetings were also outlined as essential for facilitating information sharing, problem-solving, keeping the model alive, and gaining wider awareness and buy-in. Carefully allocating resources to FREED and non-FREED cases was also important to ensure a fair distribution of resources and to guard against any resistance towards the model. Differences between FREED and the standard way of working were sometimes a barrier and could cause tensions when FREED was given special allowances. Additionally, poor integration between FREED and the wider service can result in a split in the team, which can make balancing FREED and non-FREED work more challenging.

P021: "*…one of our FREED clients was on CBT group in the main part of the service and the colleague who's running that group said "oh I've got two sessions left of my CBT group" and I was like remember I've sent you an email they need different questionnaires but they've got electronic versions, let us know within the FREED team if you want support with getting those questionnaires, we can do that bit. And the colleague said "oh well she didn't turn up for two appointment so I sent a letter discharged her". Nooo and that that's the first time something like that has happened…. I think the more that those hopefully not hiccups happen but the more that FREED gets integrated within the main team the more people will understand that flexibility…*"

5.4.2.5.3 An open dialogue: Sharing, participation, and involvement

Sharing information, active involvement in decisions making, and encouraging people to reach out if they have questions or feedback contributed towards creating an open dialogue around FREED. This open dialogue allowed clinicians to ask for support when

needed and for teams to work together through problems. FREED huddles, supervision, designated time in other meetings, and the service's pre-existing communication style were important for developing an open dialogue. While using a mini team can maintain momentum and make staying on model easier, it can also create a split within the team where FREED is not well-integrated, and others can perceive it as being 'privileged' and as 'light work' relative to standard treatment.

P017: "*I suppose that is a downside is that it's kind of potentially has sort of split the team a little bit. It's hard to say because I've just come in and this is the way it is. I haven't seen it before FREED, but I do get a kind of a sense that FREED isn't as well integrated into the service as I would have expected it to have been and so there's a bit of a split there it feels potentially*"

There were three approaches used to work against this splitting. First, everyone is involved with FREED, i.e., a whole team rather than mini team approach to FREED. To successfully use a whole team approach, a considerable amount of time is however needed to gain buy-in and integrate FREED into the whole team. Second, effortfully creating a shared and open dialogue around FREED. Third, FREED clinician involvement with non-FREED treatment.

P015: "*That's really useful to have as a team to constantly have that sort of open discussion going on and questions if we need it*"

5.4.2.6 Wider system

5.4.2.6.1 The broader system of care

Broad awareness of EDs and FREED at educational institutions, third sector organisations, and amongst healthcare services and the public was outlined as essential for enabling the earliest identification of EDs. Poor awareness of and training/skills in managing EDs amongst referrers (e.g., primary care), and receiving appropriate referrals were prominent issues and barriers to implementing FREED, especially for newer sites. Moreover, difficulties obtaining funding for patients was a barrier for one site. FREED associated outreach and awareness raising activities with healthcare professionals, educational institutions, and the public were highly valued by clinicians and perceived as a core part of the early intervention work.

P017: "*One of the biggest barriers so far is getting the referrals through and changing the behaviour of the referrers*"

5.4.2.6.2 Coronavirus diseases 2019 (COVID-19)

Coronavirus disease 2019 was primarily a barrier to implementing FREED but did bring about some positive changes. COVID-19 disrupted and restricted services (and therefore FREED), which reduced capacity and pushed many teams into a risk management mode (i.e., mainly focusing on and supporting the most unwell patients). COVID-19 also disrupted pathways into services and outreach work which initially led to a reduction in referrals. One team interviewed later in the pandemic reported a significant increase in referrals. The elevated risk, changes in working, and uncertainty were difficult for clinicians and a source of increased stress. It was challenging to keep early intervention going, FREED became less of a priority as other COVID-19 related issues took precedence. Clinicians still perceived early intervention as important and tried to implement FREED as much as possible within the constraints of what their service was allowing. Two services delayed launching their FREED pathway and one paused.

P013: "*Early intervention has kind of had to take a little bit of a backseat in that sense just because of how sparse we are with resources*"

Coronavirus disease 2019 was also a catalyst for change and innovation. This included using technology, offering video and phone appointments, virtual groups, new resources, and a greater emphasis on support networks. Virtual appointments provided greater flexibility, reduced travel time, and made treatment more accessible for patients and their families.

P011: "*I think as well it will then challenge people who perhaps previously have thought that they can't engage in therapy because they can't access- they can't get to the clinic in time, they live really far away or the journey is long. Work becomes a real demand in their lives so feel that they can't perhaps prioritise treatment. It does kind of offer an alt- you know a solution for those people who do have busy lives and actually logging onto to your laptop and having a Zoom session becomes accessible for everybody now"*

There are, however, disadvantages to virtual working too. First, team communication and learning are more difficult. Second, engagement, developing a therapeutic relationship and interpersonal connection, and therapy itself can be more challenging online. Clinicians had to navigate clinical work from their homes, patients could be more distracted, and some had limited privacy at home. Finally, clinicians found the online working more tiring and struggled with the lack of separation between work and home.

P009: "*…there's kind of a challenge in working from home as well where I guess when you go to work, and you work in the clinic, there's a very kind of clear boundary between your work and home life. And I think for like a lot of people working from home maintaining those boundaries, psychologically, is actually much more challenging and quite new*"

5.4.3 Stage 2: Normalisation Process Theory

A detailed description of each NPT mechanism underlying each theme and sub-theme is provided in Appendix G Section 10.7.2.2. FREED was largely normalised (i.e., routinely embedded into everyday work) in many services. In accordance with NPT, higher normalisation was accompanied by greater coherence, cognitive participation, collective action, and reflexive monitoring. Coherence in terms of understanding the model and its value was generally high across the FREED teams, suggesting that coherence developing activities, such as the training, were effective. There were however some understandable concerns regarding capacity and the impact on non-FREED patients. Coherence was less well-developed for newer sites, especially for referrers, the care package, and within the wider team. The FREED Champion, Network, mini team, and dedicated meetings (e.g., huddles) ensured a high level of cognitive participation, i.e., the engagement and enrolment of people in FREED work and the maintenance of this over time. Collective action, i.e., the work of integrating FREED into interactions, relations, and context, was the main mechanisms by which normalised sites differed from sites that were not yet at that point. Newer sites were still working towards integrating FREED, developing relations within and outside the team, and building confidence around the model. All of which was made more challenging by COVID-19. Insufficient capacity was the main factor inhibiting normalisation, even when FREED was well-integrated into all other aspects of the team. Changes in capacity and increased demand required teams to continually appraise and re-configure

the structure and functioning of FREED. All sites were engaged in formal (data) and informal (practice and personal experience) reflexive monitoring of what was and was not working and whether FREED was worthwhile.

5.4.4 Inter-coder reliability

The four interviews were divided into 234 data units, which were compared for similarities and differences in coding. There was a total of 107 codes. Fifty of the 107 codes were included in both coder's coding framework (*shared codes*). Fifty-two were only included in KR's coding framework and five were only included in MP's framework (*non-shared codes*). The 50 shared codes and associated ICR indices are outlined in Table 35 in Appendix G Section 10.7.2.3. The non-shared codes are displayed in Table 36 and Table 37 in Appendix G Section 10.7.2.3. The frequency of each shared codes ranged from 1 to 63 (M = 16.86, Mdn = 14, SD = 12.90). All the most frequent codes were included in the shared code list. The frequency of the non-shared codes ranged from 1 to 11 (M = 3.9, Mdn = 3, SD = 2.74). Approximately 73% of the non-shared codes had a frequency of less than 5. In contrast, only 18% of the shared codes had a total frequency of less than 5. The inclusion of the highest frequency codes in the shared code list indicates that the most prominent meanings in the data were indeed identified by both coders.

Percentage agreement was high (>90%) across all shared codes (M = 97.67, Mdn = 98.29, SD = 2.41). However, given the low baseline prevalence of codes (though the 'true' prevalence is unknown), the high percentage agreement should be interpreted cautiously. There was a high level of agreement for the absence of codes, but this was not always the case for the presence of codes (as evidenced by the codes with kappa value < .4). Kappa values ranged from fair (κ = 0.28) to perfect agreement (κ = 1.00) (M = 0.67, Mdn = 0.66, SD = 0.21). The low frequency of some codes resulted in wide confidence intervals for kappa values. The proportion of codes with kappa values demonstrating fair agreement was 10% (n = 5/50), moderate agreement was 30% (n = 15/50), substantial agreement was 34% (n = 17/50), and almost perfect agreement was 26% (n = 13/50). The codes obtaining fair agreement were re-reviewed by both coders and discussed. For codes achieving a fair level of agreement, KR tended to code these as present when MP coded them as absent. This is in keeping with the general trend that KR coded more and with a greater degree of granularity than MP. MP tended to use broader codes on larger sections of data. KR had a total code frequency of 730 using

105 different codes, whereas MP had a total code frequency of 344 using 55 different codes. On re-reviewing the codes, MP tended to agree with KR's application of the codes in most instances. There were a few instances where KR applied the code but on re-review and reflection agreed with MP that the data unit only provided weak/tangential evidence for the code. Overall, most instances provided valid evidence for the code under question.

Over half of all the codes were non-shared (57/107). Both coders reviewed the codes that were missing from their coding framework. There were five codes missing from KR's framework, these are outlined in Table 37 in Appendix G Section 10.7.2.3. On reviewing these missing codes, four ("*Anorexia nervosa may be prioritised for early intervention*", "*Young adult as a sensitive time*", "*FREED combining mental and physical health*", and "*Difficulty implementing FREED alongside Child and Adolescent Mental Health Services*") were closely aligned with and/or overlapped with four of KR's shared/non-shared codes ("*Physical risk will always need to be a priority in services*", "*Care package is valued/subcode: greater awareness to emerging adulthood", "FREED has a different treatment focus/early intervention orientation*", and "*Collaborating with other services facilitates FREED"*). The key sentiments of these codes were distinct enough to warrant separate codes/not merge them. However, KR's codes were broader codes encapsulating more and varied instances than MP's codes (e.g., while some clinicians said that perhaps anorexia nervosa may need to be prioritised for early intervention, the rationale for this was because of the physical risk associated with the disorder and other clinicians mentioned physical risk irrespective of diagnosis) or KR's codes were more related to the FREED model specifically (e.g., the sensitivity to the emerging adulthood stage of life being specifically relating to the care package code). The fifth code, "*Novelty of early intervention before FREED*", was a distinct code that KR did not include in their coding framework. This code falls within the remit of the "*Self-efficacy: Experience, stress, and resilience*" subtheme as it relates to the degree of experience individuals have with early intervention. There were 52 codes missing from MP's coding framework, these codes are outlined in Table 36 in Appendix G Section 10.7.2.3. On reviewing the missing codes, it became apparent that many of the missing codes in MP's framework were as a result coding style (KR having many more specific codes vs MP's broader codes), KR having higher-level latent codes derived from the entire data corpus, and MP's limited knowledge related to the FREED

model and the context around the implementation of FREED. Overall, MP agreed with the missing codes. MP would not have coded the data to the same level of granularity as KR and if a consensus driven codebook was developed, there would have been a process of agreeing on the degree of granularity in coding. Moreover, some codes were only subtly mentioned on one or two occasions in the interviews coded by MP, whereas these codes were much more frequent and prominent in other interviews. KR provided additional examples to MP of these codes from other interviews to check whether the codes were valid or not. There were instances where MP agreed with the code after hearing other examples of the code but felt that the data units in the four double coded transcripts provided weak/tangential evidence. Missing codes related to the data tracker, implementation supervision, and the ethos of FREED were not identified by MP due to a lack of knowledge around the model and its implementation.

While the frequency and granularity of codes was different between the coders, the proportion of positive, neutral, or negative codes was not (calculations include both shared and non-shared codes). The percentage of KR's codes classed as positive, neutral, or negative was 48% (*n* =354/730), 34% (*n* = 245/730), and 18% (*n* = 131/730), respectively. The percentage of MP's codes classed as positive, neutral, or negative was 49% (*n* =167/344), 35% (*n* = 120/344), and 17% (*n* = 57/344), respectively. This provides some evidence related to the prevalence of positive, neutral, and negative codes in the data corpus and that KR was not more inclined to code the data positively relative to an independent qualitative researcher.

5.5 Discussion

This study aimed to evaluate clinician attitudes towards and experience with early intervention for EDs and FREED. To the best of our knowledge, this is the first evaluation of ED clinician attitudes and experiences of early intervention. Overall, clinicians were highly enthusiastic and positive towards early intervention for EDs and FREED, as well as sceptical about the demand on teams and the impact on other patients. Previous studies on clinician attitudes towards early intervention in mental health have reported similar findings (e.g., Rosen et al., 2012). The most prominent facilitator was enthusiasm and 'buy-in' at all levels (e.g., clinician, wider team), and the most prominent barrier was capacity and competing demands. The FREED implementation strategy and components of the model were also effective in building adopter commitment and capabilities.

Generally, there was a high level of understanding and 'buy-in' amongst clinicians, the wider team, and senior staff. Clinicians were enthusiastic and excited by the prospect of improving outcomes and reducing the chronicity of the disorder, and they internalised early intervention as important and needed. The research evidence supporting the model and their own observations of the impact on patients were central to this internalisation and 'buy-in'. Innovations that are perceived positively and have a clear relative advantage and evidence-base are more likely to be adopted and implemented (Carlfjord, Lindberg, Bendtsen, Nilsen, & Andersson, 2010; Damschroder & Lowery, 2013; Penna et al., 2009; Wallace & von Ranson, 2012). However, ongoing promotion of the model and training were needed to gain and sustain this understanding and 'buy-in' over time. Clinicians found each type of training helpful (e.g., online, in-person/virtual, train-the-trainer), particularly the practical tasks, discussions with other teams, and the ongoing post-training support. However, some clinicians felt that more training was needed, especially for assessing and calculating DUED, engaging ambivalent patients, and applying the care package.

This study adds to the literature on the importance of enthusiastic Champions for organisational change by demonstrating their crucial role in not only initiating and developing momentum for FREED, but also maintaining momentum amongst competing demands (Miech et al., 2018). This is the first evaluation of the use of Champions within ED services specifically. While the FREED Champion was perceived as essential, they could not do it on their own and needed to be well supported by a mini team and senior staff to successfully implement FREED. Senior staff support was important and influenced wider team 'buy-in'. Previous studies have raised concerns regarding the effectiveness of solo Champions, especially for new initiatives that require notable behaviour change, as is the case for FREED (Miech et al., 2018). Multiple levels of leadership through coalitions of Champions across senior management, and frontline clinicians are more effective than solo Champions (Damschroder et al., 2009b). The FREED Network, implementation supervision, and external facilitation were also important in supporting the Champion. Inter-organisational networks have demonstrated utility in facilitating improvement initiatives and implementation, but not all are effective and can drift without adequate leadership and resources (Mervyn, Amoo, & Malby, 2019; Penna et al., 2009; The Health Foundation, 2014). Alongside the Network, timely and transparent data monitoring and

feedback were essential for guiding the implementation and sustainability of FREED. However, additional work is required to minimise the burden of the FREED data collection process in the future.

The compatibility, adaptability, and the integration of FREED facilitated its uptake and implementation. This is in accordance with evidence on the importance of innovation-system fit, developing adopter ownership, and the co-evolution of the intervention and context over time (Damschroder et al., 2009a; Greenhalgh et al., 2004; Horton et al., 2018; Kirsh, Lawrence, & Aron, 2008; Oswald et al., 2019). Flexibly adapting service delivery and treatment (the care package) to the needs of patient was also a highly valued facilitator for FREED. FREED was not only adaptable; it developed adaptive capabilities in clinicians, whereby clinicians and the team became more creative, open, and flexible because of FREED. However, adaptability and fidelity need to be carefully evaluated and balanced in the context of FREED (Horton et al., 2018). During the interviews, it became apparent that FREED was modified extensively, and in ways that were perhaps not anticipated. Going forward it will be important to document and learn from these adaptations and consequently provide clearer boundaries to the flexibility of the model, i.e., what is considered core and what can be altered. Fidelity monitoring and feedback are now central to the successful widespread scaling of early intervention services in psychosis and may be an important area for further research for FREED (Addington et al., 2021; Csillag et al., 2018).

Despite eagerness to implement the model, there was a healthy degree of scepticism about the ability to implement FREED with available skills and resources, and the potential unintended consequences for non-FREED patients. The concerns about capacity are not unfounded as limited capacity was a prominent issue and a major barrier to implementation for some teams. A lack of sufficient resources and funding has been identified as one of the main barriers to implementing other early intervention services in mental health (Csillag et al., 2018; Ghio et al., 2015b; Kotlicka-Antczak et al., 2020; Nash et al., 2021; Rosen et al., 2012). Nevertheless, clinicians expressed a drive to continue to use FREED and creatively address capacity issues. Resource constraints are generally an issue in most implementation endeavours, but perceiving these constraints as a challenge to overcome can distinguish high from low performing sites (Damschroder & Lowery, 2013; Ghio et al., 2015b; Miake-Lye et al., 2021; Nash et al., 2021; Nilsen & Bernhardsson, 2019; Rosen et al., 2012).

Concerns about the impact on non-FREED patients largely stems from capacity issues and the need to ensure that patients are aware that recovery is possible at any age or stage of illness. Participants reported that some of these concerns subsided once teams observed the impact of FREED and many recognised that FREED had positive effects beyond FREED patients (e.g., increased investment, saving money). This concern is important and requires careful monitoring and consideration during the ongoing scaling of FREED. It is a topic that has been fiercely debated within the psychosis field and can result in strong resistance towards early intervention (McGorry, 2015). Creating a collaborative and open dialogue around these issues and the model was central for working through problems and successfully implementing FREED. Indeed, implementation is to a large extent socially constructed and governed, where clinicians continually negotiate and re-negotiate a shared understanding and collective action (Greenhalgh et al., 2004; May & Finch, 2009).

Contextual factors, including awareness of EDs in the wider healthcare system, patient engagement and complexity, and COVID-19, impinged on the implementation of FREED. A lack of awareness within the broader system, especially among primary care practitioners, has consistently been identified as a key barrier to early detection and initiation of treatment in EDs and mental health more broadly (Currin & Schmidt, 2005; Kalindjian, Hirot, Stona, Huas, & Godart, 2021; Kästner et al., 2021; Thornton, 2019; Renwick et al., 2008). Historically, some teams operated strict eligibility criteria, so making referrers aware that the service was now accepting milder early intervention cases was important for FREED. Many teams were working towards creating stronger links with primary care and educational institutions and developing quicker referral process within their service. Broad awareness raising was perceived as a core part of early intervention and there was a desire for more outreach and awareness raising to encourage early identification.

Ambivalence and fluctuating levels of patient motivation and engagement are common in EDs and were identified as barriers to implementing FREED (Ali et al., 2017; Fassino, Pierò, Tomba, & Abbate-Daga, 2009; Gregertsen, Mandy, Kanakam, Armstrong, & Serpell, 2019). While the experiences of the clinicians were mixed (i.e., FREED patients were identified as more or less engaged than other patients), many participants identified the active outreach, flexibility, and rapid treatment (first positive experience of services) as crucial for working with and counteracting the ambivalence

of young people in early-stage illness (Potterton et al., 2020a). Disengagement for FREED patients was attributed to patients not feeling ready to change, a lack of recognition of the need for treatment, and treatment feeling too quick. Another challenge encountered by clinicians was determining whether ED treatment was appropriate. In certain contexts, initiating ED treatment, when another formulation was more appropriate, resulted in an exacerbation of symptoms (e.g., emerging personality disorder).

Coronavirus disease 2019 had a profound impact upon the functioning of ED services and consequently the implementation of FREED. Clinicians reported substantial disruptions to services, with almost all outpatient and day-care services shifted to virtual-delivery, and new restrictions to numbers on inpatient wards were introduced. There were also numerous challenges working virtually including difficulties monitoring physical health and risk, reduced team communication, technology issues, limited privacy at home, and difficulties developing a therapeutic relationship and delivering certain therapeutic activities online (e.g., eating in public). This was a period marked by uncertainty, elevated risk, and challenges, which made implementing early intervention difficult. Some services paused their FREED pathway or delayed launching altogether. Nevertheless, many clinicians identified positive changes, such as embracing technology, delivering groups virtually, and developing new resources, which made treatment more accessible to some. These findings largely echo the results of other evaluations of the impact of COVID-19 on ED treatment and services (Shaw, Robertson, & Ranceva, 2021; Stewart et al., 2021).

The NPT was a helpful sensitizing framework and provided further insights into the mechanisms underlying the routine embedding of FREED into clinical practice (i.e., developing ‘buy-in’, appraisal work). All four of the NPT constructs were found to be important for embedding FREED. Building upon the inductive analysis, the NPT highlighted the pivotal role of insufficient resources in preventing the normalisation of FREED. The model and its context were consistently re-appraised and re-configured to accommodate fluctuating capacity and demand. While the NPT was useful for understanding the process of embedding FREED and contextual factors that impact this, there were features that were not well captured by the theory (e.g., patient engagement, comorbidity and complexity, and COVID-19).

5.5.1 Strengths and limitations

The qualitative interviews provided a comprehensive understanding of the perceptions and experiences of frontline clinicians implementing FREED. Participant were recruited from diverse settings (e.g., rural vs urban) with varying levels of experience in EDs and implementing the model (from 5 months to 6 years). However, interviewed clinicians were FREED clinicians recruited from early adopter sites, which may have positively biased results. Early adopters can differ from late adopters in enthusiasm, resource, and team culture and climate. Later adopters or "hard-to-engage" sites are commonly characterised by limited resources, competing priorities, and "healthy scepticism" (Miake-Lye et al., 2021). Clinicians directly involved in implementing the model are also more likely to hold positive attitudes towards it and most of the participants were psychologists or therapists. The attitudes and experiences outlined in this chapter may therefore not be representative of all clinicians working in FREED or ED services. The active involvement of the interviewer in the implementation of FREED may have positively (e.g., in-depth knowledge and established relationships) or negatively (e.g., participants hesitancy to disclose negative views) impacted the content of the interviews. However, most clinicians appeared to speak quite frankly about their experiences of implementing FREED, including the downsides. Researcher bias may have also impacted the coding and analysis of the interviews. Member checking demonstrated that the results were an accurate reflection of the participants attitudes and experiences. A portion of the data (20%) were also independently coded by a qualitative researcher who was/is not part of the FREED clinical and research team. The aim of this analysis was to assess the credibility, bias and trustworthiness of the analysis. Overall, there was considerable alignment between the coders with all the most frequent codes identified by both coders and most codes obtaining a moderate to almost perfect level of agreement. There were, of course, differences in codes and coding style, e.g., KR tended to code more and with a higher degree of granularity and on occasion would include data that were only weakly or tangentially related to the code (though most other data within that code provided adequate evidence for the code). Most of the discrepancies in coding were resolved through discussions, none of which alter the key themes, attitudes and experiences identified in the analysis. A comparison of the proportions of positive, neutral, and negative codes between the coders also suggest that the lead researcher (KR) was not more inclined to code the data positively.

5.5.2 Conclusion

This study highlighted the importance of clinician attitudes as a driver for implementation and the complex interaction between attitudes, components of the intervention, implementation strategy, and broader context. This study provides valuable information about what works, and where more attention is needed in scaling and implementing FREED. Specifically, building clear referral pathways at the outset, the need for multiple "champions", creating an open and ongoing dialogue around the model, limiting the burden of data collection, additional and ongoing training, clear guidance on what is core to FREED (plus methods/examples of adapting and integrating it), and careful monitoring of the impact of FREED on the wider team and non-FREED patients. Insufficient capacity was a major barrier that requires attention during the next phase of implementation, which involves continuing to scale FREED nationally and internationally, and sustainably embedding FREED within ED services. It takes time for implementation efforts to bear fruit; the process is non-linear and punctuated by obstacles and setbacks (Greenhalgh et al., 2004; May, 2013). Drawing on the opinions and experiences of clinicians and other relevant stakeholders is consequently crucial if we are to shape the evolution and implementation of FREED in a sustainable and grounded way.

Chapter 6. A Delphi study to explore clinician and lived experience perspectives on Setting Priorities in Eating Disorder Services (SPEED)

Richards, K. L., Woolrych, I., Allen, K. L., Schmidt, U. (2022). A Delphi study to explore clinician and lived experience perspectives on setting priorities in eating disorder services. *BMC Health Services Research, 22*(788), 1-15. doi:10.1186/s12913-022-08170-4.

A copy of the article is provided in Appendix A. The formatting of this article has been amended here for stylistic consistency. The body of the text remains largely unchanged, except the following were added/changed in this chapter: (1) a section on the implications of not including caregivers; (2) an explanation of why the James Lind Alliance methodology was not used; (3) the findings were amended to highlight the low *W* statistic; (4) a note was added to the limitation section to highlight that the proportion of the participants receiving or providing FREED within the study sample was unknown; and (5) the full final list of all prioritisation factors were displayed in text rather than in the Appendix.

Author contributions: The study was conceptualised and design by the candidate (Katie Richards), Dr Karina Allen, and Professor Ulrike Schmidt. The candidate and Isabel Woolrych were responsible for collecting and managing the data. The candidate analysed the data and drafted the manuscript. Isabel Woolrych, Dr Karina Allen, and Professor Ulrike Schmidt reviewed and provided constructive feedback on the manuscript. Constructive feedback was provided by peer reviewers from *BMC Health Services Research* and the manuscript was modified accordingly.

6.1 Abstract

Background: Due to scarce resources and high demand, priority setting in mental health services is necessary and inevitable. To date, no study has examined priority setting in eating disorder (ED) services specifically. Here, we evaluate the level of consensus and perceived relative importance of factors used to determine patient prioritisation in ED services, amongst clinicians and individuals with lived experience (LE) of an ED.

Methods: A three round Delphi study and a ranking task were used to determine the level of consensus and importance. Consensus was defined as >80% agreement or disagreement. Items that reached consensus for agreement were ranked in order of importance from most to least important. Participants were 50 ED clinicians and 60 LE individuals. Participant retention across rounds 2, 3, and 4 were 92%, 85%, and 79%, respectively.

Results: Over three iterative rounds, a total of 87 statements about patient prioritisation were rated on a 5-point Likert-scale of agreement. Twenty-three items reached consensus in the clinician panel and 20 items reached consensus in the LE panel. The pattern of responding was broadly similar across the panels. The three most important items in both panels were medical risk, overall severity, and physical health deteriorating quickly. Clinicians tended to place greater emphasis on physical risk and early intervention whereas the LE panel focused more on mental health and quality of life.

Conclusions: Eating disorder services tend to prioritise patients based upon medical risk and severity, and then by the order in which patients are referred. Our findings align in some respects with what is observed in services, but diverge in others (e.g., prioritising on quality of life), providing important novel insights into clinician and LE opinions on waiting list prioritisation in EDs. More research is warranted to validate these findings using multi-criteria decision techniques and observational methods. We hope these findings provide a foundation for future research and encourage evidence-based conversations around priority setting in ED services.

6.2 Introduction

Waiting lists and their management are a major issue for publicly funded mental health services (Cawthorpe et al., 2007). Waiting can increase distress, risk, and negatively impact outcomes and functioning (Gagliardi et al., 2021; Reichert & Jacobs, 2018; Williams, Latta, & Conversano, 2008). Several initiatives have been proposed to manage waiting lists including wait time targets, and structured prioritisation tools and procedures (Déry et al., 2020; Guo et al., 2022; Kreutzberg & Jacobs, 2020). In England, wait-time targets were introduced in 2016 for early intervention in psychosis and child and adolescent ED services. These targets, alongside additional funding and performance monitoring, led to substantially improvements in rapid access to care (Kreutzberg & Jacobs, 2020; NHS England, 2022). There are now plans to introduce similar targets for all mental health services in England (Iacobucci, 2021). Despite such efforts, demand continues to exceed supply, making effective priority setting procedures necessary. There are, however, only a limited number of tools for priority setting in mental health, most of which are non-specific and for child and adolescent services (Déry et al., 2020; Grepperud, Holman, & Wangen, 2014).

Eating disorders are serious, life-threatening illnesses that cause considerable distress and have long-term implications for physical, social, and occupational functioning (Treasure et al., 2020a). The limited availability of specialist ED services in many countries, alongside the unique challenges presented by EDs (e.g., ambivalence, extreme physical risk), make ED patient prioritisation daunting, even for experienced clinicians. Prioritisation decisions can lead to ethical dilemmas where individuals are required to balance professional considerations and institutional constraints alongside personal and moral judgements about what is “right” (Kälvemark, Höglund, Hansson, Westerholm, & Arnetz, 2004; Suhonen et al., 2018). There are no explicit frameworks and limited research to support decision making for ED service prioritisation. A systematic search identified only one relevant study, where patients with either obesity or AN were prioritised based upon age, social class, and mental health history. Patients were more likely to be prioritised if they were younger, with a comorbid mental health problem and from a low social class (Gajre, McClelland, & Furnham, 2018).

Three ethical principles of distributive justice are frequently used to guide priority setting decisions in healthcare: egalitarianism, utilitarianism, and prioritarianism (Cookson & Dolan, 2000; Persad, Wertheimer, & Emanuel, 2009).

Egalitarianism aims to reduce inequalities and equalise lifetime health across the population. It is based on the premise that everyone is equally deserving of a long and healthy life and is associated with distributive mechanisms such as 'first-come first-served' or lottery allocation. The UK NHS is fundamentally egalitarian, providing access to all regardless of disadvantage (Whitehead, 1994). Utilitarianism aims to maximise the aggregate total benefit to the population by directing care to those that will benefit the most, often quantified using quality-adjusted life years. Finally, prioritarianism, which closely aligns with the 'rule of rescue' (the desire to save those facing death), gives priority to individuals who are the worst-off, sickest, or most in need of care (Cookson & Dolan, 2000; Persad et al., 2009).

The National Institute for Health and Care Excellence (NICE) recommend that patients with EDs should be treated as soon as possible, especially individuals with or at risk of severe emaciation, suggesting a tendency towards prioritarianism (National Institute for Health and Care Excellence, 2017). In line with this, ED services typically prioritise patients based upon clinical priority and urgency in the first instance (e.g., BMI <15 kg/m^2, rapid weight loss) followed by the order in which they were referred. Prioritarianism is widespread within healthcare and even without formal prioritisation policies, patients with more severe and disabling presentations tend to be seen quicker (Gutacker, Siciliani, & Cookson, 2016; Shah, 2009; Siciliani, Borowitz, & Moran, 2013). Recent early intervention initiatives in EDs are more utilitarian, as they advocate for prioritising patients in early-stage illness, where treatment can be quicker and more effective (Ambwani et al., 2020; Andrés-Pepiñá et al., 2019; Brown et al., 2018; McClelland et al., 2018; Russell et al., 1987; however, see Radunz et al., 2020). Utility and health gain are consistently valued in priority setting studies, sometimes emerging as the most important attribute (e.g., Arora, Savulescu, Maslen, Selgelid, & Wilkinson, 2016; Green & Gerard, 2009; Lancsar, Wildman, Donaldson, Ryan, & Baker, 2011). However, the importance of utilitarianism varies by context and the degree of health gained (Gu, Lancsar, Ghijben, Butler, & Donaldson, 2015; Whitty, Lancsar, Rixon, Golenko, & Ratcliffe, 2014). Moreover, utilitarian approaches create complex ethical dilemmas where individuals with chronic illnesses and disabilities risk being disadvantaged (Singer, McKie, Kuhse, & Richardson, 1995).

Balancing equity, efficiency, and prioritarian goals is a challenge for developing transparent and fair priority setting procedures and policies in healthcare (Scheunemann

& White, 2011). No single distributive theory is likely to ensure healthcare resources are allocated justly. Multi-allocation systems are often needed alongside evidence of value systems endorsed by the communities affected by such decisions (Persad et al., 2009). An evaluation of clinician and patient perspectives, i.e., the people who are most directly involved in and affected by wait list decisions, would provide some much-needed insights and currency for discussion for what is a very challenging issue faced by ED services. To the best of our knowledge, there are no priority setting studies assessing the views of ED clinicians or individuals with lived experience (LE) of an ED. Here, we describe a Delphi study in which the collective opinions of clinicians and individuals with LE were sought to evaluate the level of consensus (agreement/disagreement) and perceived relative importance of factors used to determine patient prioritisation in ED services. The Delphi method is particularly well-suited for areas where there is limited research, no set standard, and for determining collective community-based values to facilitate decision making (Jorm, 2015).

6.3 Methods

6.3.1 Study design

The Delphi method is a systematic approach for determining the level of consensus or dissensus (widespread dissent) among 'experts' on a given topic. The term 'expert' refers to someone who has professional or personal experience and knowledge on a topic (Trevelyan & Robinson, 2015). A Delphi study typically involves multiple iterative rounds of questionnaires whereby feedback on responses is provided and items are re-rated considering this feedback. Participants are anonymous and rate items independently. This technique allows participants to reflect on their own position, and answer/amend answers without pressure from domineering group members (Belton, MacDonald, Wright, & Hamlin, 2019; Khodyakov & Chen, 2020).

6.3.2 Participants

Participants were recruited online via social media platforms (Twitter, Facebook, Instagram), and professional organisations and networks (including the British Eating Disorder Society, FREED Network, and Eating Disorder Specialist Interest Groups). The recruitment materials (e.g., posters) are provided in Appendix E Section 10.5.2. Expertise was defined as: (1) a practicing healthcare professional with at least one year's worth of experience in EDs for the clinician panel; or (2) a current or previous diagnosis of DSM-5 ED for the LE panel. A total of 110 individuals (50 clinicians and

60 individuals with LE) took part in the study. The participant demographic characteristics are outlined in Table 16.

Table 16. Participant characteristics.

	Clinician (n = 50)		Lived experience (n = 60)
Age in years (M, SD)	41.24 (10.47)	Age in years (M, SD)	29.78 (2.33)
Gender (n, %)		Gender (n, %)	
Female	41 (82)	Female	53 (88)
Male	9 (18)	Male	6 (10)
Non-binary	0	Non-binary	1 (2)
Ethnicity (n, %)		Ethnicity (n, %)	
White/White British	47 (94)	White/White British	56 (93)
Asian/Asian British	1 (2)	Asian/Asian British	3 (5)
Black/Black British	1 (2)	Black/Black British	0
Mixed/Multiple or other ethnic background	1 (2)	Mixed/Multiple or other ethnic background	1 (2)
Profession (n, %)		Diagnosis[a] (n, %)	
Psychiatrist	9 (18)	Anorexia Nervosa	48 (80)
Clinical Psychologist	9 (18)	Bulimia Nervosa	12 (20)
Psychiatric nurse	14 (28)	Binge Eating Disorder	7 (12)
Psychotherapist	6 (12)	OSFED/Atypical/Purging Disorder	21 (35)
Occupational therapist	4 (8)	ARFID	5 (8)

Dietician	1 (2)	Comorbid Neurodevelopmental Disorder	8 (13)
Other	7 (14)	Other comorbid disorder (including mood, anxiety, and personality disorder)	46 (77)
Years working in EDs (*n*, %)		Time since ED onset in years (*M*, *SD*)	11.48 (8.31)
< 4 years	16 (32)	Recovered (*n*, %)	
5-15 years	28 (56)	Yes	18 (30)
> 16 years	6 (12)	Partially	16 (27)
		No	24 (40)
		Unsure	2 (3)
Work settings[a] (*n*, %)		Treatment setting[a] (*n*, %)	
Inpatient	35 (70)	Inpatient	24 (40)
Day patient	20 (40)	Day patient	22 (37)
Outpatient	25 (50)	Outpatient	55 (92)
Public	48 (96)	Public	56 (93)
Private	11 (22)	Private	28 (47)
CAMHS/CAEDS	20 (40)	CAMHS/CAEDS	23 (38)
AMHS/AEDS	45 (90)	AMHS/AEDS	46 (77)
All-age service (0-25 years)	4 (8)	All-age service (0-25 years)	8 (13)

Note. OSFED = Other Specified Feeding and Eating Disorder; ARFID = Avoidant Restrictive Food Intake Disorder; ED = eating disorder; CAMHS = Child and

adolescent mental health service; CAEDS = Child and adolescent eating disorder service; AMHS = Adult mental health service; AEDS = Adult eating disorder service.

[a]Participants can endorse multiple categories

6.3.3 Procedure

The study involved a three round Delphi (Round 1-3) and a ranking task (Round 4) distributed via the cloud-based online survey platform Qualtrics, Provo, UT, Version April-August 2021. A modified Delphi method was used for this study, where the first round consisted of structured statements rather than open-ended questions. Modified Delphi methods are frequently used to minimise participant burden or provide a *seed* list derived from the literature (Hart & Wade, 2020; Jorm, 2015; McMaster, Wade, Franklin, & Hart, 2020; Mullen, 2003). For the current study, this approach was selected to ensure that opinions were gathered on specific clinical (e.g., duration of illness) and non-clinical (e.g., socio-economic status) factors identified as important for priority setting in EDs specifically and health care more broadly. This approach was also selected to reduce the number of rounds and therefore time commitment required to take part in the study. The questionnaire for Round 1 was developed by conducting a systematic literature review followed by consultation and pre-testing with ED clinicians and individuals with LE (further details on questionnaire development are provided in Appendix F Section 10.6.2). Clinician and LE questionnaires for Round 1 are provided in Appendix F Section 10.6.3. Data collection occurred between April and August 2021. Each round took place over a 4 to 6-week period. Participants remained anonymous to one another throughout the study.

Participants contacted the researchers (KR and IW) by email to express interest in taking part. Once eligibility was confirmed, a link to the consent form and first survey was provided. In Round 1-3, participants were presented with statements about patient prioritisation (e.g., “Patients should be prioritised if they have a diagnosis of anorexia nervosa”) and asked to rate each statement on a 5-point Likert scale ranging from ‘Strongly disagree’ (1) to ‘Strongly agree’ (5). Participants were asked to rate the items in relation to priority in ED services and for what their answer would be in most situations. The order of the statements was randomised for each participant. An optional comment box was provided alongside each statement where participants could provide feedback on language/wording, difficulties in understanding, or reasons why they gave

a specific rating. The number of prioritisation statements per round are outlined in Figure 5. In Round 1, an additional open-ended question was included at the end of the survey to identify new prioritisation factors. In Rounds 2 and 3, statements that were re-rated from previous rounds were accompanied by a histogram showing the distribution of responses and the participant's own response from the previous round (see example in Figure 6). Round 4 involved a ranking task, whereby participants were presented with the list of statements that reached consensus for agreement for their panel. Participants were asked to select the 10 most important items and rank them in order of importance from most to least important. Participants could also provide feedback on the ranking task in an optional comment box.

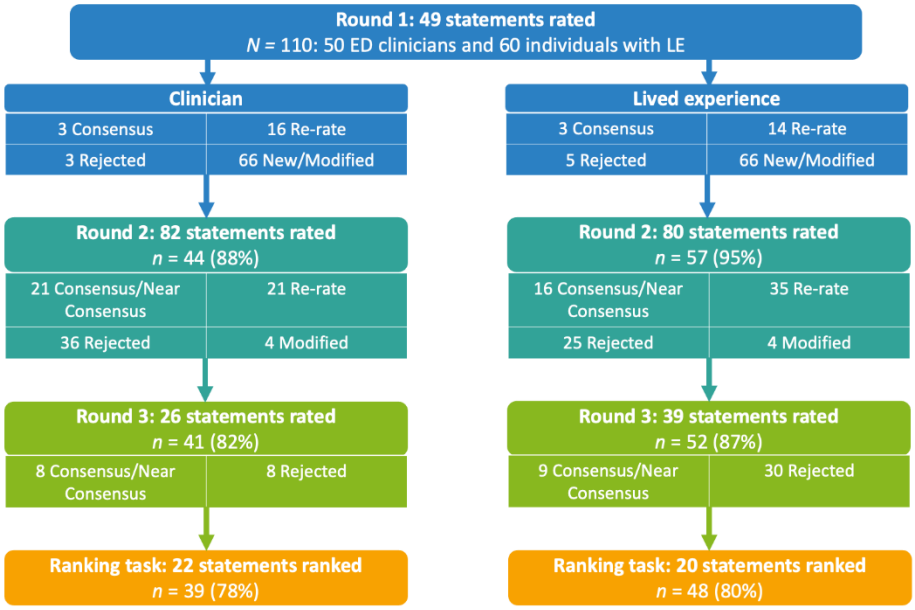

Figure 5. A flow chart of response rate, number items rated or ranked, and number of items that reached consensus/near consensus, or were re-rated, rejected, or new/modified per Delphi study round. LE = lived experience; ED = eating disorder.

Figure 6. Example item and feedback from Round 2.

6.3.4 Ethics approval and consent

The study was conducted in accordance with ethical standards of relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. The study received ethical approval from King's College London Research Ethics Committee for Psychiatry, Nursing and Midwifery (reference: HR/DP-20/21-21302). The ethical approval letter is provided in Appendix B Section 10.2.2. Informed consent was obtained from all participants using an electronic information sheet and consent form. The participant information sheets, and consent forms are provided in Appendix C Section 10.3.2 and Appendix D Section 10.4.2, respectively.

6.3.5 Analysis

The qualitative responses for each round were independently analysed by two of the study authors (KR and IW) using an inductive content analysis method (Elo & Kyngäs, 2008). Open coding was used to identify new prioritisation factors and issues in questionnaire completion. The coding was completed in NVivo (Version 12) (QSR International Pty Ltd., 2020). The results of the independent coding process were discussed by the two researchers (KR and IW). During these discussions, the coders compared and contrasted codes to identify similarities and differences, and based upon

these discussions added, modified, or removed items from each survey accordingly. All modifications and new items were integrated into clinician and LE surveys regardless of which group the qualitative feedback came from. The other study authors (KA and US) provided feedback on proposed changes and resolved discrepancies between the coders. The number of modified or new items per round are outlined in Figure 5.

Frequencies were calculated in SPSS (IBM Corp, 2020) and used to determine the percentage of consensus for each item. Consensus was calculated separately for each panel. In Rounds 1 and 2, items were sorted into three categories: 'consensus', 're-rate', and 'rejected'. 'Consensus' and 'rejected' items were removed and 're-rate' items were re-administered. Consensus was defined as items that obtained ≥80% agreement (or disagreement) (Hart & Wade, 2020; McMaster, Wade, Franklin, & Hart, 2020). Items were categorised as re-rate if they were: (1) changed due to qualitative feedback; (2) rated once and had 40-79% consensus; (3) rated twice with substantial alterations before the second rating and had a 40-79% consensus; (4) rated twice with minor alterations before the second rating, a 40-79% consensus, and >5% change towards consensus. In Round 1, there were some inconsistencies between qualitative and quantitative responses (e.g., participants explicitly saying that they did not think the factor should be used and then rating 'neither agree nor disagree'). These items were also re-administered in Round 2 alongside additional guidance to support participants with decision making. Items were categorised as 'rejected' if they: (1) had a consensus <40%; (2) were rated twice with no alterations and had a consensus <80%; (3) were rated twice with minor alterations, had a consensus <80%, and <5% change towards consensus. Following Round 3, final frequencies and consensus levels were calculated, as well as the mean score and standard deviation for each panel. The items in the final list were categorised as reaching consensus (≥80% rated disagree or agree), near-consensus (70-79% rated disagree or agree), or no consensus (<70% rated disagree or agree). Items were grouped according to broader themes and the qualitative data coded to identify common rationales for ratings.

Analysis for the ranking task involved assigning a value of 10 (most important) to 1 (least important) to the items included in the list and a value of 0 to all other items. Mean rank was calculated for each item and used to signify the overall position of the item in the list. The percentage of participants who mentioned an item in their top 10 was also calculated and used to break ties when mean ranks were equal. Kendall's

coefficient of concordance (*W*) was calculated to evaluate the degree of consensus among respondents on the ranking task. The interpretation of *W* is as follows: weak <.3, moderate <.7, and strong ≥.7. *W* was calculated using the 'irr' package in R programming software (Gamer, Lemon, Fellows, & Singh, 2012).

6.4 Results

6.4.1 Rounds 1-3: Delphi

The response rate per round, and the number of items rated/ranked, reached consensus/near consensus, re-rated, rejected, or new/modified per round are depicted in Figure 5. The final list of 87 statements, and their mean rating, and level of consensus are outlined in Table 17.

Table 17. Patient prioritisation statements and their mean rating and level of consensus.

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
Diagnostic Factors								
Eating disorder diagnosis								
…if they have a diagnosis of anorexia nervosa	3.48 (0.86)	14%	50%	No	2.93 (0.83)	29%	18%	No
…if they have a diagnosis of bulimia nervosa	2.91 (0.83)	36%	25%	No	2.91 (0.75)	27%	13%	No
…if they have a diagnosis of binge eating disorder	2.55 (0.70)	48%	7%	No	2.84 (0.73)	29%	11%	No
…if they have a diagnosis of other specified feeding or eating disorder	2.68 (0.60)	36%	2%	No	2.89 (0.68)	27%	4%	No
…if they have a diagnosis of avoidant restrictive food intake disorder (ARFID)	2.66 (0.65)	39%	7%	No	2.88 (0.72)	30%	16%	No
Comorbid diagnosis								

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
…if they have an intellectual disability	3.02 (0.66)	21%	23%	No	2.80 (0.75)	38%	16%	No
…if they are also experiencing a mild mood, anxiety, or stress-related disorder (e.g., depression, bipolar disorder, social phobia, panic disorder, post-traumatic stress disorder)	2.58 (0.74)	48%	10%	No	2.91 (0.82)	36%	25%	No
…if they are also experiencing a moderate mood, anxiety, or stress-related disorder (e.g., depression, bipolar disorder, social phobia, panic disorder, post-traumatic stress disorder)	2.95 (0.86)	32%	27%	No	3.17 (0.83)	28%	42%	No

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
…if they are also experiencing a severe mood, anxiety, or stress-related disorder (e.g., depression, bipolar disorder, social phobia, panic disorder, post-traumatic stress disorder)	3.38 (0.95)	3%	48%	No	3.76 (1.02)	16%	66%	No
…if they are also abusing or are dependent on alcohol or other drugs (substance use disorder)	2.52 (0.73)	48%	7%	No	2.79 (0.91)	43%	22%	No
…if they also have an autism spectrum disorder	2.95 (0.75)	27%	21%	No	2.93 (0.85)	36%	25%	No
…if they also have a personality disorder	2.52 (0.73)	43%	5%	No	2.50 (0.60)	48%	2%	No
…if they are also experiencing an obsessive-compulsive or related disorder (e.g., OCD, body dysmorphic disorder)	2.77 (0.68)	36%	14%	No	3.07 (0.88)	25%	27%	No

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
Duration of Eating Disorder								
…if their eating disorder developed less than 6 months ago	**3.95 (0.83)**	**9%**	**82%**	**Yes**	3.14 (1.05)	22%	34%	No
…if their eating disorder developed less than 1 year ago	**4.00 (0.60)**	**7%**	**80%**	**Yes**	3.32 (0.91)	16%	46%	No
…if their eating disorder developed less than 3 years ago	3.83 (0.74)	5%	73%	Near	3.21 (0.83)	16%	39%	No
…if they have had an eating disorder for 5 years or more	2.80 (0.59)	30%	9%	No	3.54 (0.89)	14%	56%	No
…if they have had an eating disorder for 10 years or more	2.66 (0.58)	39%	5%	No	3.68 (0.99)	14%	58%	No
…if they have had an eating disorder for 15 years or more	2.59 (0.62)	38%	2%	No	3.66 (1.00)	14%	56%	No
Body Weight and Behavioural Eating Disorder Symptoms								

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
Weight-related								
…if they are underweight (this includes all levels of being underweight)	3.53 (0.85)	10%	58%	No	3.18 (0.96)	23%	38%	No
…if they are a very low weight	**4.25 (0.72)**	**2%**	**89%**	**Yes**	**3.93 (0.87)**	**9%**	**82%**	**Yes**
…if they are experiencing obesity and an eating disorder	2.58 (0.78)	45%	10%	No	2.86 (0.82)	38%	30%	No
…if they are experiencing morbid obesity and an eating disorder	2.93 (0.87)	32%	30%	No	3.27 (0.90)	21%	39%	No
…if they are quickly losing weight (irrespective of their starting weight)	**4.30 (0.67)**	**2%**	**93%**	**Yes**	**4.18 (0.83)**	**5%**	**84%**	**Yes**
…if their weight is stable and they are underweight	2.80 (0.80)	39%	21%	No	2.86 (0.75)	34%	18%	No
…if their weight is stable and they are neither under- nor overweight	2.17 (0.71)	65%	0%	No	2.49 (0.61)	45%	0%	No
…if their weight is stable and they are overweight	2.25 (0.67)	63%	0%	No	2.51 (0.61)	47%	2%	No

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
…if their weight is unstable (changing a lot) and they are underweight	**3.93 (0.70)**	**5%**	**89%**	**Yes**	3.86 (0.78)	8%	78%	Near
…if their weight is unstable (changing a lot) and they are neither under- nor overweight	3.09 (0.74)	21%	27%	No	3.54 (0.84)	12%	62%	No
…if their weight is unstable (changing a lot) and they are overweight	2.95 (0.89)	27%	30%	No	3.40 (0.83)	18%	54%	No
Binge Eating								
…if they are binge eating once a week or less	2.08 (0.66)	75%	0%	Near[a]	2.28 (0.73)	64%	4%	No
…if they are binge eating 2-4 times a week	2.65 (0.89)	43%	18%	No	3.20 (0.84)	20%	32%	No
…if they are binge eating 5 times or more per week	3.18 (0.97)	23%	39%	No	3.62 (.92)	14%	60%	No
Compensatory								

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
…if they are exercising excessively/compulsively	3.33 (0.64)	7%	37%	No	3.56 (0.71)	12%	68%	No
…if they are making themselves vomit once a week or less	2.28 (0.64)	63%	0%	No	2.62 (0.67)	48%	10%	No
…if they are making themselves vomit 2-4 times per week	3.11 (0.90)	23%	36%	No	3.41 (0.81)	16%	53%	No
…if they are making themselves vomit 5 times or more per week	3.95 (0.69)	3%	79%	Near	4.02 (0.94)	2%	76%	Near
…if they are abusing laxatives or diuretics once a week or less	2.48 (0.76)	48%	5%	No	2.60 (0.61)	42%	4%	No
…if they are abusing laxatives or diuretics 2-4 times per week	3.03 (0.86)	25%	32%	No	3.33 (0.66)	8%	39%	No
…if they are abusing laxatives or diuretics 5 times or more per week	3.65 (0.83)	8%	65%	No	3.88 (0.75)	4%	74%	Near

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
…if they have reduced the amount or type of food they are eating (dietary restriction) at a mild to moderate level (e.g., restricting on some days and not others, or restriction of a specific food group)	2.55 (0.55)	48%	3%	No	2.82 (0.80)	38%	22%	No
…if they have reduced the amount or type of food they are eating (dietary restriction) at an extreme level (e.g., very little dietary intake almost every day)	**4.25 (0.62)**	**0%**	**91%**	**Yes**	**4.07 (0.76)**	**5%**	**86%**	**Yes**
…if they have diabetes and are purposefully restricting their insulin to lose weight (diabulimia)	**4.36 (0.75)**	**2%**	**89%**	**Yes**	**4.29 (0.80)**	**5%**	**89%**	**Yes**

Illness Severity

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
…if they are experiencing mild eating disorder symptoms (e.g., weight/shape concerns, infrequent binge eating or fasting)	2.78 (0.95)	36%	22%	No	2.92 (1.01)	37%	25%	No
…based upon the severity of their illness (taking into account psychological, physical, and social severity)	**4.50 (0.76)**	**2%**	**95%**	**Yes**	**4.13 (0.79)**	**5%**	**86%**	**Yes**
Individual Treatment Factors								
…if they have had several rounds of previous eating disorder treatment	2.40 (0.78)	60%	5%	No	2.54 (0.65)	46%	4%	No
…if they have not accessed eating disorder services before	3.06 (0.88)	29%	29%	No	3.08 (1.12)	33%	32%	No
…if they have recently had treatment (within the last 6 months) but are now relapsing	**3.77 (0.57)**	**5%**	**80%**	**Yes**	3.84 (0.90)	11%	73%	Near

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
…if they are receiving treatment from another public mental health service	2.61 (0.49)	39%	0%	No	2.42 (0.73)	60%	8%	No
…if they are transitioning between child and adult services	**4.25 (0.69)**	**2%**	**91%**	**Yes**	3.68 (0.89)	10%	60%	No
…if they are transitioning between inpatient and community services	**4.27 (0.76)**	**5%**	**91%**	**Yes**	**4.20 (0.88)**	**4%**	**84%**	**Yes**
…if they are transitioning between services in different areas	3.90 (0.80)	5%	78%	Near	3.60 (0.86)	36%	64%	No
…based upon how much they are likely to benefit from treatment	3.00 (1.10)	33%	37%	No	3.02 (1.28)	37%	40%	No
Service-related Factors								
…on a 'first-come first-serve' basis (people will receive treatment in the order in which they are referred, i.e., if Patient X's referral arrived before	**2.05 (0.94)**	**80%**	**9%**	**Yes[a]**	2.61 (1.14)	55%	29%	No

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
Patient Y's, Patient X will be seen first)								
…if they found it difficult to get a referral to the eating disorder service (possible reasons for difficulties include lack of recognition, internal delays between services, and referrals being missed)	2.95 (0.75)	27%	21%	No	3.20 (0.83)	18%	33%	No
…if their treatment was inappropriate, limited, or of poor quality (e.g., only re-feeding with limited therapeutic input)	3.63 (0.48)	0%	63%	No	**4.02 (0.87)**	**8%**	**80%**	**Yes**
…if they do not have access to specialist eating disorder care within their area (i.e., have to be sent out of area for treatment)	3.16 (0.65)	9%	27%	No	3.28 (0.78)	16%	46%	No

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
…if they have been waiting a long time for treatment	**3.90 (0.59)**	**3%**	**83%**	**Yes**	**4.14 (0.73)**	**2%**	**84%**	**Yes**
Physical Health Factors								
…if they are at significant medical risk (e.g., very slow or irregular heartbeat, abnormal blood results)	**4.73 (0.49)**	**0%**	**98%**	**Yes**	**4.72 (0.64)**	**2%**	**93%**	**Yes**
…if their physical health is getting worse quickly (any metric of physical health)	**4.47 (0.74)**	**2%**	**98%**	**Yes**	**4.23 (0.81)**	**5%**	**93%**	**Yes**
…if they are experiencing medical problems because of their eating disorder (e.g., osteoporosis, fertility problems, bowel problems, problems with their heart or circulation)	**4.14 (0.79)**	**4%**	**84%**	**Yes**	**4.40 (0.72)**	**3%**	**93%**	**Yes**

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
…if they have a major physical disorder (e.g., cardiovascular disease, diabetes, cancer) that is made worse by their eating disorder	**4.20 (0.59)**	**0%**	**91%**	**Yes**	**4.07 (0.71)**	**5%**	**89%**	**Yes**
…if they are pregnant	**4.52 (0.58)**	**0%**	**96%**	**Yes**	**4.25 (0.82)**	**5%**	**87%**	**Yes**
…if they are experiencing malnutrition (as indicated by blood tests and irrespective of weight)	**4.27 (0.66)**	**0%**	**89%**	**Yes**	**4.18 (0.81)**	**5%**	**86%**	**Yes**
Mental Health Factors								
…if they are constantly having intrusive eating disorder related thoughts and feelings (e.g., thoughts about their body shape and weight, fear of putting on weight)	3.20 (0.88)	2%	48%	No	**4.14 (0.73)**	**2%**	**84%**	**Yes**
…if they are thinking or planning to end their life (suicide risk)	3.60 (1.05)	11%	55%	No	**4.30 (1.08)**	**9%**	**88%**	**Yes**

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
…if they have escalating non-suicidal self-injury behaviours (i.e., becoming more intense or frequent)	2.89 (0.87)	34%	27%	No	3.61 (0.94)	18%	71%	Near
…if they have stable non-suicidal self-injury behaviours (i.e., has not changed in frequency or presentation for a while)	2.53 (0.55)	50%	3%	No	2.98 (0.84)	30%	29%	No
…if their mental health and well-being is getting worse quickly (any metric of mental health)	**4.09 (0.64)**	**0%**	**84%**	**Yes**	**4.29 (0.76)**	**4%**	**95%**	**Yes**
…if they are highly distressed by their eating disorder	3.65 (0.66)	8%	70%	Near	4.24 (0.85)	2%	78%	Near
…if they have impaired or poor mental capacity/decision making because of their eating disorder	**4.23 (0.64)**	**0%**	**89%**	**Yes**	**4.11 (0.76)**	**4%**	**84%**	**Yes**
…if they are motivated for treatment or to get better	3.86 (0.98)	14%	73%	Near	3.41 (1.16)	23%	25%	No

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
Life and Social Factors								
Individual Characteristics and Circumstances								
…if they are less than 12 years old	**4.23 (0.71)**	**2%**	**89%**	**Yes**	**4.30 (0.85)**	**5%**	**88%**	**Yes**
…if they are less than 18 years old	**3.98 (0.70)**	**5%**	**84%**	**Yes**	3.55 (0.89)	13%	59%	No
…if they are less than 25 years old	3.59 (0.73)	7%	59%	No	3.00 (0.99)	27%	30%	No
…if they are a member of an ethnic minority group	2.68 (0.57)	38%	5%	No	2.62 (0.73)	44%	10%	No
…if they are starting university soon	3.00 (0.75)	25%	23%	No	2.72 (0.90)	40%	18%	No
…if they only have a small window of time before they move somewhere else	2.66 (0.75)	46%	14%	No	2.27 (0.67)	73%	4%	Near[a]
…if their eating disorder is negatively impacting their quality of life (e.g., stops them from doing leisure activities, impacts how they interact	3.68 (0.92)	15%	75%	Near	**4.14 (0.72)**	**4%**	**88%**	**Yes**

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
with other people or makes it difficult to work/study, financial problems)								
…if they have or do live in a household with a low income	2.52 (0.76)	50%	9%	No	2.84 (0.95)	36%	23%	No
…if they are homeless or do not have secure housing	2.89 (0.90)	32%	27%	No	3.25 (1.05)	29%	38%	No
…if they have or do live in a household with a high income	1.68 (0.83)	77%	0%	Near[a]	1.73 (0.80)	79%	0%	Near[a]
Social Context								
…if they are a parent or have a child that depends on them or are the main carer for an elderly relative	3.63 (0.49)	0%	63%	No	3.55 (0.88)	14%	57%	No
…if they have very little social support (i.e., are isolated, have very	3.68 (0.66)	8%	73%	Near	3.60 (0.94)	16%	68%	No

Items	Clinician				Lived experience			
Patients should be prioritised….	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved	Mean (*SD*)	Disagree (%)	Agree (%)	Consensus achieved
little support or contact/interaction with others)								
…if they are at-risk of harm from others	3.25 (0.69)	14%	39%	No	3.32 (0.97)	26%	39%	No
…if another member of their family is receiving treatment for an eating disorder	2.93 (0.82)	27%	25%	No	2.70 (0.81)	40%	16%	No
…if another member of their family is receiving treatment for any other mental health problem	2.82 (0.76)	30%	16%	No	2.38 (0.73)	60%	6%	No
…if the person's carer/family/friends/significant other is experiencing a high level of fatigue and stress (related to supporting the person with the eating disorder)	3.11 (0.72)	21%	32%	No	3.00 (0.95)	29%	29%	No

Note. Items in bold reached consensus. ARFID = avoidant/restrictive food intake disorder; OCD = obsessive compulsive disorder.

[a]Consensus or near consensus for disagreement.

Diagnosis: None of the ED diagnoses nor comorbid diagnoses reached consensus/near consensus in either panel. Common reasons for ratings were the belief that all ED diagnoses are equally serious and disruptive, and other factors, such as, impact on functioning, severity, and risk also needed to be considered. However, AN, bulimia nervosa (BN), and comorbidities were perceived by some respondents as elevating complexity and acute risk and therefore warranting prioritisation. Some perceived comorbidities as the responsibility of other services and/or requiring adapted treatment.

Duration of Eating Disorder: An illness duration of <6 months, <1 year, and <3 years reached consensus/near consensus for agreement in the clinician panel, but not the LE panel. Despite differences in ratings, qualitative comments were remarkably similar across the panels. There were numerous comments regarding the importance of early intervention for improving outcomes and increasing the likelihood of recovery. However, there were concerns regarding limited resources/capacity and the detrimental impact on individuals with longer illnesses (i.e., this group being deprioritised/excluded/given up on). Severity, risk, and willingness to engage were thought to take precedence over illness duration.

Body weight and behavioural ED Symptoms: For weight-related, binge eating, and compensatory ED symptoms, greater frequency/severity were associated with a higher level of agreement. Consensus was reached for very low weight, quickly losing weight (irrespective of starting weight), extreme dietary restriction, low and unstable weight, and if a diabetic patient was purposefully restricting/omitting their insulin. Any ED symptom in isolation, especially weight, was generally perceived as insufficient for priority setting. An understanding of severity, risk, distress, willingness to engage, and functioning were required for decision-making. Many were opposed to weight-based prioritisation as it can result in patients feeling they are ‘not sick enough’ to ‘deserve’ treatment.

Illness severity: Overall severity considering psychological, physical, and social aspects reached consensus for agreement in both panels. It was important, particularly for LE experts, that severity incorporated all aspects of severity and not just physical or weight-related metrics. The dissensus for mild ED symptoms stems from the belief that intervening early will prevent worsening, but services do not have the capacity to do this and need to prioritise higher severity patients.

Individual Treatment Factors: For items related to patients' treatment history and responsiveness, consensus/near consensus was reached for prioritising patients who were relapsing after recent treatment or transitioning between inpatient and community, child and adult services, or to services in a different area. These were perceived as critical points in treatment where continuity of care is needed to prevent relapse and promote sustained recovery. Although the panels tended to disagree with prioritising those who had several rounds of previous treatment, there were comments on the need to not give up on this patient group. One item was removed after Round 1, as there were many comments about benefit from treatment being difficult, if not, impossible to objectively define, measure, or predict.

Service-related Factors: Service-related factors that reached consensus for agreement were waiting a long time for treatment in both panels and if the patient had received inappropriate, limited, or poor-quality care in the LE panel. Waiting a long time for treatment was perceived as detrimental for engagement and outcomes. Clinicians reached consensus for disagreement (i.e., to not use) for a 'first-come first-served' approach with a trend towards disagreeing in the LE panel. Participants felt that with resource constraints, patients should be prioritised according to severity, risk, and clinical need. Dissensus in prioritising patients who found it difficult to get a referral was due to the rating depending upon why the patient found it difficult.

Physical Health Factors: All physical health-related items reached consensus for agreement across both panels. The items in this category had some of the highest levels of consensus. The high consensus was due to the imminent threat to health and life associated with these items and in the case of pregnancy, the risk to mother and baby.

Mental Health Factors: Mental health getting worse quickly, impaired/poor cognitive capacity and decision-making, and high distress reached consensus/near consensus in both panels. Constantly having intrusive ED thoughts, suicide risk, and escalating non-suicidal self-injury reached consensus/near consensus in the LE panel. Some perceived intrusive ED thoughts as something experienced by all patients, and suicide risk and self-harm as the responsibility of other services. There were also frequent comments for the need to ensure that the mental health aspects of the ED should be considered equally important, if not more, than physical health. Motivation reached near consensus in the clinician panel as treatment can be more successful and shorter for motivated patients.

However, others felt that lack of motivation is an indicator of severity, and that developing motivation is a key part of the treatment process.

Life and Social Factors: Both panels reached consensus for agreement for prioritising patients <12 years old, and clinicians reached consensus for patients <18 years old. Early intervention to prevent the ED becoming entrenched/chronic/persistent and minimising the impact on the person's development were the most frequently cited reasons for ratings. However, some felt that early intervention should be based on illness duration rather than age, and that younger patients already had separate services and better support systems. The ED negatively impacting quality of life reached consensus/near consensus for agreement in both panels. However, some felt that this item would apply to all patients and would therefore be difficult to prioritise. There was a trend towards disagreeing with prioritising based upon income, ethnicity, and if the patient was starting university soon, or had a small window of time before they moved. Having or living in a household with a high income reached near consensus for disagreement in both panels and only having a small window of time before they move somewhere else reached near consensus for disagreement in the LE panel. There were numerous comments on how ethnicity and income should not impact priority, and many felt that it was more important to support the patient in establishing care in the new area for university or a small window before they moved. Moreover, many felt that housing issues (e.g., homelessness) would need to be addressed before ED treatment. Of the social context items, having very little social support was the only item that reached near consensus for agreement. Social issues were perceived as increasing stress, but outside the remit of ED services.

6.4.2 Round 4: Ranking

The results of the ranking task and *W* are outlined in Table 18 in rank order from most to least important. The ranks align closely with final consensus ratings. Medical risk, overall severity, and physical deterioration were unanimously identified as the most important factors for priority setting in both panels. For clinicians, most of the other 'top 10' items were associated with heightened physiological risk (e.g., very low weight, rapidly losing weight), except for being <12 years old and transitioning between inpatient and community. Clinicians commented on how physical risk needs to be addressed before psychological work can begin. Although physical risk items were prominent in the LE panel 'top 10', there was a greater emphasis on mental health

factors, with items such as rapid mental deterioration, quality of life, suicide risk, and intrusive ED thoughts included. Participants with LE indicated that they felt uncomfortable placing physical risk items high on the list because mental health/emotional components are such an important and often neglected aspect of care that drives the ED, but also recognised that with limited resources physical risk needs to be a priority. It is important to note that the *W* statistic, a measure of inter-rater reliability, was weak. In other words, there was a low level of consensus on the precise ordering of the 20 and 22 items that the LE and clinician ranked, respectively. This low level of consensus is further reflected in the "% Rated in top 10" column. Apart from the first item (medical risk), most of the items in each group's top 10 were only included in the top 10 by approximately 40-60% of participants. This means that the position of most of the items (except maybe medical risk) is not very stable. If this ranking task was to be re-administered to another group of participants, the precise ordering would likely change given this low level of consensus.

Table 18. Rank order of the top 10 items from most to least important.

Clinician					Lived experience				
Rank	and item	Mean rank (*SD*)	% Rated in top 10	% Consensus	Rank	and item	Mean rank (*SD*)	% Rated in top 10	% Consensus
1.	**if they are at significant medical risk (e.g., very slow or irregular heartbeat, abnormal blood results)**	**6.13 (3.96)**	**80%**	**98%**	**1.**	**if they are at significant medical risk (e.g., very slow or irregular heartbeat, abnormal blood results)**	**6.17 (3.66)**	**81%**	**93%**
2.	**based upon the severity of their illness (taking into account psychological, physical, and social severity)**	**4.13 (4.42)**	**56%**	**95%**	**2.**	**based upon the severity of their illness (taking into account psychological, physical, and social severity)**	**5.98 (3.68)**	**83%**	**86%**
3.	**if their physical health is getting worse quickly (any metric of physical health)**	**3.95 (4.08)**	**51%**	**98%**	**3.**	**if their physical health is getting worse quickly (any metric of physical health)**	**3.38 (3.47)**	**63%**	**93%**
4.	if they are pregnant	3.54 (3.24)	64%	96%	4.	if their mental health and well-being is getting worse quickly (any metric of mental health)	3.31 (3.42)	60%	95%

5.	if they have diabetes and are purposefully restricting their insulin to lose weight (diabulimia)	2.97 (3.20)	59%	89%	5.	if they have a major physical disorder (e.g., cardiovascular disease, diabetes, cancer) that is made worse by their eating disorder	3.00 (3.31)	54%	89%
6.	if they are transitioning between inpatient and community services	2.97 (3.50)	56%	91%	6.	if their eating disorder is negatively impacting their quality of life (e.g., stops them from doing leisure activities, impacts how they interact with other people or makes it difficult to work/study, financial problems)	3.00 (3.59)	52%	88%
7.	if they are quickly losing weight (irrespective of their starting weight)	2.69 (3.29)	46%	93%	7.	if they are less than 12 years old	2.98 (3.52)	52%	88%
8.	if they have reduced the amount or type of food they are eating (dietary restriction) at an extreme level	2.54 (3.32)	41%	91%	8.	if they are pregnant	2.90 (3.81)	44%	87%

	(e.g., very little dietary intake almost every day)								
9.	if they are a very low weight	2.41 (3.27)	44%	89%	9.	if they are thinking or planning to end their life (suicide risk)	2.85 (3.80)	42%	88%
					10.	if they are constantly having intrusive eating disorder related thoughts and feelings (e.g., thoughts about their body shape and weight, fear of putting on weight)	2.69 (3.52)	54%	84%
10.	if they are less than 12 years old	1.97 (3.07)	41%	89%					
		W	.14				*W*	.11	

Note. Items in bold obtained the same rank across participant groups.

6.5 Discussion

The aim of this study was to evaluate the degree of consensus and perceived relative importance of factors for priority setting decisions in ED services for two key stakeholder groups: clinicians and individuals with LE of an ED. To our knowledge, this is the first evaluation of clinician and LE opinions on priority setting in ED services. Despite differences in 'expertise', the pattern of responding was similar across the panels, with some notable differences. This is in accordance with previous Delphi studies in EDs and mental health more broadly, whereby consumers and professionals converge in their consensus (Hart & Wade, 2020; Jorm, 2015).

Medical risk, overall severity, and rapid physical deterioration were ranked as the top three factors for determining priority in clinician and LE panels. There was a strong view, particularly amongst LE participants, that severity should incorporate social and psychological aspects, not only physical. Most of the other items included in the 'top 10' for both panels were associated with a high degree of physical or mental risk (e.g., pregnancy, diabulimia, suicide). Clinicians included more physical risk and weight-related items, whereas the LE panel included mental health-related items, which were absent from the clinician's 'top 10'. It is important to note the low levels of inter-rater reliability (*W* statistic) for the 'top 10' lists, i.e., there was low consensus amongst the participants on the precise ordering of these lists. Severity, physical health factors, and mental health risk items also obtained some of the highest levels of consensus across both panels in the rating task (Rounds 1 to 3). Moreover, consensus for weight and behavioural ED symptoms was greatest for the most severe/frequent and risky symptoms (e.g., vomiting 5 or more times per week). Qualitative comments also suggest that judgements throughout the study were largely influenced by the degree of risk or severity. Severity and acute risk are consistently identified as important for priority setting decisions in physical and mental healthcare and align with prioritarian principles of distributive justice. There appears to be a drive to treat those who are suffering the most or facing death (Oudhoff, Timmermans, Rietberg, Knol, & van der Wal, 2007; Shah, 2009; Whitty et al., 2014). These findings are consistent with ED clinical guidelines (i.e., National Institute for Health and Care Excellence, 2017) and practice, where the urgency of the patient's condition tends to take precedence.

Some authors argue that preferentially allocating resources to those who are most unwell unjustly ignores those who will be worse later if left untreated, particularly

when the most unwell will only benefit slightly (Persad et al., 2009). The use of utilitarian principles such as this to justify choices were evident in the current study, albeit to a lesser extent than prioritarian (e.g., "*Early intervention is key, however, if another patient is deemed at greater physical & mental risk then this needs to be evaluated*"). This is in line with evidence demonstrating that people are generally willing to sacrifice some aggregate health gains to give priority to the most severely ill (Shah, 2009). Utilitarian rationales were provided for many items, including transitions, age, illness duration, mild ED symptoms, and motivation.

Participants described transitions as poorly managed and crucial points where priority and continuity of care could promote sustained recovery and prevent relapse. The transition between inpatient and community services reached consensus in both panels and was included in the clinician's 'top 10', underscoring its importance in priority setting. The transition between child and adult services and different areas reached consensus/near consensus in the clinician panel. Transitions have long been perceived as particularly challenging in EDs and requiring careful co-ordination (Crockett, 2018; Treasure, Schmidt, & Hugo, 2005). The dangers of poorly managed transitions are evident in high profile cases, such as the death of 19-year-old Averil Hart in the UK (Parliamentary and Health Service Ombudsman, 2017).

An age of <12 years old reached consensus and was included in the 'top 10' for both panels, suggesting a strong preference for prioritising the very young. Clinicians also reached consensus for patients <18 years old. Comments suggest that younger patients were prioritised because of the belief that early intervention can lead to better outcomes and minimise the impact on development. This rationale did not hold as strongly for adolescents and emerging adults, despite evidence suggesting that a similar rationale may also be applicable to these age groups (e.g., Austin et al., 2021b; Flynn et al., 2020). These findings largely align with recent efforts to ensure early access to ED treatment for children and young people (NHS England, 2015) and broader healthcare priority setting literature, where younger patients tend to be prioritised for treatment (Gu et al., 2015; Whitty et al., 2014).

The consensus for illness duration items was notably different in clinician and LE panels. Only the clinician panel reached consensus/near consensus for prioritising patients with an illness duration of <6 months, <1 year, and <3 years. The lack of

endorsement of these items in the LE panel is likely due to concerns regarding the exclusion and neglect of patients with longer illness durations. Personal experiences of exclusion or difficulties accessing appropriate treatment may increase the strength of this concern in the LE panel. Indeed, clinical and research observations suggest that individuals with severe and enduring EDs are less likely to be in active ED treatment (for a myriad of reasons) (Wonderlich, Bulik, Schmidt, Steiger, & Hoek, 2020). Moreover, despite evidence in support of early intervention, predicting who will respond to what treatment and when, remains limited in EDs (Kan et al., 2019; Kaplan & Strober, 2019). Predictive uncertainty such as this makes the application of utilitarian principles difficult, leading to more egalitarian responses (Wilkinson & Savulescu, 2014). The LE panel appear to have a stronger preference for equity over utility in these circumstances. Conversely, clinical experience and observing the impact of early intervention on patients could strengthen ratings in the opposite direction. First Episode Rapid Early Intervention for EDs (FREED) is an early intervention service for emerging adults (16-25 years old) with recent onset EDs (<3 years duration). FREED functions as a 'service-within-a-service', i.e., a smaller sub-group of clinicians in an evidence-based ED service are responsible for delivering FREED. FREED aims to reduce service-related delays to care and adapts evidence-based ED treatments to the needs of emerging adults in early-stage illness (Allen et al., 2020; Brown et al., 2018). Qualitative data gathered during the scaling of FREED in England (in Chapter 5), generally did not find that early intervention had a detrimental impact on non-FREED patients, if anything, the benefits were perceived as extending beyond FREED patients. Specifically, increased service efficiencies and the rapid response to treatment observed in FREED patients were seen as freeing up resources for non-FREED patients. Some of the materials and principles of FREED (e.g., attention to social media use) were also beneficial to non-FREED patients. Observing the impact of FREED on patients was also noted as a key driver for using the model (findings in Chapter 5). Clinical experience of rationing treatment and considering the long-term implications of prioritisation decisions may also contribute towards the clinician preference for utility over equity.

The notably higher consensus for mental health and quality of life items in the LE panel and the inclusion of these items in the 'top 10' as well as the exclusion of weight-related items could, in part, stem from a drive to promote equity and parity of

esteem between physical and mental health in ED services. There were numerous qualitative comments to support this: "*there needs to be equivalence of physical and mental symptoms*" or "*it should be based on the distress the person is experiencing and the impact it has on their life - NOT their weight*". Mental health impacts were also described as the most problematic for patients and as the main driver of the ED. Physical health metrics, especially weight, have historically been used as one of the defining features of gaining access to ED services (Marsh, 2021; McCubbin, 2016; Women and Equalities Committee, 2021). In recent years, there have been widespread campaigns (e.g., dump the scales (Virgo, 2022)) and explicit instructions in clinical guidelines to not use weight or BMI as the only means of determining access treatment (National Institute for Health and Care Excellence, 2017). However, as this study and others demonstrate, the disparity between the physical and mental health components of the ED remains. More work is needed to consider the mental health and quality of life aspects of the ED in service access and priority setting.

Egalitarian principles were evident for diagnosis and broader life and social context. Many perceived all ED diagnoses as equally serious and debilitating, and that priority should be based on severity/risk/distress/impact on life rather than diagnosis. There was also limited endorsement of many items related to the patient's life and social context. Age, the impact of the ED on quality of life, and very limited social support were considered as pertinent factors. However, ethnicity, income, going to university, and a small window of time before moving somewhere else were deemed less relevant. Egalitarian rationales were provided for these items (i.e., individuals should not be disadvantaged by personal circumstances), which parallels findings in the wider priority setting literature (Gu et al., 2015; Whitty et al., 2014). However, a "pure" equity approach was not sought. The 'first-come first-served' method was the only item to reach consensus for disagreement (i.e., should not be used). The blindness of this approach to factors that would be inappropriate to ignore (e.g., medical risk) led to the rejection of this item (Persad et al., 2009). Participants did however comment on how they wished that priority could be determined in this way (e.g., "*Whilst I would like this to be the case, there will be some people who are more urgently in need*").

6.5.1 Clinical implications

One of the key findings of this study is the greater emphasis on mental health symptoms and quality of life in the LE panel. There were strong opinions against prioritising solely

based upon physical metrics, especially weight-related criteria. Physical risk is currently one of the main prioritisation factors used in services, and as pressure escalates, the focus on physical risk becomes greater. It is important to raise awareness of and address this over-reliance on physical metrics within ED services. Given current pressures on services, prioritising based upon anything else can feel like a luxury, however, these findings indicate that this is not a luxury and that the whole person needs to be kept in mind as much as possible. The development of an ED prioritisation tool to facilitate discussions around priority setting and to ensure that all aspects of the person are considered could help address this imbalance. Prioritisation tools incorporating measures of risk, symptoms, psychosocial functioning, and the impact on the person's life have been used to promote transparent and equitable priority setting in other areas of healthcare (e.g., Srikumar, Eglinton, & MacCormick, 2020). There will be a degree of subjectivity in quantifying certain metrics (e.g., quality of life), as every patient is different, and some may lack insight into their ED symptoms and the impact of these on their daily functioning. However, this does not necessarily mean that these features cannot be meaningfully considered alongside other metrics to inform patient priority decisions. Such prioritisation tools could also be used as an indicator for the condition of services (e.g., the discrepancy between demand and capacity) and stimulate discussions with service commissioners and policy makers around adequately funding services.

Another important discrepancy between clinician and LE opinions was the greater endorsement of prioritising patients in early-stage illness in the clinician panel. Participants with LE did not perceive patients in early-stage illness as a priority, largely because they did not want other patient groups to be disadvantaged. To be considered as a priority, early intervention therefore needs to be adequately resourced to ensure that it does not negatively impact the care of others. In addition to effective priority setting procedures, there is also a pressing need to address capacity issues and pressures on specialist ED services. Promising avenues to relieve pressure on services include increasing the reach of effective prevention programs (Stice, Onipede, & Marti, 2021), implementing task-sharing interventions (e.g., peer support, guided self-help) (Kazdin, Fitzsimmons-Craft, & Wilfley, 2017), and more initiatives for the early identification and treatment of EDs in educational and primary care settings (Kalindjian et al., 2021; Radunz et al., 2021).

6.5.2 Strengths and limitations

A major strength of this study was that we were able to recruit a large sample with high retention across the rounds. Participants also provided detailed responses to the optional comment boxes and open-ended questions, which provided insights into why people gave specific ratings and increased the validity of our conclusions. The inclusion of both clinician and LE opinions from across the UK was another strength of this study. However, there are several limitations that need to be considered.

First, the recruitment method, i.e., self-selection and largely through social media, may have introduced a bias in the sample. Only those who were motivated and active on social media would have the opportunity to participate. Participant motivation for taking part was not assessed and may have biased the results. Diagnoses and recovery/illness status were also not verified with standardised criteria or clinical interviews and may have impacted how participants responded to the questionnaires. Additionally, while the inclusion criteria were deliberately broad to increase diversity of experiences, one year's worth of experience in EDs may not be sufficient to develop clinical 'expertise' in this area. Moreover, although the sample was diverse in some respects (e.g., profession), it was not in others (e.g., ethnicity). Caution is therefore needed when generalising these findings, particularly for items that relate to under-represented characteristics.

Second, given research resource constraints, many other important groups could not be included in the Delphi study, such as friends, family, and caregivers. Caregivers are a particularly important group given their role in supporting the person with an ED while they wait for and during treatment. Caregivers are impacted by prioritisation procedures and would have brought this unique perspective into the Delphi study, e.g., knowledge of the most challenging issues to manage/support at home and the impact of lengthy waits on the caregiver's and patient's life. The exclusion of caregivers from this study has implications for its clinical applicability and relevance, caregivers are key partners in the care process and should be included in conversations around how care is organised and managed. The exclusion of this group could have resulted in important prioritisation factors being missed or under-rated.

Third, information on the number of participants who were FREED clinicians or patients was not gathered. This information would have been important to determine the potential bias in the sample and the representativeness of the opinions. While this

information was not gathered directly, most of the participants with LE had illness durations outside of the FREED eligibility criteria (<3 years illness), so were unlikely to be FREED patients. Only 16% of the participants with LE had an illness duration of less than 3 years and 65% had an illness duration of 5 years or more. Fourth, as comment boxes and open-ended questions were optional, not everyone provided a rationale for their choice. This makes the qualitative data on why participants chose certain options "incomplete".

Finally, participants expressed difficulties in rating and ranking items. Prioritisation decisions are highly complex and difficult, and single item ratings vastly underestimate this complexity. In practice, decisions are rarely made on a single factor and dimensions of the decision-making process were not included in this study. For example, one issue, which was raised by participants in their qualitative feedback, was the lack of specification on precisely what type of intervention or care the patient was being prioritised for. Decision making is likely to differ for prioritising patients for physical monitoring/observations/care versus psychosocial interventions. There was also overlap between factors which complicated the decision making in the ranking task. The overlap and complexity may have contributed to the low level of consensus on the ranking task. The low level of consensus on the ranking task is important to bear in mind when interpreting the findings of this study. While this study provides an important starting point for discussions around priority setting in EDs, more research is needed utilising more ecologically valid techniques and to confirm/refute the current findings (especially for the ranking task). The James Lind Alliance (JLA) approach is a rigorous and widely used priority setting methodology used within EDs research that could have enabled greater insights into the complexity of the ranking task (Obeid, McVey, Seale, Preskow, & Norris, 2020). In addition to a survey to rank priorities, JLA participants are invited to an in-person workshop to discuss and rank the top 10 priorities. Time and resources constraints limited our ability to conduct something that was closer to the JLA approach (i.e., using a combination of both surveys and in-person discussions). A JLA approach would also have limited the geographical area from which we could recruit participants. Additionally, an in-depth ethnographic study using observations of priority setting behaviour alongside interviews with clinicians and patients would be a useful addition to this evidence-base.

6.5.3 Conclusion

Priority setting decisions are ethically complex, difficult, and can have considerable consequences for those involved. Yet, research to guide discussions and support clinical decision making in ED services is absent. EDs are unique as they carry considerable physical and psychological risks that need to be considered during priority setting decisions. Our findings demonstrate that clinicians and individuals with LE place physical and psychological risk and severity (prioritarianism) at the top of determining priority in ED services. Followed by a mix of utilitarian and egalitarian approaches with clinicians placing greater emphasis on the former and individuals with LE on the latter. While further testing of these findings is warranted in more heterogenous samples and with more ecologically valid designs, we hope that this paper will stimulate discussion for this important topic. Now more than ever, there is a pressing need for research to support conversation regarding fair, just, and transparent priority setting in EDs.

Chapter 7. National roll-out of early intervention for eating disorders: Process and clinical outcomes from First Episode Rapid Early Intervention for Eating Disorders

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A copy of the article is provided in Appendix A. The formatting of this article has been amended here for stylistic consistency. While the body of the text remains largely unchanged, the following were added to this chapter to provide greater clarity on the study and its results: (1) an expanded participant flow diagram detailing questionnaire timeframes and potential reasons for missing data; (2) an evaluation on the impact of COVID-19 on missing data; (3) further details and clarity on the questionnaire timeframes for each cohort; (4) further details on the limitations of the study findings; (5) information on how missing data were handled; (6) median waiting times; (7) further details on the different types of analyses conducted and how these relate to the data displayed in the tables.

Author contributions: The study was conceptualised and designed by the candidate (Katie Richards), Dr Karina Allen, and Professor Ulrike Schmidt. The candidate and Lucy Hyam were responsible for collecting and managing the data. The candidate, Lucy Hyam, Danielle Glennon, Dr Giulia Di Clemente, Amy Semple, Aileen Jackson, Stefano Belli, Elizabeth Dodge, Charmaine Kilonzo, Leah Holland, and Professor Ulrike Schmidt contributed towards the national implementation of FREED. The candidate analysed the data and drafted the manuscript with assistance from Dr Karina Allen and Professor Ulrike Schmidt. All authors reviewed and contributed to the final manuscript. Constructive feedback was provided by peer reviewers from *Early Intervention in Psychiatry* and the manuscript modified accordingly.

7.1 Abstract

Aim: First Episode Rapid Early Intervention for Eating Disorders (FREED) is an early intervention model for young people with a recent-onset eating disorder. Promising results from a previous single-centre study and a four-centre study (FREED-Up) have led to the rapid national scaling of FREED to eating disorder services in England (FREED-4-All, currently involving 30 FREED services). Our aim was to evaluate duration of an untreated eating disorder (DUED), wait time target adherence, and clinical outcomes in FREED-4-All and compare these to the (benchmark) findings of the earlier FREED-Up study.

Method: FREED services submit a set of de-identified data to the central FREED team quarterly. The current study covers the period between September 2018–September 2021. This national FREED-4-All dataset includes 2473 patients. These were compared to 278 patients from the FREED-Up study.

Results: DUED was substantially shorter in the FREED-4-All dataset relative to the FREED-Up study (15 versus 18 months). Adherence to the wait time targets was comparable in both cohorts (~85% of engagement calls attempted in <2 days, ~50-60% of assessments offered in <14 days, ~40% of treatment offered in <28 days). Patients in the FREED-4-All dataset experienced significant improvements in eating disorder and general psychological symptoms from pre- to post-treatment that were comparable to the FREED-Up study. The clinical outcome findings should be interpreted cautiously as only 6% of FREED-4-All patients had post-treatment data.

Conclusions: Data from the FREED-4-All evaluation suggest that FREED is replicating at scale. However, these data are flawed, uncertain, proximate, and sparse (FUPS) and should therefore be used carefully alongside other research evidence and clinical experience to inform decision making.

7.2 Introduction

Eating disorders (ED) are costly and complex illnesses with serious physical, psychiatric, and psychosocial consequences (Treasure et al., 2020a). Adolescence and emerging adulthood are a peak risk period for the onset of EDs as well as a key developmental phase where people acquire the skills, knowledge, and confidence to flourish in adult roles (Potterton et al., 2020b; Solmi et al., 2021a). Evidence suggests that earlier, faster, and easier access to specialist ED services can improve outcomes and limit the deleterious effects of EDs on health, quality of life, and functioning (Ambwani et al., 2020; Treasure et al., 2015).

Despite evidence in support of early intervention, there is typically a protracted period before patients start treatment. The average duration of an untreated ED (DUED) is alarmingly long, ranging from 2.5 years in anorexia nervosa (AN) to 6 years in binge eating disorder (BED) (Austin et al., 2020). First Episode Rapid Early Intervention for EDs (FREED) is one of few evidence-based initiatives aimed at facilitating early intervention and reducing DUED.

FREED is an early intervention service for emerging adults (16-25-year-olds) with recent-onset EDs (<3 years duration) (Schmidt et al., 2016b). The central aims of the model are to reduce wait times and DUED and provide treatment which is tailored to illness stage and developmental needs. The FREED service model and care package have been described in detail elsewhere (Allen et al., 2020; Brown et al., 2018; Richards et al., 2021). Of relevance to the current study, the service model includes an engagement call provided within 48-hours of referral, wait time targets of 2-weeks for assessment and 4-weeks for treatment, and a 'FREED Tracker' to monitor and manage patient throughput.

The FREED model has been evaluated in a single-centre pilot study and a multi-site FREED-Upscaled (FREED-Up) study (Austin et al., 2021b; Brown et al., 2018; Flynn et al., 2020; McClelland et al., 2018). Both studies employed quasi-experimental pre-post designs comparing FREED patients to a historical treatment as usual (TAU) group. The TAU group were patients of a similar age and illness duration seen in the services immediately before FREED was introduced. FREED-Up took place across four ED services in England. Compared to TAU, FREED patients waited significantly less time for assessment (3-3.5 weeks less) and treatment (10-12 weeks less) and had a

notably shorter DUED (2-3 months shorter). FREED also led to significant improvements in treatment uptake and clinical outcomes. Weight recovery for patients with AN was substantially higher in FREED compared to TAU (17-18% vs 53-59%). The proportion of FREED patients requiring day- or in-patient treatment was also lower than TAU, which resulted in cost savings (FREED: £8,781 vs TAU: £13,604).

FREED therefore has demonstrated utility in improving outcomes and reducing wait times, DUED, and treatment costs in settings beyond where it was initially developed. Assessing the impact of an intervention at scale and comparing it to results from earlier research studies is essential to determine whether the intervention can replicate desired effects and warrants further scaling, or whether more refinement is needed. Since the FREED-Up study, the aim has been to continue to scale and implement FREED to reach as many young people as possible (Allen et al., 2020). The term FREED-4-All has been used to describe this implementation phase. In April 2020, FREED became part of the Academic Health Sciences Network's national adoption and spread programme (Academic Health Science Network, 2020). To date, FREED has been scaled to 32 ED services in England (64% of all eligible services) with more interested or preparing to launch in 2022. Most of this scaling has occurred during the coronavirus 2019 (COVID-19) pandemic, which had a profound effect on the normal functioning of ED services. Decreases in capacity, coupled with a marked increase in the acuity and volume of referrals, pushed already underfunded ED teams to their limits and continue to provide major challenges (Solmi, Downs, & Nicholls, 2021).

The ongoing evaluation of FREED was built into the model's operational processes. Specifically, the data collected on the FREED Tracker are used locally and nationally for monitoring and evaluation purposes (Allen et al., 2020). Routinely collected data such as this are invariably flawed (missing or incorrectly entered), uncertain (differences in how items are understood and rated), proximate (data are a proxy for what is of interest), and sparse (low volumes of data for subgroups) (FUPS; Wolpert et al., 2016). Caution is therefore needed when using this type of data because the missingness and uncertainty around the data introduce unknown and unmeasurable biases. Nonetheless, FUPS data remain valuable and are, in many circumstances, all that is available. Three key principles have been proposed for analysing and working with FUPS data: (1) acknowledgement of their limited validity, reliability, and generalisability; (2) transparency and simplicity in analytical procedure; and (3)

considering the data in the context of all other available information (Wolpert & Rutter, 2018). The FUPS framework was used to guide the analysis and interpretation in the current study.

The aim of this study was to evaluate DUED, adherence to FREED wait time targets, and clinical outcomes in the FREED-4-All cohort and compare these to the FREED-Up study to examine whether the findings are replicated at scale.

7.3 Method

7.3.1 Study design and sample

This study involved a descriptive, pre-post, and comparative evaluation of routinely collected data (FREED-4-All) gathered from 30 specialist ED services implementing FREED in NHS England. The data cover the period between September 2018 and September 2021. At the outset, there were three services providing data, this increased to five in 2019, eight in 2020, and 30 in 2021. The sample consists of 2473 FREED patients (16–25-year-olds with an ED diagnosis of less than 3 years duration) referred to the pathway during this period. The FREED-4-All data were compared to data collected during the FREED-Up study. Only data from the FREED (not TAU) patients and demographic and clinical outcomes at baseline, and 6- and 12-months from the FREED-Up study were used. Diagnostic information was also taken from clinician rather than researcher estimates (unlike previous FREED-Up papers (Austin et al., 2021b; Flynn et al., 2020)).

7.3.2 FREED-4-All: Data collection and procedure

An Excel spreadsheet (the 'FREED Tracker') was used to collect FREED-4-All data at each site. ED and psychological outcomes were gathered pre-treatment and post-treatment, but the precise timing was flexible so that sites could fit the data collection into their local processes. On average, the post-treatment measures were collected 6-months (*SD* = 3.2 months; range = 1 month to 15 months) after the referral was received. De-identified Trackers were submitted quarterly to the central FREED team who provided performance and data quality feedback.

All sites sign an Operational Agreement prior to data collection and sharing. Written informed consent is not required. Instead, patients are informed about the data sharing via an information sheet and/or other fair processing notices and given the opportunity to opt out of the data sharing, without any implications for treatment. The

justification is that the data offers significant benefits to the evaluation of FREED without requiring personal patient information, and complies with the General Data Protection Regulation (Information Commissioner's Office, 2018).

7.3.3 Outcomes

Engagement call, assessment, and treatment wait times and target adherence: Wait times for the engagement call, assessment, and treatment were defined as the time in days (including and excluding weekends) from when the referral was received to when the engagement call was first attempted (regardless of whether it was successful) and completed, the assessment was first offered (regardless of whether it took place) and attended, and when the first treatment session was offered (regardless of whether it took place) and attended. Adherence to the FREED wait time targets was calculated as the number of patients who had their engagement call attempted and completed in ≤2 days, were offered or received an assessment in ≤14 days and were offered or received treatment in ≤28 days.

Eating Disorder Examination Questionnaire (EDE-Q; Fairburn & Beglin, 2008): A 28-item self-report questionnaire measuring ED symptomatology in the past 28 days. Only the global score is reported and consists of 22-items measuring attitudinal and behavioural aspects of EDs. Each item is rated on a 7-point scale (0 to 6) for severity or frequency, with higher scores indicating greater severity or frequency. A global score of ≥2.8 is suggestive of clinically significant ED symptoms (Mond et al., 2008).

Binge eating, vomiting, and laxative episodes per month: Within the FREED-Up study, binge eating, vomiting, and laxative episodes per month were measured using the behavioural items on the EDE-Q. For the FREED-4-All dataset, clinicians were able to decide how they collected this information locally.

Body mass index (BMI): BMI was calculated by dividing the patient's weight by the square of their height (kg/m^2). A BMI of >18.5 kg/m^2 is considered as not underweight in current ED classifications.

Clinical Outcomes in Routine Evaluation-10/Outcome Measure (CORE-10/OM; Barkham et al., 2013): CORE-OM and CORE-10 are global measures of psychological distress. CORE-10 is made up of 10-items drawn from the CORE-OM, which is a 34-

item measure. Each item is rated on a 5-point scale ranging from 0 (*not at all*) to 4 (*most of the time*), with higher scores indicating greater psychological distress.

7.3.4 Data analysis

The analysis was conducted using R programming software version 4.0.5 (R Core Team, 2021). The primary focus of the analysis was descriptive. Means and standard deviations were calculated for continuous variables, including age at referral, DUED, wait in days (including and excluding weekends) for the engagement call, assessment, and treatment, and the global EDE-Q, binge eating/vomiting/laxative episodes per month, BMI, and CORE-10/OM at pre-treatment (Time 1 (T1)) and post-treatment (Time 2/Time 3 (T2/T3)) for FREED-4-All and pre-treatment, 6-months (Time 2 (T2)), and 12-months (Time 3 (T3)) for FREED-Up. Medians were also calculated for the wait in days (including and excluding weekends) for the engagement call, assessment, and treatment. Frequencies were calculated for count data, namely, diagnosis, adherence to FREED wait time targets, and the proportion of patients above the EDE-Q clinical cut-off (≥2.8) and above the underweight BMI criterion (>18.5 kg/m^2) at pre- and post-treatment (T2/T3), 6-months (T2), and 12-months (T3). To account for missing data in the evaluation of patients above the EDE-Q clinical cut-off (≥2.8) and the underweight BMI criterion (>18.5 kg/m^2), predictive mean matching using the 'mice' R package was used to impute missing BMI and EDE-Q scores for individuals who had at least one BMI and EDE-Q score at one time point (van Buuren, 2018). The percentage above each threshold was then calculated based upon these imputed scores and are displayed in Table 23. Missing cases (i.e., individuals whose scores could not be imputed or were not available) were omitted from all percentage calculations to enable a comparison of proportions between FREED-Up and FREED-4-All.

Secondary to this descriptive evaluation, differences between FREED-Up and FREED-4-All were tested using robust statistical procedures. For continuous variables, a robust *t*-test (Yuen-Welch test; T_y) using 20% trimmed means, Winsorized variances, and percentile *t*-bootstrapping (2,000 bootstrapped samples) from 'WRS2' package were used (Mair & Wilcox, 2020). A robust explanatory measure of effect size (ξ) was also used for continuous variables. Values of .15, .35, and .50 correspond to small, medium, and large effects, respectively (Wilcox & Tian, 2011). Chi-squared or Fisher's exact tests were used to investigate differences in categorical variables and adjusted

standardised residuals were used to determine which categories had substantially larger or smaller frequencies than expected.

Two sets of multi-level models were used to evaluate change in clinical outcomes from pre- to post-treatment. The first set evaluated changes in clinical outcomes over time in each FREED cohort separately (displayed in Table 21). For FREED-Up, changes between baseline (T1) and 6-months (T2), and baseline (T1) and 12-months (T3) were tested. For FREED-4-All, changes between pre- (T1) and post-treatment (T2/T3) were tested. The second set of models evaluated differences in change between FREED-Up and FREED-4-All (displayed in Table 22). In the models in Table 22, the FREED-4-All post-treatment time point (T2/T3) was compared to both the 6-month (T2) and 12-month (T3) FREED-Up time points. The FREED-4-All post-treatment time point (T2/T3) was compared to both 6- and 12-month FREED-Up time points because the time between the referral and the post-treatment questionnaire completion for FREED-4-All patients ranged from 1 to 15 months, encompassing both the 6- and 12-month FREED-Up time points. However, the FREED-Up 6-month (T2) time point was closest to most of the post-treatment questionnaire data for the FREED-4-All patients (T2/T3) (approximately 64% of FREED-4-All patients completed their post-treatment questionnaire between 3 to 9 months after the referral was received). The mismatch between the time points is important to bear in mind while evaluating the results in Table 22 and the in-text chi-squared tests related to the data in Table 23. The mismatch could over-estimate the differences between the FREED-Up and FREED-4-All cohorts. Specifically, given that 85% of FREED-4-All patients completed their post-treatment questionnaires in <9 months, these patients would have had less time to get better relative to the FREED-Up patients at the 12-month time point. Equally, 15% of FREED-4-All patients completed their post-treatment questionnaires between 9 and 15 months after the referral. These patients would have had more time to get better relative to FREED-Up patients at the 6-month time point. Given that the same FREED-4-All data were used twice (for T2 and T3), the overall pattern of change in scores over time displayed in Table 22 is of less interest (i.e., “Time (1 vs 2)” and “Time (1 vs 3)” in Table 22). The primary focus of the analysis displayed in Table 22 is on the differences in the change over time for the FREED cohorts (i.e., the interaction terms: “Time (1 vs 2)*FREED cohort” and “Time (1 vs 3)*FREED cohort”). In contrast, the first set of models displayed in Table 21 were primarily focused on evaluating the pattern of

change in scores over time. The models were fit using 'nlme' package and Bliese's procedure (Bliese, 2016; Pinheiro, Bates, DebRoy, Sarkar, & R Core Team, 2021).

All available data were included in the multi-level models (Table 21 and Table 22) and comparisons of the percentage of patients above BMI and EDE-Q clinical cut-offs at pre- and post-treatment (Table 23). In other words, cases with some missing data (partial cases) were included in these analyses, akin to a pairwise deletion approach. Given that many (~66%) referrals in the FREED-4-All cohort had no data for clinical outcomes (neither pre- nor post-treatment scores), a true intention-to-treat analysis was not performed (i.e., including all patient in the analysis regardless of whether they satisfy entry criteria, received treatment, and/or withdraw/deviate from the protocol; Hollis & Campbell, 1999). Moreover, it is not known if FREED-4-All clinicians followed up all patients for post-treatment questionnaires regardless of whether they started treatment or not. An intention-to-treat procedure was used in the FREED-Up study and analysis, i.e., all participants were followed up regardless of whether they completed treatment or not and all had baseline (pre-treatment) questionnaires so could be included in the analysis.

7.3.5 Missing data

An analysis of missing data was conducted to understand patterns of missingness. A detailed overview of missing data per variable is available in Appendix G Section 10.7.3.1. Numerous reasons for missingness were identified during the data collection period, including patients not returning questionnaires, clinicians not having the capacity to collect (e.g., extract it from medical records, "chase" the questionnaires) and enter the data onto the FREED tracker, staff changes, clinicians not being accustomed to or invested in data collection and limited IT support. The COVID-19 pandemic also had an impact on the amount of missing data and attrition as FREED services had to stop/pause the service and/or treatment provision, technical issues with accessing data while working from home, and staffing issues. A table of the data completion rates for different data items before and after the onset of the COVID-19 pandemic has been provided in Appendix G Section 10.7.3.2. It is important to note that only four sites were included in this analysis. These four sites were the only sites that had sufficient data before and after the onset of the COVID-19 pandemic. There is also typically a delay from referral and patients starting treatment and from referral and patients completing post-treatment questionnaires. Therefore, patients referred between mid/late

2019 to early 2020 were not included in the treatment start date and post-treatment questionnaire completion rate calculations. As outlined in the patient flow diagram in Figure 7, patient disengagement, seeking treatment elsewhere, inpatient treatment, referral to a different service, moving out of area, and early agreed treatment ending would have also contributed towards the missing data. The missing data are unlikely to be missing at completely random, although some might be. Given the high degree of missing data for baseline variables, it was deemed inappropriate to use baseline variables to evaluate or control for missingness.

7.4 Results

7.4.1 Patient characteristics

A flow diagram of the number of patients from intake to start of treatment and the amount of questionnaire data available at each time point are provided in Figure 7. Potential reasons for missing data at each stage of the FREED pathway have also been included in the diagram. However, data on reasons for missingness were limited as evidenced by the substantial portion of patients labelled as “other/unknown/missing”. Demographic and clinical characteristics are presented in Table 19. Only 20% (*n* = 503) of FREED-4-All patients were referred before the onset of COVID-19 in the UK. On average, FREED-4-All patients were significantly younger and had a shorter DUED than FREED-Up patients. FREED-4-All patients were substantially more likely to be diagnosed with AN or BED and less likely to be diagnosed with other specified feeding or eating disorder (OSFED) than FREED-Up patients. Closer inspection of the FREED-4-All data over time suggests that the proportion of AN cases increased from 34% in September 2018 – February 2020 (before the pandemic) to 46% in March 2020-September 2021 (during the pandemic).


FREED-Up
Dec 2016 – Oct 2018
1334 referrals aged 16-25
278 included in FREED-Up study
Excluded/lost (n=1056), reasons:
Not eligible for FREED (n=761)
No assessment/contact/baseline (n=160)
Declined to participate (n=21)
Learning disability (n=1)
260/278 (94%) engagement calls completed
Excluded/lost (n=18), potential reasons:
Other/unknown/missing (n=18)
278/278 (100%) assessments completed
Excluded/lost (n=0)
278/278 (100%) Time 1 (T1) pre-treatment questionnaires available
Excluded/lost (n=0)
272/278 (98%) start date for treatment
Excluded/lost (n=6), potential reasons:
Other/unknown/missing (n=6)
182/278 (65%) 6-month Time 2 (T2) questionnaires available
Excluded/lost (n=96), potential reasons:
Other/unknown/missing (n=96)
175/278 (63%) 12-month Time 3 (T3) questionnaires available
Excluded/lost (n=103), potential reasons:
Other/unknown/missing (n=103)
FREED-4-All
Sept 2018 – Sept 2021
2473 FREED referrals received
1871/2473 (76%) engagement calls completed
Excluded/lost (n=602), potential reasons:
Discharged: Agreed early ending/declined (n=11)
Discharged: DNA/disengaged (n=37)
Discharged: Moved out of area (n=10)
Discharged: Referred to other service (n=8)
Inpatient treatment (n=4)
Other/unknown/missing (n=532)
1803/2473 (73%) assessments completed
Excluded/lost (n=670), potential reasons:
Discharged: Agreed early ending/declined (n=11)
Discharged: DNA/disengaged (n=40)
Discharged: Moved out of area (n=11)
Discharged: Referred to other service (n=8)
Discharged: Accessing private care (n=3)
Inpatient treatment(n=2)
Other/unknown/missing (n =595)
823/2473 (33%) Time 1 (T1) pre-treatment questionnaires available†
Excluded/lost (n=1680), potential reasons:
Did not have an assessment completed date (n=651)
Of those that had an assessment date (n=1029):
Discharged: Agreed early ending/declined (n=36)
Discharged: DNA/disengaged (n=66)
Discharged: Moved out of area (n=24)
Discharged: Referred to other service (n=19)
Discharged: Accessing private care (n=6)
Inpatient treatment (n=1)
Other/unknown/missing (n=877)
1023/2473 (41%) start date for treatment
Excluded/lost (n=1450), potential reasons:
Did not have an assessment completed date (n=650)
Of those that had an assessment date (n=800):
Discharged: Agreed early ending/declined (n=26)
Discharged: DNA/disengaged (n=54)
Discharged: Moved out of area (n=22)
Discharged: Referred to other service (n=23)
Discharged: Accessing private care (n=8)
Inpatient treatment (n=4)
Other/unknown/missing (n=663)
153/2473 (6%) post-treatment (T2/T3) questionnaires available† [Average time between referral and post-treatment questionnaire completion was ~ 6 months (SD = 3.2 months) and ranged between 1 month to 15 months]
Excluded/lost (n=2320), potential reasons:
Did not have a treatment start date (n=1445)
Of those that did start treatment (n=875):
Currently in treatment (n=239)
Discharged: Agreed early ending/declined (n=38)
Discharged: DNA/disengaged (n=72)
Discharged: Moved out of area (n=25)
Discharged: Referred to other service (n=15)
Inpatient treatment (n=12)
Other/unknown/missing (n=474)

Figure 7. Flow diagram of patients that completed/started each component of the FREED pathway and the number of pre- and post-treatment questionnaires in FREED-Up and FREED-4-All cohort. †The number of pre- and post-treatment questionnaires in the FREED-4-All cohort varied by questionnaire. The value in the diagram is the highest estimate. DNA = Did not attend.

Table 19. Baseline patient characteristics of FREED-Up and FREED-4-All cohorts.

	FREED-Up (N = 278)	FREED-4-All (N = 2473)	T_y or χ^2	p	ξ
Age: *M* (*SD*)	20.19 (2.39) [n = 278]	19.87 (2.29) [n = 2458]	-2.00	.04*	.09
Diagnosis: % (*n*)			33.76	<.001***	
Anorexia nervosa	35% (96/278)*	46% (819/1779)			
Bulimia nervosa	27% (75/278)	25% (450/1779)			
Binge Eating Disorder	1% (3/278)*	4% (67/1779)			
Avoidant/restrictive food intake disorder	0% (0/278)	1% (22/1779)			
Other specified feeding or eating disorder	37% (104/278)***	24% (421/1779)			
Duration of untreated eating disorder: *M* (*SD*)	17.85 (10.38) [n = 267]	14.86 (9.73) [n = 1136]	-3.96	<.001***	.22

Note. FREED = First Episode Rapid Early Intervention for Eating Disorders. Missing data cases were not included in the percentage calculations. The asterisks denoting significance for each diagnosis relates to the degree to which the observed frequencies significantly differed from expected frequency for each cell as indicated by the adjusted standardised residuals.

*p <.05 **p <.01 ***p <.001

7.4.2 Waiting times

Adherence to the wait time targets and the average wait for the engagement call, assessment, and treatment are outlined in Table 20. Adherence to the wait time targets were similar in FREED-Up and FREED-4-All, except for offered assessment, which was moderately higher in FREED-Up. The average wait for receiving an engagement call was significantly shorter for FREED-4-All patients, whereas the average wait for offered and attended assessment and offered treatment were substantially shorter for FREED-Up patients.

Table 20. Adherence to the wait time targets and mean and median wait in days for the 48-hour engagement call, assessment, and treatment for FREED-Up and FREED-4-All cohorts.

		FREED-Up			FREED-4-All					
		Adherence to target: % (*n*)	Mean wait in days (*SD*)	Median wait in days	Adherence to target: % (*n*)	Mean wait in days (*SD*)	Median wait in days	T_y	*p*	ξ
Engagement call										
Attempted <48-hours	Excluding weekends	86% (216/251)	2.23 (6.33)	1	85% (1650/1953)	1.87 (5.18)	1	1.06	.27	.05
	Including weekends	75% (188/251)	3.09 (8.86)	1	75% (1474/1953)	2.55 (7.28)	1	0.52	.62	.03
Completed <48-hours	Excluding weekends	65% (170/260)	4.02 (7.17)	2	73% (1373/1870)	2.69 (5.81)	1	-3.61	<.001***	.19
	Including weekends	56% (145/260)	5.54 (10.06)	2	64% (1199/1870)	3.68 (8.14)	1	-3.55	<.001***	.18
Assessment										
Offered <2-weeks	Excluding weekends	63% (168/265)*	16.40 (16.53)	11	51% (1005/1970)	21.72 (21.98)	14	5.32	<.001***	.21

	Including weekends	46% (123/265)*	23.07 (23.09)	15	39% (760/1970)	30.54 (30.75)	20	5.29	<.001***	.21
Completed <2-weeks	Excluding weekends	56% (155/277)	18.38 (17.45)	13	48% (871/1799)	23.09 (23.76)	15	3.59	<.001***	.15
	Including weekends	40% (111/277)	25.83 (24.38)	19	36% (644/1799)	32.46 (33.23)	21	3.68	<.001***	.16
Treatment Offered <4-weeks	Excluding weekends	44% (114/257)	38.02 (26.73)	30	42% (475/1120)	46.58 (40.84)	34	2.09	.02*	.10
	Including weekends	26% (66/257)	53.25 (57.13)	42	26% (294/1120)	65.15 (57.13)	48	2.06	.04*	.11
Started <4-weeks	Excluding weekends	38% (103/271)	41.13 (28.38)	34	39% (402/1021)	47.71 (39.88)	36	1.48	.14	.07
	Including weekends	22% (59/271)	57.61 (39.69)	47	24% (244/1021)	66.72 (55.82)	50	1.46	.15	.07

Note. FREED = First Episode Rapid Early Intervention for Eating Disorders. Missing data cases were not included in the percentage calculations. The asterisks denoting significance for the percentage adherence estimates relates to the degree to which the observed frequencies significantly differed from expected frequency for that cell as indicated by the adjusted standardised residuals. The robust t-test (T_y) and explanatory measure of effect size (ξ) relate to comparing the trimmed mean wait time in days between FREED-Up and FREED-4-All groups.

$^{*}p < .05$ $^{**}p < .01$ $^{***}p < .001$

7.4.3 Clinical outcomes

Only about a third of FREED-4-All patients had baseline clinical outcomes (n = 823/2473; 33%) and 18.6% (n = 153/823) of these also had post-treatment data (see Figure 7). These findings must therefore be regarded as preliminary and used alongside other information. The mean scores and mean difference for clinical outcomes pre- and post-treatment for each cohort are outlined in Table 21. The asterisks in Table 21 relate to the significance levels derived from the first set of multi-level models, which evaluated the changes in clinical outcome over time in each FREED cohort separately. The results of the second set of multi-level models, which evaluated differences in changes over time between FREED-Up and FREED-4-All cohorts, are outlined in Table 22. It is important to note that in Table 22, the FREED-4-All post-treatment time point (T2/T3) was used twice, once to compare against the FREED-Up participants at Time 2 (6 months) and once to compare against the FREED-Up participants at Time 3 (12 months). As displayed in Table 21, FREED led to significant improvements in all clinical outcomes from Time 1 to Time 2 and Time 1 to Time 3 in FREED-Up and Time 1 to Time 2/3 in FREED-4-All. The only exception was laxative episodes per month in the FREED-4-All cohort, which did not significantly improve. In Table 22, the only significant time by FREED cohort interaction effect was for EDE-Q for the Time 1 vs Time 2 contrast, suggesting significantly higher reductions in EDE-Q for FREED-4-All patients at post-treatment (T2/T3) relative to FREED-Up patients at 6-months (T2). The proportion of patients scoring above the EDE-Q clinical cut-off (≥2.8) and BMI threshold (>18.5 kg/m^2) are presented in Table 23. The FREED cohorts were significantly different in the percentage above the BMI threshold at pre-treatment ($\chi^2(1) = 25.29$, $p < .001$) and in BMI and EDE-Q when comparing FREED-Up at 6-months to FREED-4-All at post-treatment (EDE-Q: $\chi^2(1) = 25.06$, $p < .001$; BMI: $\chi^2(1) = 27.12$, $p < .001$). There was no significant difference between the FREED cohorts in the percentage above the EDE-Q threshold at pre-treatment ($\chi^2(1) = 0.02$, $p = .90$) and the BMI and EDE-Q thresholds when comparing FREED-Up at 12-months to FREED-4-All at post-treatment (EDE-Q: $\chi^2(1) = 2.15$, $p = .14$; BMI: $\chi^2(1) = 1.97$, $p = .16$).

Table 21. Mean and mean difference in clinical outcomes before and after treatment in FREED-Up and FREED-4-All cohorts.

	FREED-Up					FREED-4-All		
	T1: Baseline *M* (*SD*)	T2: 6-month *M* (*SD*)	T3: 12-month *M* (*SD*)	T1-T2[†] *MD*	T1-T3[†] *MD*	T1: Baseline *M* (*SD*)	T2/T3: Post-treatment *M* (*SD*)	T1-T2/T3[†] *MD*
EDE-Q	4.08 (1.21) [*n* = 278]	2.85 (1.57) [*n* = 182]	2.31 (1.55) [*n* = 175]	1.23[***]	1.77[***]	4.06 (1.29) [*n* = 793]	2.04 (1.39) [*n* = 135]	2.02[***]
Binge episodes per month	6.41 (8.39) [*n* = 278]	3.70 (8.17) [*n* = 182]	2.39 (4.60) [*n* = 175]	2.71[***]	4.02[***]	4.83 (10.17) [*n* = 820]	2.19 (4.84) [*n* = 151]	2.64[***]
Vomit episodes per month	6.97 (11.76) [*n* = 278]	3.27 (9.73) [*n* = 182]	2.18 (6.80) [*n* = 175]	3.70[***]	4.79[***]	5.84 (15.07) [*n* = 821]	1.43 (3.98) [*n* = 150]	4.41[***]
Laxative episodes per month	2.03 (6.52) [*n* =278]	1.13 (4.22) [*n* = 182]	0.55 (2.93) [*n* = 175]	0.90[*]	1.48[***]	1.30 (5.71) [*n* = 823]	0.46 (2.83) [*n* = 153]	0.84
BMI (AN only)	16.42 (1.19) [*n* = 96]	17.67 (1.77) [*n* = 76]	18.43 (2.23) [*n* = 66]	-1.25[***]	-2.01[***]	17.41 (2.24) [*n* = 429]	19.08 (2.55) [*n* = 88]	-1.67[***]
CORE-10/OM	1.97 (0.75) [*n* = 277]	1.45 (0.74) [*n* = 182]	1.39 (0.85) [*n* = 175]	0.52[***]	0.58[***]	1.93 (0.72) [*n* = 577]	1.42 (0.83) [*n* = 76]	0.51[***]

Note. MD = mean difference; EDE-Q = eating disorder examination questionnaire; BMI = body mass index; AN = anorexia nervosa; CORE-10/OM = clinical outcomes in routine evaluation-10/outcome measure; T1 = time 1; T2 = time 2; T3 = time 3; FREED = First Episode Rapid Early Intervention for Eating Disorders.

[†]Significance values calculated using multi-level models for each FREED cohort separately.

[*]$p < .05$ [**]$p < .01$ [***]$p < .001$

Table 22. Multi-level models evaluating the differences in change over time between the FREED cohort on clinical outcomes.

Outcome	ICC	Predictors	*b* (*SE*)	β (*SE*)	*t*	df	*p*
EDE-Q	0.37	Time (1 vs 2)[†]	-1.23 (0.10)	-0.77 (0.06)	-12.23	604	<.001[***]
		Time (1 vs 3)[‡]	-1.74 (0.11)	-1.08 (0.07)	-16.45	604	<.001[***]
		FREED cohort[§]	-0.06 (0.09)	-0.03 (0.06)	-0.61	1094	.54
		Time (1 vs 2)*FREED cohort[§]	-0.69 (0.16)	-0.43 (0.10)	-4.45	604	<.001[***]
		Time (1 vs 3)*FREED cohort[§]	-0.19 (0.16)	-0.12 (0.10)	-1.17	604	.24
Binge eating episodes per month	0.62	Time (1 vs 2)[†]	-2.41 (0.58)	-0.28 (0.07)	-4.16	634	<.001[***]
		Time (1 vs 3)[‡]	-3.90 (0.57)	-0.45 (0.07)	-6.86	634	<.001[***]
		FREED cohort[§]	-1.60 (0.67)	-0.19 (0.08)	-2.37	1123	.02[*]
		Time (1 vs 2)*FREED cohort[§]	-0.45 (0.81)	-0.05 (0.09)	-0.56	634	.58
		Time (1 vs 3)*FREED cohort[§]	1.16 (0.73)	0.13 (0.08)	1.59	634	.11
Vomit episodes per month	0.86	Time (1 vs 2)[†]	-3.20 (0.62)	-0.26 (0.05)	-5.12	631	<.001[***]
		Time (1 vs 3)[‡]	-4.40 (0.67)	-0.36 (0.05)	-6.58	631	<.001[***]
		FREED cohort[§]	-1.18 (0.98)	-0.10 (0.08)	-1.20	1126	.23
		Time (1 vs 2)*FREED cohort[§]	-0.46 (0.86)	-0.04 (0.07)	-0.54	631	.59

		Time (1 vs 3)*FREED cohort§	0.51 (0.85)	0.04 (0.07)	0.60	631	.55
Laxative episodes per month	0.47	Time (1 vs 2)†	-0.88 (0.37)	-0.17 (0.07)	-2.36	637	.02*
		Time (1 vs 3)‡	-1.48 (0.38)	-0.29 (0.08)	-3.85	637	<.001***
		FREED cohort§	-0.74 (0.41)	-0.15 (0.08)	-1.79	1127	.07
		Time (1 vs 2)*FREED cohort§	0.10 (0.49)	0.02 (0.10)	0.20	637	.84
		Time (1 vs 3)*FREED cohort§	0.67 (0.49)	0.13 (0.10)	1.38	637	.17
BMI (AN only)	0.48	Time (1 vs 2)†	1.17 (0.25)	-0.05 (0.12)	4.75	314	<.001***
		Time (1 vs 3)‡	2.18 (0.26)	-0.10 (0.10)	8.33	314	<.001***
		FREED cohort§	0.99 (0.24)	0.01 (0.12)	4.18	523	<.001***
		Time (1 vs 2)*FREED cohort§	0.53 (0.33)	-0.03 (0.16)	1.62	314	.11
		Time (1 vs 3)*FREED cohort§	-0.47 (0.35)	0.06 (0.14)	-1.35	314	.18
CORE-10/OM	0.47	Time (1 vs 2)†	-0.51 (0.05)	-0.63 (0.07)	-9.66	517	<.001***
		Time (1 vs 3)‡	-0.56 (0.06)	-0.69 (0.07)	-9.66	517	<.001***
		FREED cohort§	-0.06 (0.05)	-0.07 (0.07)	-1.03	868	.30
		Time (1 vs 2)*FREED cohort§	0.03 (0.09)	0.04 (0.11)	0.35	517	.73
		Time (1 vs 3)*FREED cohort§	0.08 (0.10)	0.10 (0.12)	0.77	517	.44

Note. EDE-Q = eating disorder examination questionnaire; BMI = body mass index; AN = anorexia nervosa; CORE-10/OM = clinical outcomes in routine evaluation-10/outcome measure; ICC = intraclass correlation; FREED = First Episode Rapid Early Intervention for Eating Disorders.

[†]Time 2 for the FREED-Up cohort is the 6-month follow-up and for the FREED-4-All cohort is the post-treatment time point.

[‡]Time 3 for the FREED-Up cohort is the 12-month follow-up and for the FREED-4-All cohort is the post-treatment time point.

[§]The FREED-Up cohort served as the statistical reference group.

$^{*}p < .05$ $^{**}p < .01$ $^{***}p < .001$

Table 23. Percentage of patients above the EDE-Q clinical cut-off and BMI threshold pre- and post-treatment in FREED-Up and FREED-4-All cohorts.

	FREED-Up			FREED-4-All	
	T1: Baseline	T2: 6-month	T3: 12-month	T1: Baseline	T2/T3: Post-treatment
% (*n*) above EDE-Q clinical cut-off (≥2.8)	84% (233/278)	49% (137/278)	37% (102/278)	84% (678/812)	32% (259/812)
% (*n*) of patients with AN above the BMI threshold (>18.5 kg/m^2)	0% (0/96)	29% (28/96)	52% (50/96)	22% (93/429)	60% (257/429)

Notes. Missing values for EDE-Q and BMI were imputed for this analysis using predictive mean matching. AN = anorexia nervosa; BMI = body mass index; EDE-Q = eating disorder examination questionnaire; T1 = time 1; T2 = time 2; T3 = time 3.

7.5 Discussion

This study used routinely collected data to evaluate DUED, adherence to the wait time targets, and clinical outcomes in 30 FREED services in NHS England. Data from the FREED-Up study were used as a benchmark to assess whether FREED is replicating at scale. DUED, adherence to the wait time targets, and the impact on clinical outcomes were comparable in FREED-4-All and FREED-Up cohorts. While this suggests that FREED might be replicating at scale, conclusions such as this are limited by the FUPS characteristics of the data. There was a small but significant increase in the average wait for assessment (by 5-8 days) and treatment (by 7-12 days) for FREED-4-All patients. The wait for assessment was 20-30 days and for treatment was 45-65 days. To put these numbers into context, a survey conducted in 2017 found the average wait for adults with EDs in the UK was 70 days for assessment and 147 days for treatment (Beat, 2017). Most patients were referred during the pandemic, which may account for the significantly longer wait times. Preliminary analysis of the impact of COVID-19 on FREED is underway and suggests that this might be the case. However, more data is needed to confirm or refute these conclusions.

The FREED-4-All cohort were slightly younger, had a higher proportion of patients with a diagnosis of AN relative to OSFED, and a shorter DUED. The increased proportion of patients with AN appears to be largely driven by the onset of COVID-19, which is in keeping with other reports of increased rates of AN presentations during the pandemic (Haripersad et al., 2021; Taquet et al., 2021). This relative increase in AN is likely to put greater pressure on already stretched teams due to the higher medical risk associated with AN compared to other EDs. Patients with AN often require more intensive and multidisciplinary input.

The average DUED of FREED-4-All patients was shorter than FREED-Up patients' by approximately 3 months. This finding suggests that FREED is not only replicating but possibly doing better at scale. Moreover, the 15-month DUED in FREED-4-All is substantially shorter than the 30-60 months reported in the literature (Austin et al., 2020). However, with the current data it is not possible to attribute the shorter DUED directly to FREED, especially as the waits for assessment and treatment were not substantially shorter. The shorter DUED could be due to newer sites having a shorter DUED at the outset, the rapid deterioration of patients during the pandemic, or increased awareness of EDs.

The clinical outcomes in the FREED-4-All cohort are in line with the FREED-Up study and previously reported estimates of symptom change (e.g., Byrne, Fursland, Allen, & Watson, 2011; Turner, Marshall, Stopa, & Waller, 2015). The only difference was the substantially greater improvements in EDE-Q and BMI weight recovery when comparing FREED-4-All at post-treatment to FREED-Up at 6-months. However, it is important not to over-interpret these findings due to the FUPS characteristics of the data. The missing data are particularly problematic for post-treatment clinical outcomes, which substantially limits the validity and generalisability of these results. Outcome data in FREED-Up were collected via an online portal, where participants directly entered their data and with dedicated researchers reminding participants to complete questionnaires. In contrast, outcome data collection in FREED-4-All relied on busy clinicians and their local processes and procedures. Reasons for missingness included patients not returning questionnaires, clinicians not being accustomed to or invested in collecting outcome measures, limited IT support, staff changes, pausing FREED due to COVID-19, and insufficient capacity. Patient-related reasons for missingness (e.g., disengagement, moving out of area) are also outlined in Figure 7. However, data on patient-related reasons for missingness were also limited. This provides important insights into the difficulties of gathering FREED data alongside clinical work and the need for additional support and innovation to improve data quality and quantity.

Despite the pandemic, FREED appears to be largely replicating at scale with DUED, wait time target adherence, and clinical improvements comparable to earlier FREED studies and reported in the literature. However, the data quality significantly limits the validity and generalisability of the conclusions of this study. We hope that over time and with improvements in data quality that we can have greater confidence in the findings derived from the FREED-4-All dataset and ultimately make progress towards reducing the impact of EDs.

Chapter 8. General overview

Author contribution: The candidate conceptualised and drafted the chapter. Dr Karina Allen, Professor Ulrike Schmidt, and Amelia Austin reviewed the chapter and provided constructive feedback.

8.1 Main findings

Clinician (P001): "*It just makes sense. Otherwise, we're going to be trying to keep the fire away from the door the whole time. It's like go back and look at the source of the fire for God's sake, take out some of the coal, pour some water on the fire rather than just dealing with the smoke. It makes sense doesn't it.*"

Early intervention in EDs is intuitively appealing and evidence so far is promising (Austin et al., 2021b; Brown et al., 2018; Flynn et al., 2020; McClelland et al., 2018). The broad aim of this thesis was to continue to advance our knowledge on the implementation and effectiveness of early intervention services in mental health, particularly early intervention in EDs and the FREED model. The specific aims were to evaluate the implementation and effectiveness of FREED during initial and national scaling of the model in the English National Health Service and key factors that can impede or facilitate its implementation and effectiveness as it is scaled and embedded into routine care. The knowledge generated during this thesis can provide insights into whether, how, and under what conditions FREED may be effective. These aims were achieved, firstly, by systematically reviewing and evaluating the literature on early intervention services in non-psychotic mental health disorders using the RE-AIM implementation framework (Chapter 2 and 3). This review provided a comprehensive baseline understanding of the literature and research on the structure, implementation, and effectiveness of early intervention services in non-psychotic disorders. Following this, two studies focused on evaluating implementation fidelity (how well FREED was implemented), implementation processes, and key barriers and facilitators during the FREED-Up study and initial scaling of FREED (Chapter 4 and 5). Then, the broader collective attitudes of clinicians and individuals with lived experience of an ED on the perceived relative importance of early intervention in EDs compared to other service prioritisation factors was explored (Chapter 6). Lastly, the implementation and effectiveness of FREED during national scaling was evaluated using routine clinical data (Chapter 7).

In Section 8.1, the key findings from the chapters are summarised in relation to the two main aims of this thesis. In Sections 8.2 and 8.3, the strengths and weaknesses of the

studies in the chapters and the implications of these findings for clinical practice and future research are discussed.

8.1.1 Aim 1: Evaluating the implementation and effectiveness of FREED during initial and national scaling

Aim 1 of this thesis, namely, evaluating the implementation and effectiveness of FREED during initial and national scaling, was addressed in Chapters 4, 5 and 7. Chapter 3, the systematic scoping review, provided important contextual information on the broader literature regarding the structure, implementation and effectiveness of early intervention services in non-psychotic disorders. Below the findings of this thesis that relate to Aim 1 are summarised. First, I reflect on how the structure of FREED does or does not align with the findings of the scoping review and then summarise the findings across the chapters on the implementation and effectiveness of early intervention services and FREED. Although evaluating the structure of services was not an explicit aim of this thesis, reflecting on how FREED does or does not align with other services may be fruitful when considering how early intervention in EDs could be structured and implemented in the future.

There were notable similarities and differences between FREED and the early intervention services in the scoping review. First, as with many of the services in the scoping review, FREED targets a peak risk period for the onset of EDs, specifically, individuals between 16 to 25 years old. Similar to FREED, mood, personality, and trans-diagnostic services also tended to target adolescents and emerging adults. The age bracket for some of these services was however wider than FREED's, for example, Dresden's early recognition centre for bipolar disorder included individuals between 16 to 40 years old. In contrast, trauma and stress-related and perinatal mental health services tended to focus on the time of the trauma or birth. This split in targeting an age range or event is understandable given when people are most likely to develop these disorders. Anxiety and alcohol use disorder services did not target a specific age or event. Many clinicians in the qualitative study in Chapter 5 did express a desire to see FREED become ageless, similar to the shift in early intervention in psychosis (EIP) services (O'Driscoll et al., 2021). Clinicians also recognised the age criterion as targeting a sensitive and high-risk period and that if FREED was to become ageless that the care package would need to be adapted for the older age groups. Services who expanded the upper age limit in the qualitative study found that they either did not have

the capacity for the increased demand (this service also increased the duration of illness criterion to five years) or found that the older FREED patients did not engage with or benefit from FREED in the same way as the under-25 age group. The utility and feasibility of expanding the age range for FREED and any future early intervention in ED services needs to be further explored.

Many services in the scoping review focused on treating people who had minimal or no previous treatment or were displaying at-risk criteria or early symptoms of disorder. In contrast, FREED focuses on individuals with full threshold disorders of less than three years illness duration as the criterion for early-stage illness. There was little discussion on the merits of different types of early-stage illness inclusion criteria in in the studies included in the scoping review, and some were evidence-based (similar to FREED), while others were not. Unlike the age criterion, there was no strong desire to change the duration of illness criterion in the qualitative study. Clinicians felt that the duration criterion made sense and that it was evidence-based. The main challenge with the duration of illness criterion was assessing and calculating it. More support and guidance are required during FREED training on assessing and calculating the duration of illness. Given that the early-stage criteria are used determine who does or does not gain access to the services, it will be of paramount importance for services to clearly state why they have chosen a specific inclusion criterion and optimise its evaluation and calculation for the service.

Second, the setting and referral routes for FREED services were different to many of the early intervention services identified in the review. Services included in the review were typically based in community or non-psychiatric settings that were either youth-friendly or designed in a way that minimised the stigma associated with mental health disorders (e.g., co-location with physical health services, home treatment options). In contrast, FREED tends to be based in more traditional psychiatric hospital outpatient settings (though not all FREED services are, and some are co-located with other organisations). The setting of a service is important given that the stigma associated with mental health disorders and that a limited perceived need for treatment can act as barriers to help-seeking and engagement for early intervention services (Arcaro et al., 2019; Chen et al., 2011; Leopold et al., 2013; Leopold et al., 2013). Moreover, some qualitative feedback in the review found that less formal treatment settings facilitated uptake and engagement (Haver & Franck, 1997; Judd et al., 2011;

Marriott et al., 2007). Many services also had direct and low threshold access to the service via self-referral or screening all potentially eligible individuals in a medical setting. When available, self-referral and non-physician referral routes were typically the most frequently used methods for gaining access to the service. Self-referral was also higher amongst males and individuals with no prior help-seeking (Arcaro et al., 2017; Leopold et al., 2013). Gatekeeping, referral and access issues were identified in Chapters 4 and 5 as notable barriers to quickly accessing FREED treatment. Direct, low-threshold access to the service via self-referral and FREED being embedded in youth-friendly non-psychiatric community settings could address these gatekeeping and access issues.

Third, despite the early intervention aims of the services, FREED was one of few services that used wait time targets to hasten and monitor the speed of access to the service. As outlined in Chapter 4, FREED was associated with significant increases in adherence to the wait time targets relative to TAU and the adherence levels in this study were associated with significant reductions in the wait for assessment and treatment (Flynn et al., 2020). Indeed, the introduction of wait time targets for EIP services in England was associated with reductions in the wait for care (Adamson et al., 2018; Kreutzberg & Jacobs, 2020; Singh et al., 2018). Wait time targets are therefore something that other early intervention services might consider in the future as a means to speed-up access to treatment. However, some of the challenges related to the wait time targets are described below.

Fourth, similar to FREED, many of the services provided holistic evidence-based treatment packages incorporating psychoeducation, psychological and pharmacological treatments and family involvement. This treatment was also typically provided by multi-disciplinary teams, as is the case for FREED. Some services (including FREED) tailored treatment to the specific population and/or adopted a clinical staging or stepped care approach to treatment. Qualitative evidence suggests that this tailoring was valued by patients (Arcaro et al., 2019; Potterton et al., 2021). However, unlike FREED, a portion of the services provided additional health and social/functional rehabilitation services (e.g., peer support, sexual health services, physiotherapy, accommodation support, art drop-in sessions, forensic support, and education or vocational support). While the FREED care package does address broader life issues (e.g., transitions, developmental stage) and there is a degree of functional

rehabilitation in FREED treatment (e.g., university preparation groups), FREED does not have an explicit package of add-on services to support broader social and life rehabilitation and skills. In the qualitative study by Potterton et al. (2021), FREED's focus on building support networks and life beyond the ED was perceived as contributing towards the progress of FREED patients. Together, these findings suggest that perhaps, there could be an even greater emphasis on supporting social and functional rehabilitation beyond the ED in FREED.

Finally, some services in the review used broader outreach and awareness raising activities, assertive engagement strategies and an explicit case management/care co-ordination model. As highlighted by the results in Chapter 5, outreach and awareness raising activities and assertive and flexible engagement (i.e., not discharging people quickly if they disengage) were highly valued and integral features of the FREED model. The aim of the case manager/care co-ordinators was to provide integrated, collaborative and individualised care and to enhance engagement with the service through building rapport over time. Indeed, qualitative feedback indicated that for many patients in the ICEBREAK service the care co-ordinator played a central role in supporting patients (Gilbert et al., 2012). An assertive outreach case management approach is also frequently used in EIP services to promote integration and recovery and address difficulties engaging with services (Bone, Terry, & Whitfield, 2022; Wong et al., 2019). Systematic reviews and meta-analyses demonstrate that case management (in its various forms) can have a positive effect on the number of hospital days, patient satisfaction and retention in mental health services. The impact on symptoms and quality of life is less consistent and smaller (Dieterich et al., 2017; Lim et al., 2021). To some degree, the FREED Champion and treating clinician take on a care coordinator type role, but this is not explicit and adopting such an approach could further facilitate the development and maintenance of engagement in FREED treatment.

More directly relevant to the first aim of this thesis is the evidence related to the implementation of services in the scoping review. Specific evaluations of implementation fidelity, feasibility, processes, and costs were limited in the scoping review. Where implementation fidelity and processes were evaluated, the findings were mixed, and no study investigated the implications of low or high fidelity. Similar to the findings in Chapter 4, adherence to various components of the Stepped Collaborative Care intervention for PTSD varied from low (32% offered pharmacotherapy) to high

(89% assessed for CBT) (Zatzick et al., 2004; Zatzick et al., 2013; Zatzick et al., 2015). Without evaluations of fidelity, it is challenging to assess which of the previously outlined service components are the "active" ingredients and the feasibility of different service models, and where the models may need to be adapted or modified in the future.

In Chapters 4 and 7, fidelity to key components of the FREED model were evaluated. Namely, adherence to the wait time targets and use of the care package. In Chapters 4 and 7, adherence to the FREED wait time targets was ~85-90% for first attempted engagement call, ~50-60% for first offered assessment session, and ~30-40% for first offered treatment session. These adherence levels reduced to ~50-70%, ~35-40%, and ~20-25% when the completed dates rather than first attempted/offered dates were used. While these adherence levels were associated with significant reductions in the wait for care (Flynn et al., 2020), the low to moderate adherence to the assessment and treatment wait time targets warrant special consideration in the future implementation of FREED. Targets should be challenging but realistically achievable with the available skills and resources. Continuously failing to miss a target can impact morale and result in stress (Locke & Latham, 2019; McCann, Granter, Hassard, & Hyde, 2015). Indeed, some clinicians in the qualitative study in Chapter 5 found the wait times targets for assessment and treatment challenging to meet, and an inability to meet the targets was difficult for the clinicians and impacted their motivation.

P003: "*I think it can feel very hard to keep the momentum going when you've never met a target and that perhaps it would be better to make them slightly more realistic for our service and then it might feel easier to work so hard to meet them*"

Despite the challenges, some clinicians reported valuing the wait time targets, i.e., they provided a clear timeframe and targets to aim and strive for. In Chapter 5, two services had extended their wait time targets by 2-weeks for assessment and treatment to make the targets more achievable for their service. When extending the assessment and treatment wait time targets to 4- and 8-weeks in Chapter 4, adherence rates significantly increased to ~80% and ~70%, respectively, highlighting this as an option for increasing adherence. However, the implications of extending the wait time targets on clinician behaviour and patient outcomes were not assessed. Further research is needed on the impact of extending the wait time targets for FREED.

In Chapter 5, clinicians reported that other aspects of the FREED model were easier to use than the assessment and treatment wait time targets, including the care package, which was also assessed in Chapter 4. In accordance with the 85-90% adherence to first attempted engagement call target, clinician in Chapter 5 consistently perceived the engagement call as an easy and valued component of the model. Clinicians reported that the most challenging aspect of the engagement call was getting the young person on the phone. This echoes the large discrepancy in adherence rates between the engagement call attempt (~85-90%) and completion (~50-70%). Similarly, the care package was well-used in the FREED-Up study (Chapter 4) and perceived as valuable, easy and beneficial by clinicians in the qualitative interviews. However, again reflecting the low use of family therapy and attendance in Chapter 4, clinicians described family involvement as one of the more challenging aspects of the care package as it depends upon patients' and their family's willingness and ability to engage. The low use of FREED booklets/resources in Chapter 4 was however not reflected in the clinician interviews. In the qualitative study, the FREED booklets/resources were seen as helpful in supporting the use of the care package and working with young people. Other findings in Chapter 4 that warrant attention in the future implementation of FREED but were not explicitly mentioned in Chapter 5 were the low use of early dietary change, especially for patients with BN and BED, and moderate use of the "attention to transitions" component. There were some general barriers to using the care package that were mentioned in the qualitative study. These barriers were clinicians knowing how to integrate the components into evidence-based treatments and remembering to use them. The FREED psychoeducational materials and prompts and reminders (e.g., incorporated into the paperwork) were identified as facilitators for using the care package. Unfortunately, due to limited data I was unable to assess the use of the care package in the national FREED data set in Chapter 7.

In the scoping review in Chapter 3, participants included in the studies tended to be largely "representative" of the intended target population (i.e., limited inclusion/exclusion criteria, unbiased recruitment strategies) with high levels of symptoms, distress, and impairment. However, formal evaluations of reach were often not provided. Approximately 80% of the services provided effectiveness data. The services were associated with significant improvements on a variety of symptomatic and functional outcomes over time. However, less than half of the studies provided some

form of comparison data and improvements were sometimes but not always superior to the comparison group. Adoption of the services was also often restricted to single specialised sites, limiting our understanding of the generalisability and replicability of the treatment effects beyond the originating centre. To build on the findings in the scoping review, the aim of Chapter 7 was to evaluate whether the findings in Chapter 4 and other key FREED-Up publications (Austin et al., 2021b; Flynn et al., 2020) were replicating during national scaling of the model (FREED-4-All cohort). Unfortunately, due to limited data, a non-FREED comparison group could not be included in Chapter 7. Routinely collected clinical data from 30 FREED services in England were used to evaluate the impact of FREED on DUED, wait times, and clinical outcomes. The findings in Chapter 7 are promising and suggest that so far, the impact of FREED is largely replicating at scale. Relative to the FREED-Up study, the DUED was shorter and the average waits for assessment and treatment were longer in the national data set. The longer average wait for assessment and treatment is important to hold in mind as FREED is further scaled and especially considering the findings in Chapter 5, i.e., the detrimental impact on clinicians of not achieving the wait time targets. Given the flawed, uncertain, proximate, and sparse (FUPS) characteristics of the FREED-4-All national dataset, these findings should be treated as preliminary and used carefully alongside other information and research. In the qualitative study in Chapter 5, clinicians perceived the data collection as beneficial but challenging due to limited staff resources, and this is reflected in the high level of missing data in the national dataset. Data in Chapter 5 also provide additional, albeit subjective, support for the positive impact on clinical outcomes reported in Chapter 7. Clinicians reported quick and positive outcomes for FREED patients in the qualitative interviews, which is reflected in the significant improvements in clinical outcomes in FREED-Up and FREED-4-All cohorts.

P005: "*I suppose seeing that as well, that people in early intervention can make those changes quite quickly and that being full and really positive*"

In summary, FREED shares some similarities with the structure of other early intervention services in non-psychotic disorders. These include targeting a peak risk period (adolescents and emerging adults) and providing multi-disciplinary, holistic and evidence-based treatments. However, there were features of these service models that are not part of the FREED model (e.g., community settings and care-coordination).

Some of these features could be incorporated into the FREED model to address some of the challenges faced by FREED (e.g., gatekeeping and engagement issues). However, due to limited implementation research, understanding the relative merit of these different features and their feasibility is challenging. For FREED specifically, the feasibility and long-term utility of the assessment and treatment wait time targets are under question given the findings of Chapters 4, 5, and 7. While even moderate adherence can result in improvements in waiting times, much more research is needed to evaluate these targets, their impact and the possibility of tailoring them to the capacity of the team. There was more support for the FREED care package in Chapters 4 and 5, i.e., it was perceived positively and highly used. However, some components were not as well used (e.g., early nutritional change, attention to transitions, family involvement). While some of the barriers to these components were mentioned in the qualitative study, others were not. More research is required to determine the importance of these care package components and ways to increase their use (e.g., more training on how to integrate and embed the care package components). Finally, many of the early intervention services in the scoping review demonstrated significant improvements in clinical and functional outcomes over time, but standard treatment comparison groups and evaluations of these services in settings outside of the originating centres were limited. Building on this, Chapter 7 provides some evidence that FREED is replicating in routine clinical practice across England and outside of the originating centre. However, the findings are limited by the FUPS characteristics of the data. The clinical and research implications of these findings are further elaborated on in Section 8.3.

8.1.2 Aim 2: Evaluating barriers and facilitators for the implementation and effectiveness of FREED

Aim 2 of this thesis, namely, evaluating barriers and facilitators for the implementation and effectiveness of FREED, was addressed in Chapters 5 and 6. Where possible, information regarding barriers and facilitators was also gathered in the scoping review in Chapter 3. However, similar to other implementation related factors, evaluating barriers and facilitators to implementation was rarely the focus of the studies included in the review. Information regarding barriers and facilitators were often taken from qualitative studies and feedback and narrative descriptions of the authors experiences of trying to implement and embed the service. Below the findings related to Aim 2 of this

thesis are summarised. First, the evidence pertaining to attitudes towards early intervention and FREED (key barriers and/or facilitators to implementation) from Chapters 5 and 6 are described. Following this, the findings on a broader array of barriers and facilitators for FREED and early intervention services are outlined.

People's attitudes towards an evidence-based practice are arguable one of the most fundamental barriers and/or facilitators to adopting, scaling and effectively implementing it (i.e., favourable or unfavourable opinions towards an evidence-based practice due to beliefs about the relative advantages and disadvantages of implementing it) (Fishman et al., 2021). Moreover, acceptability of an intervention (part of attitudes) has been proposed as one of the first concepts to assess during the implementation of an intervention (Klaic et al., 2022). To date, there has been limited research evaluating attitudes towards early intervention for EDs specifically. Evaluating attitudes was therefore central to the aims of Chapters 5 and 6. The study in Chapter 5 involved semi-structured interviews with 21 clinicians implementing FREED from eight early adopter FREED services. This Chapter provides an in-depth evaluation of attitudes towards and the implementation of FREED from the perspective of clinicians. Previous work by Potterton et al. (2021) provided an in-depth evaluation of FREED from the perspective of patients receiving FREED treatment.

Overall, in Chapter 5 the interviewed clinicians were positive towards and enthusiastic about early intervention in EDs and FREED and this was a key facilitator for the model, especially to overcome obstacles and challenges (e.g., capacity issues, scepticism). Positive attitudes were primarily driven by the belief that FREED would improve patient outcomes and recovery. Clinicians also simultaneously held conflicting feelings towards the model due to concerns about the impact on capacity, waiting times and patients who were not eligible for FREED. As outlined in the section for Aim 1, many of the clinicians expressed a desire to expand the age range (eligibility criteria) for FREED. There was a belief that FREED could be effective for anyone in early-stage illness regardless of their age. Another belief which sometimes caused tensions within teams towards the model was FREED being perceived as 'special' and as easier work relative to standard treatment. These more negative attitudes sometimes (but not always) acted as barriers to adopting and implementing FREED, especially early in the implementation when trying to gain 'buy-in' from the wider team.

The qualitative study in Chapter 5 demonstrated the centrality of clinician attitudes as a barrier and/or facilitator in the implementation of FREED. The aim of the Delphi study in Chapter 6 was to build on this work by evaluating the collective community opinions of clinicians and individuals with lived experience of an ED. This study included individuals who were not necessarily receiving or providing FREED treatment (though this was not explicitly evaluated in the study and is a major limitation). Understanding the broader collective community attitudes of clinicians and individuals with lived experience is important as these individuals are likely to be affected by and to affect the implementation of FREED. Individuals who are directly or indirectly affected by a new way of working should be consulted on their opinions of the change. The study used a Delphi method to investigate the degree of consensus on what factors should or should not be used to prioritise patients in ED services and the relative importance of these. This enabled us to evaluate collective opinions on the relative importance of prioritising patients in early-stage illness against other prioritisation factors. Given the restricted resources available to services, it is important to establish the relative importance of factors rather than simply whether something is seen as "good" or not. This is particularly important given the intuitive appeal of early intervention.

In the Delphi study, medical risk, overall severity (including psychological, physical, and social severity), and rapidly deteriorating physical health were identified as the top three prioritisation factors in both groups. There were numerous qualitative comments and ratings that suggest that risk and severity were the main reasons why people rated certain items more highly than others (e.g., high severity symptoms were rated higher, all physical health items reached consensus in both groups). The lived experience group tended to rate mental health items more highly and included these in their 'top 10', whereas these were not as highly rated or featured in the clinician 'top 10' priorities. The clinician 'top 10' included more items associated with physical risk and weight, which were missing from the lived experience 'top 10' (e.g., losing weight quickly, being a very low weight, and extreme dietary restriction). Factors that were considered as a priority in both groups included patients less than 12 years old, patients who recently received treatment but were relapsing, the transition between inpatient and community, and individuals who had waited a long time for treatment. Diagnoses, comorbidities, and most broader life factors (except quality of life and having very little

social support) were not considered as key prioritisation factors. Numerous qualitative comments from both groups suggest that they perceived early intervention as important but were concerned about the resources/capacity to do early intervention and certain patient groups (i.e., those with long-standing illnesses) being neglected/de-prioritised. The early intervention items (e.g., prioritising patients with an illness duration <6 months, <1 year, or <3 years) only reached consensus or near consensus for agreement in the clinician (not lived experience) group and were not included in the clinician 'top 10'. These findings suggest that while early intervention is seen as a priority issue by clinicians, this is less so than other factors (i.e., those included in the 'top 10'), and that collectively individuals with lived experience do not consider it as a priority.

The qualitative comments and ratings in the Delphi study aligned with the views and concerns expressed by clinicians in Chapter 5 and individuals with lived experience in the study by Potterton et al. (2021). Specifically, that individuals are positive about early intervention but feel worried and guilty because others are not receiving treatment as quickly and it could have a knock-on effect on the standard waiting list and capacity. Moreover, when asked about opinions on prioritising based on medical risk and duration of illness in the qualitative study in Chapter 5, many made the point that medical risk will always need to be a priority, but that early intervention can be advantageous as it does not solely focus on weight and/or can stop people from getting to the medically risky state in the first place. Qualitative and quantitative data in the scoping review also indicated that patients and healthcare professionals valued and/or were satisfied or very satisfied with the early intervention services. Together, these findings indicate that while early intervention is seen positively, that it is not as much of a priority as other factors (e.g., medical risk, very young age) or for individuals with lived experience, and that if it is to be implemented, it must be done in a way where it is adequately resourced and does not disadvantage other patient groups.

In addition to attitudes, a broader array of barriers and facilitators were evaluated in Chapter 5 using the Normalisation Process Theory (NPT) as a sensitising framework. The NPT outlines four generative mechanisms that are important for implementing, integrating, and embedding a new way of working in healthcare. Developing an understanding of the barriers and facilitators and how they interact with these generative mechanisms can allow for the FREED model and its implementation to be improved and optimised in the future. The NPT mechanisms of coherence (sense-

making work) and cognitive participation (initiation, enrolment, and sustained engagement work) were high within FREED teams and contributed towards the development of positive attitudes. Key facilitators were the FREED evidence-base and continued evaluation/feedback, observing the impact of FREED on patients, the practical and ongoing training (including implementation supervision/support), and the FREED Network, which were all important contributors to the NPT mechanisms and consequently the development of positive attitudes and beliefs about early intervention and FREED. The FREED Champion also played a vital role in cognitive participation and integrating and embedding the model. Creating an open dialogue around the model (which was largely accomplished by the FREED Champion) was also important for coherence, cognitive participation, collective action (interaction and integration work), and reflexive monitoring (appraising work), especially in the wider team. However, the Champion could not do it on their own and needed additional support from leaders and other members of the team (e.g., mini team). Other features of the service model that were perceived as particularly important facilitators included tailoring treatment to young people in early-stage illness and the adaptability and flexibility of the model. The model was however altered in ways that were not anticipated (e.g., modifying targets and eligibility criteria). It will be important to have clearer boundaries on what is integral to the FREED model and what can be flexed in the future.

The NPT mechanism collective action was largely encapsulated within the compatibility and integration sub-theme. High compatibility between the service and FREED and integrating FREED into the services processes, meetings, culture, and resources were key for effectively implementing the model. Conversely, differences between FREED and the standard way of working were sometimes a barrier (e.g., FREED required more data, was faster and had a higher level of outreach and engagement). Many of the newer teams were still in the process of integrating FREED into the broader service. Additional guidance and examples of how FREED is being integrated into services could support clinicians in the early stages of implementation when they are setting up and trying to embed the model. Similarly, clinician self-efficacy (i.e., belief in their ability to implement the model), another important barrier and/or facilitator in the uptake of FREED, increased over time. A degree of anxiety and apprehension were common at the outset and can act as barrier to implementing the model.

Limited capacity and competing demands from other initiatives and non-FREED work were the main barriers to implementing, embedding, and sustaining momentum with FREED in many teams. Almost all interviewed clinicians were concerned about service capacity. Capacity issues disrupted the NPT mechanisms and consequently the normalisation of FREED. Capacity issues were also related to the previously outlined conflicting feelings about FREED, namely the potential impact on the standard waiting list and non-FREED patients (i.e., they are not getting early intervention and must wait for a long time). Two of the services reported that FREED put pressure on their standard waiting list. As highlighted by the findings in the previous section (for Aim 1), features of the service model that were challenging to implement were determining the duration of illness, the FREED tracker and data collection, and the FREED assessment and treatment wait time targets. These features were largely challenging due to capacity issues (except for calculating duration of illness). Patient engagement and complexity were also identified as a barrier. However, FREED was perceived as providing a first positive experience of services (e.g., engagement call, rapid access) that worked against the ambivalence and built engagement in early-stage illness. Complexity and comorbidity can make it more difficult to determine whether FREED treatment is appropriate. Finally, features of the wider system, namely broader awareness of EDs and FREED in the healthcare system and general public, and COVID-19, were largely barriers to implementing FREED. Lack of awareness in the broader system can make receiving prompt early intervention referrals difficult. COVID-19 substantially disrupted the normal functioning and capacity of teams pushing many into crisis mode. The wider system was not well-captured in the generative mechanisms outlined by the NPT. The generative mechanisms are focused on the work that clinicians in the team are engage in to implement and embed the model rather than the wider system. An overview of the key barriers and facilitators for FREED (subthemes) in Chapter 5 are outlined in Figure 8.

Some of the barriers and facilitators for FREED overlapped with those identified in the scoping review. Similar to FREED, limited and fluctuating capacity, long wait times, collaboration with other services (i.e., 'broader system of care'), and differences between early intervention and standard services were major barriers to implementing the services (Choudhury-Peters & Dain, 2016; Nash et al., 2021; Osuch et al., 2016; White et al., 2021). Patient-related factors, such as under-recognition and a limited

perceived need for treatment, were also identified as barriers in the review and for FREED (Arcaro et al., 2019; Chen et al., 2011; Leopold et al., 2014). Other barriers identified in the review but not identified in Chapter 5 included assuming care for inappropriate patient groups and patients needing longer term care, time-limited treatment, incompatible IT systems and a lack of clarity on the role of the service (Arcaro et al., 2019; Choudhury-Peters & Dain, 2016; Nash et al., 2021; Osuch et al., 2016). The facilitative factors identified for FREED that were shared with the services in the review included active outreach and a quick triage process (i.e., the engagement call), skilled and empathetic clinicians, and comprehensive treatment tailored to the needs of young people (Arcaro et al., 2019; Osuch et al., 2016). Other key facilitators in the review included open and low-threshold access and informal treatment settings, evening and weekend appointments, close collaboration across services and capacity building for other non-specialist healthcare staff, integrated treatment, consistent support within and between appointments, and addressing a "gap" in services (Arcaro et al., 2019; Chick, 1984; Choudhury-Peters & Dain, 2016; Haver & Franck, 1997; Judd et al., 2011; Marriott et al., 2007; Nash et al., 2021).

In summary, attitudes and NPT mechanisms appear to be important in the implementation of FREED. They were shaped by and interacted with features of the FREED model, implementation strategy, and context to facilitate or hinder FREED. Much of these findings are in accordance with the broader implementation literature and the literature on attitudes towards and barriers and facilitators for early intervention services in mental health (e.g., Ghio et al., 2015b; Greenhalgh et al., 2004; Nash et al., 2021; Rosen et al., 2012). However, some barriers and facilitators were identified for other early intervention services that were not identified in the qualitative study in Chapter 5. Overall, attitudes were positive towards early intervention and FREED but concerns about capacity and those not eligible for FREED warrant special attention in the future implementation of the model or any other type of early intervention model in EDs. Much more research is needed to understand if FREED does have a detrimental impact on other patients, and if so, how this can be mitigated. Relatedly, there is also a pressing need to explore the utility of early intervention in older age groups. Evidence from Chapter 5 suggests that perhaps FREED may not be suitable for older age groups, but the data were highly limited, so it is challenging to draw any conclusions from this. The qualitative study highlighted several features of the FREED model and

implementation which were valued by and facilitated the use of the model (e.g., the FREED evidence-base, Champion, and Network). Conversely, there were also features of the model which were challenging to implement (e.g., wait time targets and data). These features need to be carefully considered and perhaps modified if FREED is to be implemented and scaled further. The clinical and research implications of these findings are further elaborated on in Section 8.3.

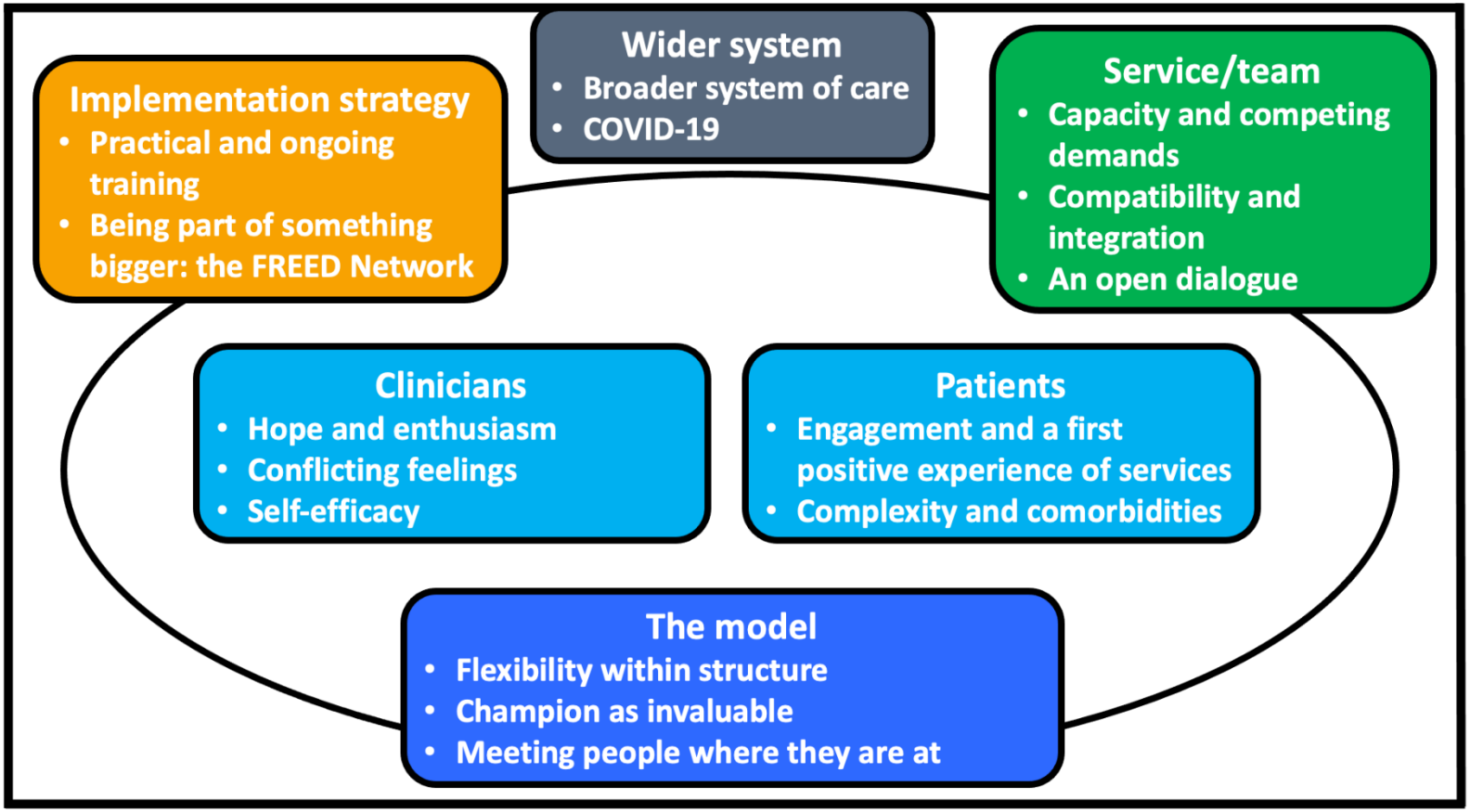

Figure 8. Key barriers and facilitators (themes/subthemes) identified in the qualitative study in Chapter 5

8.2 Strengths and limitations

There are several methodological strengths and limitations that need to be considered when interpreting these collective findings and considering the implications for clinical practice and further research. The main strength of this body of work is the diversity in methodological approaches and types and sources of data. Integrating qualitative and quantitative data from different diagnostic groups, published and grey literature, a variety of different types of ED services and contexts (e.g., rural vs urban, adult vs all-age services), and different types of participants (e.g., implementers vs broader community opinions, clinician vs lived experience) creates a comprehensive picture of the implementation and effectiveness of early intervention and FREED. Triangulating data sources in this way provides converging evidence and cross-validation of findings. Qualitative data provide an in-depth nuanced understanding of early intervention, whereas quantitative data provide a broader and more objective perspective. Another strength of this work is its focus on external validity and pragmatism. Much of the research in this thesis is directly applicable or translatable to routine clinical practice. However, the single factor ratings in the Delphi study in Chapter 6 were somewhat removed from the complex multi-faceted decision making that occurs in services.

A major limitation to some of the studies in this thesis is missing data. First, the inability to access and screen 13% of the full-text articles in the scoping review, service models and evaluations may have been missed. Second, the high level of missing clinical outcome data in the FREED national dataset severely limits the conclusions that can be drawn from the pre- to post-treatment symptom change. These findings must be regarded as preliminary and used alongside other data and information. Finally, even though data saturation was achieved in the clinician perspective study, limited capacity within two teams (especially due to the additional pressures of COVID-19) meant that only one clinician was interviewed from these services.

Although concerted efforts were made to obtain diverse and representative samples, the samples included in these studies may have been biased. The clinicians included in the clinician perspective study in Chapter 5 were all early adopters directly involved in implementing FREED and are therefore more likely hold positive attitudes towards early intervention and FREED. The Delphi study recruitment strategy (online and via social media) may have biased the sample as participants were largely individuals using social media that self-selected into the study. Almost all the studies

included in the scoping review and in this thesis were conducted in Western, educated, industrialized, rich and democratic (WEIRD) countries. These findings may not be applicable to low and middle-income countries and low resource settings. Researcher positive bias towards early intervention and FREED and lack of independence from the implementation may have impacted the data collection and interpretation of the findings. Efforts were made to reflect on and address researcher bias. Reflexive notes and member checking (i.e., feedback from participants on the results to assess if they are an accurate depiction of their experience) were used in the qualitative clinician perspective study to assess and address researcher bias. A portion (20%) of the data in Chapter 5 were also double coded by a researcher who was independent from the FREED team and implementation. The feedback from the participants (member checking) and the double coding suggests that the findings in Chapter 5 reflect the participants' experiences and that the lead researcher was not more inclined to code the data positively. In the Delphi study, the qualitative data were also collected and coded by a researcher who is not involved with the implementation of early intervention or FREED. For data presented in Chapter 4 and 7, there was no randomisation and/or control group. This limits any conclusions regarding causal relationships and the relative advantage of FREED compared to standard practice.

8.3 Implications and future directions

The studies in this thesis have highlighted several important areas that warrant attention during the future implementation and evaluations of early intervention, FREED, and priority setting in ED services. These included the need for further evidence to support the implementation of early intervention services in real-world clinical settings; insights into features of the FREED model and implementation strategy that were effective, as well as areas of concern and where more work is needed; and the need for more research on priority setting in ED services. These are described in more detail below.

8.3.1 Laying the foundation: Evidence for the implementation and effectiveness of early intervention in the real-world

The scoping review of early intervention services for non-psychotic disorders highlighted several key areas where more research is needed. Specifically, evaluations of reach and patient representativeness, the relative effectiveness and cost of early intervention compared to standard treatment, adoption and independent replication, and implementation processes and outcomes. These areas of weakness were largely

identified through the application of the RE-AIM framework and are important for implementation and scaling. Some of these were addressed in this thesis, namely implementation processes and adoption and replication in new settings. However, more work is needed to investigate the reach, relative effectiveness, and implementation outcomes of FREED. It is also imperative that there are evaluations of FREED by researchers that are independent of the development and implementation of the model. All the research to date on FREED has been led by the originating centre at South London and Maudsley NHS Trust and King's College London.

Five services in the scoping review evaluated the reach of their service using census data, health administrative data, and by comparing characteristics of intervention patients to all patients at the centre. These services found that some groups were under-represented relative to the comparison populations. Intervention patients were less likely to be from lower socioeconomic groups, male, older, and Indigenous (Anderson et al., 2019; Haver & Dahlgren, 1995; Haver & Franck, 1997; Ross et al., 2012; Schürmann, 2010; Wang et al., 2020; Zatzick et al., 2011; Zatzick et al., 2013; Zatzick et al., 2015). While demographic data have been collected in previous FREED studies, there has been no evaluation of the reach or representativeness of the patients. Efforts were made part way through the FREED-4-All national data collection to include more demographic variables in the data set to eventually evaluate reach. However, due to data governance for the national dataset, we were unable to collect this information centrally. Evaluations of reach are of paramount importance in health care research more broadly and early intervention in EDs specifically to ensure that certain groups are not underserved, and if necessary, strategies are employed to improve access, awareness, and equity. For example, treatment seeking and/or uptake following an online ED screen in the US were more common in individuals who were female, White, >24 years old, non-Hispanic, or had a higher income, highlighting the importance of evaluating the reach of FREED for different groups (Grammer et al., 2022). One notable challenge in evaluating reach is the selection of an appropriate and representative comparison (denominator) group (Glasgow et al., 2019).

Researchers and practitioners have a moral and ethical duty to ensure that the interventions they implement are effective, minimally harmful (for patients and the wider system), and reasonably priced for the degree of benefit and relative to standard treatment (White, 2021). In the scoping review, eight services provided comparison data

(three RCTs), two provided information on relative cost, and one provided an explicit statement about unintended consequences (Austin et al., 2021b; Chanen et al., 2008; Chanen et al., 2009a; Chen et al., 2011; Dahlgren & Willander, 1989; Fukutomi et al., 2020; Kassam-Adams et al., 2011; McClelland et al., 2018; Osuch et al., 2015; Osuch et al., 2019; Rassenhofer et al., 2016; Zatzick et al., 2004; Zatzick et al., 2013; Zatzick et al., 2015). There were also no comparative data for the FREED national data set in Chapter 7. The need for comparative data, especially RCTs, is reinforced by the inconsistent superiority of early intervention over standard treatment in some studies. RCTs and quasi-experimental designs attempt to attribute any change in outcome to the intervention rather than extraneous or confounding variables. While RCTs and experimental studies are difficult and restricted in their own way (e.g., limited external validity, ethics of withholding treatment), they are an important component of the overall evaluation of interventions, especially early in the research process. Parallel or stepped wedge cluster RCTs, where randomisation occurs at the site rather than individual patient level, might be a more viable option for evaluating early intervention services (Oliver et al., 2018). In parallel cluster RCTs, only half of the clusters (i.e., sites) deliver the intervention while the other half act as controls. In the stepped wedge cluster RCT, there is an initial period where no cluster delivers the intervention. Clusters are then randomly and sequentially crossed over from control to intervention at regular intervals ("steps") until all clusters are delivering the intervention. The decision of whether to conduct a parallel or stepped wedge cluster RCT depends upon political, logistical, and ethical constraints and the size and homogeneity of clusters (Hemming, Haines, Chilton, Girling, & Lilford, 2015). At a minimum, there should be greater efforts in the early intervention literature and for FREED to source comparative data to understand the relative effectiveness. FREED has yet to be tested in an RCT and parallel or stepped wedge cluster designs could be a suitable, albeit expensive, option to do this. Given that FREED has been implemented nationally in England, the parallel or stepped wedge cluster RCT would need to be conducted in a different country.

Understanding the cost-effectiveness of early intervention services is also vital. Economic considerations should be built into the intervention's evaluation from the outset. Healthcare leaders and policy makers are required to make complex decisions on allocating limited resources and require data to support such decisions. There were only two evaluations of cost in the scoping review, one of which was for FREED and one for

the First Episode Mood and Anxiety Program (FEMAP). Based on service utilisation and cost data, FREED treatment was associated with cost savings (Austin et al., 2021b), whereas the FEMAP service was not (John-Baptiste et al., 2019). Finally, as highlighted by the concerns in Chapters 5 and 6 (e.g., the impact of early intervention on other patients and the wider system), there can be unintended consequences associated with implementing early intervention and these need to be sufficiently explored and reported in the early intervention literature and for FREED. Only one study in the scoping review measured unintended consequences. More objective quantitative evaluations of the potential unintended consequences of FREED are sorely needed. If the intention is to continue to scale FREED further, it is vital to evaluate unintended consequences and potential implications of early intervention and FREED for patients with longer term illnesses and individuals not eligible for FREED.

Evaluations of adoption and implementation are hugely important for the generalisation and population-based impact of an intervention but were inadequately assessed or addressed for most early intervention services. Most services were only assessed in single specialised sites in WEIRD countries, and implementation processes were infrequently reported. Given the volume of evidence demonstrating the challenges of replicating effects, understanding the level of adoption and the effectiveness of interventions in new settings and contexts is important. For FREED this was addressed in Chapter 7. The findings tentatively suggest that as of September 2021, FREED is largely replicating at scale. There are many facets of implementation that require attention to successfully scale a new intervention, namely understanding the balance between fidelity and adaptation (i.e., how well is it implemented and how much can the model be changed and still be effective?), acceptability, feasibility in new settings, barriers and facilitators to implementation and effectiveness, effective implementation strategies, and sustainability and maintenance. The studies in this thesis went some way to addressing questions around fidelity, feasibility, acceptability, and barriers and facilitators for FREED, but undoubtedly more work is needed.

8.3.2 Implications for FREED model and implementation

The positive impact on patients, staff and services reported in Chapter 5 and the quantitative results in Chapter 7 provide some support for the continued scaling of FREED. However, the early adopter sample and high levels of missing data limit the conclusions that can be drawn from these studies. Therefore, this support for scaling is

tentative and should be reassessed once more of the national data accrues and a wider pool of clinicians have been interviewed about their experiences. As outlined in the previous section, unintended consequences and the potential impact on other patients, not eligible for FREED, also requires monitoring and consideration in any decisions to continue to scale the model. As highlighted by the findings in Chapters 5 and 6, early intervention should not be implemented at the expense of other patient groups.

The studies in this thesis provided important insights into which features of the model and implementation strategy are effective and where more attention is needed. In terms of the model, in Chapter 5 the structure and flexibility, FREED Champion, 'mini' team, care package, 48-hour engagement call, active engagement efforts, data collection and feedback, and rapid access to treatment were all perceived as important and contributed towards the implementation of FREED. The high use of most components of the care package in Chapter 4 provides additional support for this aspect of the model. However, attention to transitions, some carer-related components, and early nutritional change (at assessment) were less well-used. Further work is needed to evaluate the importance of these care package components and barriers to their use. Additional documentation/prompts, further guidance on how and when to integrate them into treatment and highlighting their importance during the FREED training and implementation support could increase their use. Features of the implementation strategy that were found to be effective in Chapter 5 included the FREED Network and shared learning approach, training package, FREED resources and materials, providing information online and using social media, disseminating evidence at conferences and professional events, and the implementation support and supervision. Together, these were effective at developing adopter commitment and capabilities. However, there were several key areas of concern that warrant attention in the future implementation of FREED.

First, the ongoing data collection and feedback process were important for maintaining adherence, engagement, and developing wider team buy-in, and support. However, many teams found the data collection process difficult due to limited capacity and data quantity for clinical outcomes was poor. This poor-quality data limited the conclusions that could be drawn in Chapter 7. Until the quality of the national data set can be enhanced, definitive conclusions from the national data set are limited. Efforts have been made to enhance the quality and quantity of the data, including additional

guidance documents, one-to-one support, alterations to the FREED Tracker (the Excel spreadsheet used to collect the data), and a consistent emphasis on the importance of the data collection throughout training and implementation supervision. However, more work is needed to make the process of retrieving and entering the FREED data easier and more sustainable for teams. A qualitative study found that ED clinicians perceive routine outcome measures as beneficial but have doubts about their validity, were uncertain on how to use them in a meaningful way, and lacked the time to collect data and 'chase' patients (Chow, Lewis, Robson, & Smart, 2021). Further training and guidance on how to use the measures to inform clinical decision making could increase self-efficacy and their use, and guard against them being perceived as a 'tickbox exercise' (Fleming, Jones, Bradley, & Wolpert, 2016). Using technology (e.g., text messages with links to questionnaires) and greater integration with local electronic health records could also make the data collection process easier for teams and indeed some sites are exploring this already. Finally, short session-by-session measures have been shown to yield higher levels of outcome data than more lengthy questionnaires at the beginning and end of treatment. Changing to shorter session-by-session measures in FREED could increase the amount of outcome data per patient but could also increase work load, so further research is needed to trial this (Clark et al., 2018; Radunz et al., 2021).

Second, further evaluations of implementation fidelity are needed. Chapter 4 provided benchmarks for wait time target adherence and care package use, but no evaluation of the quality of implementation and whether other features of the model were performed (e.g., weekly FREED 'huddles'). The study also only used clinician estimates of fidelity, which are known to be biased. Independent objective evaluations of fidelity are therefore warranted, possibly through interviews, observational, and ethnographic methods. Moreover, evaluating the link between fidelity and clinical and functional outcomes is another interesting avenue to explore. In Chapter 5, the flexibility and adaptability of FREED were highly valued facilitators for uptake and implementation, but throughout the interviews it became apparent that the model was altered in ways that were perhaps not anticipated. Carefully balancing fidelity and adaptability is a widely recognised challenge in large scale implementation projects (Horton et al., 2018). While guidance and training on the core features of FREED are already provided, the development of an easy-to-use fidelity-adaptability tool and

repeated independent measures and feedback on fidelity could improve clarity on what is core and adaptable and increase adherence over time. This approach has been effective in early intervention in psychosis (EIP) (Addington et al., 2021; Williams et al., 2021).

Third, insufficient capacity is almost always an issue in publicly funded health services and was a prominent barrier and concern for FREED services. Insufficient capacity was identified as the main factor contributing to the inability to meet the wait time targets and the low to moderate adherence to the assessment and treatment targets in Chapters 4 and 7. The findings in Chapters 4, 5 and 7 suggest that the wait time targets may not be feasible for some sites and that this can impact clinician morale. Capacity issues also led to concerns about the impact on the standard waiting list and patients not eligible for FREED. These concerns (i.e., that early intervention could disadvantage other patients) are very important and warrant evaluation and monitoring to ensure that early intervention is adequately resourced and not negatively impacting others. When implemented optimally, FREED should not have a knock-on effect on the standard waiting list and other patients. The additional investment, increased efficiencies, and rapid response to treatment should, in theory, free up resources for the rest of the service. However, dwindling resources, high staff turnover, and increased demand, especially due to COVID-19, have put tremendous pressure on services with some clinicians reporting that they thought FREED did impact their standard waiting list. Continuous capacity issues will inevitably impact all aspects of the service and its implementation and can result in stress and burnout. Services need to be adequately resourced to meet the demand of FREED referrals within their local area. Close monitoring and evaluations of service capacity and demand and the impact on other patient groups are required alongside a toolkit of strategies to support services. The shared learning, and implementation support and supervision provided by the 'Maudsley FREED team' and the Academic Health Science Network have already supported services in addressing funding and capacity issues, although major challenges persist. An in-depth evaluation of effective strategies across sites and services could further facilitate this support and shared learning. Clinician enthusiasm for early intervention and FREED has been central to overcoming capacity issues as clinicians work tirelessly to problem solve and balance FREED and non-FREED work. Two potential ways of addressing capacity issues and/or meeting the wait time targets are:

(1) increasing the capacity of services either by direct investment or through improved efficiencies in the services, or (2) increasing the wait time targets themselves. In accordance with this, effective strategies to address capacity issues that were identified in Chapter 5 include delivering evidence-based treatment in group formats, lower-level/briefer interventions, carefully and flexibly balancing FREED and non-FREED waiting lists, developing resilience skills and self-compassion amongst clinicians, and altering the wait time targets. While extending wait time targets can increase adherence (Chapter 4), the consequences of this for patient outcomes and clinician attitudes/behaviour still need to be established.

One important and interesting avenue for further research is evaluating the utility of task-sharing/shifting interventions to address capacity issues in FREED. Task-sharing involves moving some or even most of the care from highly trained specialists to less highly trained individuals or informal modes of care (e.g., family, communities, peer support, self-care) (Hoeft, Fortney, Patel, & Unützer, 2018). Task-sharing was recently described as one of the most important priorities to address unmet need in mental health (Patel, 2022). Evidence-based treatments for EDs already incorporate a degree of task-sharing (Albano, Hodsoll, Kan, Lo Coco, & Cardi, 2019). For example, family therapy for adolescents with AN supports parents to re-establish regular eating and reduce ED behaviours in their child (Lock & le Grange, 2005). Guided self-help, which can be delivered by peer workers with lived experience and non-clinical trained individuals, is recommended as one of the first line treatments for BN and BED (National Institute for Health and Care Excellence, 2017). Outside of clinical services, training undergraduate peers to deliver dissonance-based ED prevention interventions has been central to the successful scaling of these interventions (Becker & Stice, 2017). Additionally, peer-led dissonance-based interventions were associated with significantly greater reductions in ED onset at 4 years compared to clinician-led and internet delivered dissonance interventions, and an educational video control group (Stice, Rohde, Shaw, & Gau, 2020). There is a growing and promising literature of task-sharing interventions in EDs that could be drawn upon to address capacity issues in FREED (e.g., Albano et al., 2019; Hannah et al., 2021; Lewis & Foye, 2022; Yim & Schmidt, 2019). Peer-based interventions may be particularly well-suited for FREED as they align with FREED principles (e.g., inspire hope for recovery, encourage reconnection with life beyond the ED) and draw on the power of relatable and

reciprocal peer relationships, which are important in the emerging adulthood stage of life (Lewis & Foye, 2022).

Fourth, during the qualitative interviews clinicians expressed a desire to expand the age range for FREED, similar to EIP services. This was driven by the belief that early intervention could be beneficial for any age. This is in accordance with recent calls to develop and evaluate early intervention in EDs across the lifespan (Allen et al., 2023). The age range for FREED was chosen due limited resources (i.e., focusing resources on the peak risk period for ED onset) and allowed for treatment to be tailored to this life stage. While most EDs develop before the age of 25, a sizable minority (10-30%) of individuals develop an ED after this age (Davies et al., 2021). Relatedly, perimenopause (~40-55 years old) has been hypothesised as a later peak risk period for the development of EDs, but data remain limited and conflicting (Baker & Runfola, 2016; Baker et al., 2017; Mangweth-Matzek et al., 2013; Mangweth-Matzek et al., 2021). A recent review suggests that approximately 50% of individuals 65 years or older with an ED developed their ED in later life (>40 years), highlighting the substantial burden of disease and disability associated with this late onset group (Mulchandani, Shetty, Conrad, Muir, & Mah, 2021). Early intervention could potentially prevent individuals in this late onset group developing longer-term illnesses by disrupting learning and habit mechanisms and the embedding of the ED in bio-psycho-social routines. The physical consequences and risks associated with EDs may be even more pronounced in older adults, however, specific evaluations of individuals with a late onset ED are limited (Elran-Barak et al., 2015; Mulchandani et al., 2021).

Data in this thesis suggest that perhaps FREED in its current form may not be the best model for early intervention in older patient groups as clinicians found that older patients did not engage with or benefit from FREED in the same way as the younger age group. However, further research is needed to confirm or refute these findings, which were derived from a small number of interviews. FREED services would also require additional funding if they were to expand their age range. If early intervention is to be developed for older age groups, the service will need to be adapted to the unique experiences of EDs in midlife and beyond. Factors such as age-related hormone and physical changes, and the cultural expectations and life roles of older adults would need to be considered. Considerable outreach and awareness raising activities would also be required to work against the stereotype that only young people

develop EDs (Samuels, Maine, & Tantillo, 2019). In keeping with this, studies in EIP suggest that early intervention for late onset psychosis (>35 years) is justified (though evidence on outcome is limited) but that the care of older groups may need a greater focus on physical health issues and support for parenting, dependents/young carers, independent living and returning to work (Greenfield et al., 2018; Lasalvia et al., 2017; O'Driscoll et al., 2021; Taylor, Orucu, Nandha, & Cella, 2023). Much more research is required in late onset EDs more generally and for the structure, feasibility and utility of an age inclusive early intervention service specifically.

While the above areas are of particular interest, there are several other areas identified by the studies that warrant attention in the future. Specifically, the need for multiple champions (i.e., the FREED Champion cannot do it on their own), additional training and support for involving family/carers and assessing suitability for FREED and DUED, understanding optimal methods of integrating FREED into the local context, and the need to create an open dialogue around FREED within the team. The importance of the wider system of care and receiving appropriate referrals early were also identified as prominent barriers for early intervention. This is addressed in the next section.

8.3.3 The broader system of care: Outreach and access to early intervention

In Chapter 5, the broader system of care, namely public and professional awareness of EDs and FREED, was identified as important for enabling early intervention, and in some cases was a barrier to implementing FREED. Gatekeeping procedures (e.g., restricted access to care via a primary care referral) were previously identified as major barriers to rapidly accessing FREED treatment (Brown et al., 2018; Flynn et al., 2020). Accurate and rapid detection and referral of cases by primary care and educational professionals has long been perceived as an obvious and necessary step in facilitating early intervention in EDs (Currin & Schmidt, 2005). The frequency of ED cases reported by primary care practices is lower than anticipated given epidemiological data and a substantial number of primary care practitioners (and other health professionals) have difficulties recognising and managing ED presentations and symptoms (Bullivant, Rhydderch, Griffiths, Mitchison, & Mond, 2020; Currin, Waller, & Schmidt, 2009; Higgins & Cahn, 2018; Kalindjian et al., 2021; McNicholas, O'Connor, O'Hara, & McNamara, 2016). This partial knowledge and low detection have been attributed to limited clinical experience, education, and training in EDs (Anderson, Accurso, Kinasz,

& Le Grange, 2017; Ayton & Ibrahim, 2018; Linville, Brown, & O'Neil, 2012). Indeed, an evaluation of medical schools in the UK found that, on average, medical professionals receive less the 2 hours of training in EDs (Ayton & Ibrahim, 2018). In the education sector, a survey of 548 UK schools and colleges found that staff had limited training, and guidance to support students at risk of, or suffering with an ED, and consequently felt uncomfortable talking about EDs with students (Knightsmith, Treasure, & Schmidt, 2014). Recognition or self-recognition of EDs from vignettes has also been shown to be poor in members of the public and individuals with elevated ED symptoms (Bullivant et al., 2020; Darby, Hay, Mond, & Quirk, 2012; Gratwick-Sarll, Bentley, Harrison, & Mond, 2016; Jeon & Furnham, 2017; Mond, Hay, Rodgers, & Owen, 2006). Poor self-recognition has been associated with lower help-seeking (Gratwick-Sarll et al., 2016; Mond et al., 2006). Shame, stigma, a lack of perceived need for treatment, and the desire for self-sufficiency are all prominent barriers to help-seeking in EDs (Ali et al., 2017; Ali et al., 2020). For FREED patients specifically, barriers and facilitators to help-seeking had a temporal sequence. Initially, ED symptoms and behaviours were highly egosyntonic (e.g., seen positively and valued by the individual), which prevented help-seeking. The negative impact of the ED on health and functioning and the onset of binging and purging behaviours then led to a gradual re-appraisal of symptoms, until eventually, individuals reached a phase of problem recognition. During this phase, deviating from social stereotypes about EDs (e.g., they are teenage illnesses, you need to be extremely thin) and associated shame and embarrassment were major barriers to help-seeking (Potterton et al., 2020a). Together, these findings underline some of the challenges in identifying individuals with EDs more generally, let alone in early-stage illness when symptoms might be milder and/or egosyntonic. These external sources of delays are captured in the limited impact of FREED on duration until first contact with specialist services (Brown et al., 2018; Flynn et al., 2020).

In the qualitative interviews in Chapter 5, clinicians reported using various outreach activities to engage healthcare professionals, students and educational institutions, and members of the public. Activities included attending freshers' fairs, presentations at universities and schools, networking and meetings with primary care and mental health professionals and distributing promotional materials. For newer sites, it was particularly important to ensure that primary care staff were aware that the

service was now accepting milder early intervention cases. Monitoring the success of these different strategies to engage certain groups would be of great interest to understand early detection and referral routes into FREED. To date, there has been limited research evaluating broader system interventions to improve early detection and referrals in EDs. Most have occurred in educational settings and involved screening and education/training with some evidence of benefit, at least in the short term (Kalindjian et al., 2021). However, the impressive multi-component *Psychenet* intervention did not impact duration until first contact with services or DUED (Gumz et al., 2018).

Broad awareness raising activities and low threshold access to services (e.g., self-referral) were a central feature of many early intervention services in the scoping review in Chapter 3. However, only one service (First Episode Mood and Anxiety Program) evaluated their access and community engagement activities, which included non-physician referral routes, informal question-and-answer sessions, school art campaigns, community partnerships, attendance at drop-in centres, public talks, and newspaper articles. Based upon the source and types of referrals, the authors concluded that the community engagement activities had been effective at increasing the number of symptomatic young people contacting the service (Ross et al., 2012). However, some groups were not reached (e.g., older young people, low socioeconomic status groups) and the study did not provide a pre- and post-intervention comparison. Even within EIP, there have been relatively few evaluations of interventions to improve early detection and reduce external delays to treatment (Malla, 2022). There is evidence that some interventions impact duration of untreated psychosis, but others do not (Oliver et al., 2018). This highlights the need to evaluate early detection and outreach efforts since they may not be effective and require a considerable amount of time and resources. Across the early intervention services described in Chapter 3, non-medical referral routes, such as self- or family-referral, were often the most frequent method of gaining access to services and higher amongst males and individuals with no prior help-seeking (Arcaro et al., 2017; Leopold et al., 2013). Self-referral may therefore be another important area of interest to increase accessibility for FREED.

Findings from the scoping review also suggest that service setting and location are important contributors to access and engagement in early intervention services (Arcaro et al., 2019; Judd et al., 2011; Marriott et al., 2007). The broader literature on setting and location/co-location of youth and adult mental health services also advocate

for informal, accessible, low stigma, and community-based rather than hospital-based settings (Colucci, Minas, Szwarc, Guerra, & Paxton, 2015; Hawke et al., 2019; McGorry et al., 2014; Moroz, Moroz, & D'Angelo, 2020; Semrau, Barley, Law, & Thornicroft, 2011; Settipani et al., 2019). Research evaluating the integration and co-location of mental health services with other services/organisations, such as primary care and educational settings, find that co-location can improve acceptability, accessibility and utilisation of services, amongst other benefits (e.g., smooth transitions, enhanced inter-service communication) (Ellins et al., 2023; Elrashidi et al., 2018; So, McCord, & Kaminski, 2019; Vickers et al., 2013; Wray, Szymanski, Kearney, & McCarthy, 2012). Co-location of services can reduce stigma-related barriers as it is not clear which of the co-located services people are accessing (Hawkes et al., 2019). Moreover, a preliminary report suggests that prevention orientated public mental health services based in community locations, such as libraries, food banks, and community hubs, provide a non-judgemental and psychological safe space and reduce barriers to accessing services (e.g., time and cost, stigma) (Welford, 2022).

Mental health services for young people also focus on creating youth-friendly services and environments to address issues of access and engagement (Hawkes et al., 2019; McGorry et al., 2014; Settipani et al., 2019). Key characteristics of youth friendliness include: co-located/integrated services ('one-stop shop'); clear policies around confidentiality and information sharing; use of technology and social media; inclusive, culturally diverse and safe-space values (e.g., no discrimination); developmentally informed; non-stigmatising language; non-clinical, informal, and bright physical environments and décor; peer workers; welcoming, non-judgemental and genuine staff members; services located in easily accessible places; flexible appointments; free or low-cost services; youth involvement in treatment decisions; and recreational and creative approaches. Moreover, continuous and meaningful youth involvement in the planning, design and delivery of services helps services to become more youth friendly and allow them to keep pace with the rapidly changing youth culture and language. Research specifically evaluating the impact of these features on service utilisation and engagement are however limited (Hawke et al., 2019). Qualitative findings suggest that the youth friendly, non-clinical environment of *headspace* centres (youth primary mental health services) was one of the main reasons why young people felt comfortable accessing and attending the service (Patulny, Muir,

Powell, Flaxman, & Oprea, 2013). Several of these youth-friendly characteristics are also not specific to youth and could make services more accessible and acceptable to all ages (e.g., welcoming and non-judgemental staff) (Hawke et al., 2019). Many of these youth-friendly service characteristics (e.g., using social media, flexibility) are already integral aspects of the FREED model, but others related to setting and location are not. A greater consideration of the setting, location and the youth-friendliness of the physical environment of FREED services could address some of the previously outlined issues of access, and engagement. Indeed, early intervention in ED initiatives in Australia, Canada, and the US have embedded their initiatives within easily accessible, low-stigma community settings (e.g., educational settings, youth-focused primary mental health services) to reduce barriers to quickly accessing specialist ED treatment (Allen et al., 2023).

8.3.4 Priority setting in eating disorder services

In resource restricted settings, such as publicly funded health services, early intervention becomes part of the many factors clinicians and services must balance when prioritising patients for care. During the qualitative interviews in Chapter 5, some clinicians spoke of their informal prioritisation procedures for FREED-like patients before adopting the FREED model (e.g., prioritising patients that were new to services). Despite the importance priority setting procedures in services, the systematic review (Appendix F, Section 10.6.2) conducted for the Delphi study in Chapter 6 revealed a dearth of research on wait list priority setting in EDs. Only one relevant study was identified, and even in this study, only 3 different prioritisation factors (i.e., age, mental health history, and socio-economic status) were evaluated. Priority setting is a complex process that is highly context specific, i.e., the weight attributed to different factors in priority setting decisions depends upon the presence of all other factors (Whitty et al., 2014). There is limited research, guidance, or tools to support these complex priority setting decisions in ED services. The National Institute of Health and Care Excellence recommends that patients with, or at risk of, severe emaciation should be given priority (National Institute for Health and Care Excellence, 2017). Indeed, physical risk tends to take precedence in ED services, and this was reflected in the high agreement amongst clinicians and individuals with lived experience of an ED that medical risk is the most important prioritisation factor in Chapter 6 and reports by clinicians in Chapter 5. However, there were concerns regarding the disproportionate emphasis on physical

health and weight at the expense of mental health in priority setting, especially in the lived experience group. This is likely due to the participants experiences of struggling to gain access to treatment when not underweight or very physically unwell, and the emphasis on weight and physical health in treatment. Addressing this imbalance in services is important and further research is required. Observational studies of access to ED services and priority setting processes and procedures would be an important initial step in further understanding and address this imbalance.

The Delphi study has provided an extensive list of potential prioritisation factors that were reviewed, critiqued, and added to by 110 clinicians and individuals with lived experience. The study also provided insights into the collective opinions of these groups on which factors they value and why. However, more research is needed. Qualitative studies would provide a more in-depth understanding of why participants gave specific ratings. Multi-criteria decision making tasks would more closely resemble real-world decisions and enable the derivation of prioritisation factor weights (Whitty et al., 2014). This information could be used alongside evidence on clinical outcomes to create a prioritisation tool to facilitate clinical decision making. This is an approach that has been successfully used in other areas of healthcare to promote equitable, transparent, and reliable prioritisation of patients on waiting lists (e.g., Srikumar, Eglinton, & MacCormick, 2020; Taherkhani, Sepehri, Khasha, & Shafaghi, 2022).

8.4 Overall conclusions

This thesis evaluated implementation processes and outcomes of early intervention in general and of FREED specifically using a multi-method approach. First, a scoping review of early intervention services for non-psychotic mental health disorders found a growing and promising evidence-base of early intervention services that provided accessible multi-disciplinary treatment to individuals in peak risk periods with early-stage mental health symptoms. However, much more research is needed, particularly to evaluate the reach, relative effectiveness and cost, and implementation processes and outcomes of these services. Second, data from FREED-Up and the national FREED-4-All dataset showed varying (low to high) adherence to the FREED wait time targets, high use of the FREED care package, and the replication of the impact of FREED at scale. However, more data, especially for clinical outcomes, are needed to confirm or refute these conclusions, as well as comparative data to evaluate the impact of FREED compared to standard treatment. Third, one-to-one qualitative interviews with clinicians

implementing FREED found that clinicians were highly enthusiastic towards early intervention and that features of the FREED model, and associated implementation strategy, were important in developing this 'buy-in' and supporting the implementation of FREED in routine practice. Simultaneously, clinicians were also concerned about service capacity and the impact on service provision for non-FREED patients. These opinions were largely echoed in the Delphi study, where collectively clinicians agreed that patients in early-stage illness should receive priority, albeit to a lesser extent than high risk and transition cases and patients <12 years old. Finally, in the Delphi study, individuals with lived experience also described early intervention as important, but collectively did not identify it as a priority issue, largely because of concerns about individuals with longer illness durations being de-prioritised. To be considered as a priority, early intervention needs to be adequately resourced to ensure that it does not impact the care of other patients and research data are needed to monitor any unintended consequences of early intervention and FREED. Medical risk and overall severity were unanimously agreed upon as the most important factors in clinician and lived experience groups. The findings of the Delphi study need to be replicated using different designs and data collection methods, e.g., qualitative, multi-criteria, and observational studies. The studies in this thesis highlighted several important areas for further research and development. Specifically, optimising the FREED data collection procedure; ongoing evaluations of implementation fidelity and adaptation; consideration of capacity issues and solutions; evaluations of the impact on other patients and potential unintended consequences; and attending to the role of the wider system in early intervention (i.e., making early intervention earlier, broader attitudes towards early intervention). Overall, this thesis provides tentative support for the continued scaling of FREED and has advanced our knowledge on factors that are important in the implementation of early intervention services and FREED. Early intervention in ED is in its infancy and much more research is required to understand whether and how to operationalise and implement it across different patient groups and settings (Allen et al., 2023).

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Chapter 10. Appendices

10.1 Appendix A: Published papers

10.1.1 Chapter 2: Early intervention service for non-psychotic disorders: a scoping review protocol

Open access Protocol

BMJ Open

Early intervention services for non-psychotic mental health disorders: a scoping review protocol

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ABSTRACT

Introduction Worldwide mental health disorders are associated with a considerable amount of human suffering, disability and mortality. Yet, the provision of rapid evidence-based care to mitigate the human and economic costs of these disorders is limited. The greatest progress in developing and delivering early intervention services has occurred within psychosis. There is now growing support for and calls to extend such approaches to other diagnostic groups. The aim of this scoping review is to systematically map the emerging literature on early intervention services for non-psychotic mental health disorders, with a focus on outlining how services are structured, implemented and scaled.

Methods and analysis The protocol was developed using the guidance for scoping reviews in the Joanna Briggs Institute manual and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews checklist. A systematic search for published and unpublished literature will be conducted using the following databases: (1) MEDLINE, (2) PsycINFO, (3) HMIC, (4) EMBASE and (5) ProQuest. To be included, documents must describe and/or evaluate an early intervention service for adolescents or adults with a non-psychotic mental health disorder. There will be no restrictions on publication type, study design and date. Title and abstract, and full-text screening will be completed by one reviewer, with a proportion of articles screened in duplicate. Data analysis will primarily involve a qualitatively summary of the early intervention literature, the characteristics of early intervention services and key findings relating to their evaluation and implementation.

Ethics and dissemination The synthesis of published and unpublished articles will not require ethical approval. The results of this scoping review will be published in a peer-reviewed journal and disseminated via social media, conference presentations and other knowledge translation activities.

Strengths and limitations of this study

- This scoping review will provide a comprehensive overview of both published and unpublished literature for the emerging research field of early intervention services for non-psychotic mental health disorders.
- The review will be conducted according to the standardised methodology outlined in the Joanna Briggs Institute manual and using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses checklist for scoping reviews.
- Part of the screening and charting process will be completed in duplicate to ensure reliability of these methods.
- Only articles written in English, German, French and Spanish will be included, the review may, therefore, be biassed.

INTRODUCTION

Early intervention is widely perceived as beneficial in medicine and refers to the early detection and initiation of stage-specific treatment.[1] Proactive treatments matched to the stage of illness can limit or even avert unfavourable outcomes, reducing the need for costly and more invasive treatments in the future.[2 3] Despite such promise, early intervention approaches have been slow to gain momentum in mental health.[4 5] Mental illnesses are a major contributor to mortality and disability worldwide, particularly for young people.[6–8] The typical age of onset for mental disorders is adolescence and early adulthood (12–30 years), a period of marked social, psychological and biological change.[9 10] A delay in or lack of access to effective treatments during this time could disrupt key developmental milestones and have long-lasting effects on health, social and occupational trajectories.[11]

Service provision does not match the topography of onset or burden of disease associated with mental disorders, even in relatively well-developed health systems.[12] Globally, access to evidence-based care is poor, and even for those that do access it, this is often after lengthy delays.[13–15] The duration of untreated illness (DUI), defined as the period between the onset of psychiatric disorder and the initiation of treatment, ranges from 1 to 2 years for psychosis to 10 years for obsessive–compulsive disorder (OCD).[16–19] Over time, mental disorders can become more entrenched through functional deterioration, neuroadaptation

and habitual behaviour patterns.[20–23] Indeed, a longer DUI is associated with worse symptomatic and functional outcomes, and a lower treatment response across diagnostic groups.[19 24–27] More worryingly, young people, the group at highest risk for psychiatric difficulties, tend to have the worst access to timely care.[13 18 28–30]

Together, such findings provide a compelling case for establishing early intervention services that match the developmental needs and symptomatic profile of individuals with recent-onset mental disorders.[4 14] The greatest strides in early intervention have been made within psychosis. Over the past 30 years, early intervention for psychosis (EIP) has gained tremendous support from researchers and healthcare professionals worldwide.[14] EIP services have two fundamental aims: to reduce the duration of untreated psychosis, and to provide evidence-based, stage-specific treatment.[31] EIP services use a clinical staging approach to map the extent of illness progression from early presymptomatic risk to severe and enduring, enabling a prevention orientated framework that matches the intensity of treatment to the level of need.[32 33] A comprehensive body of high-quality research shows that compared with standard care, multicomponent EIP services are associated with a reduction in symptom severity, relapse rates and hospitalisation risk, as well as improved global functioning and quality of life.[34] Moreover, consistent evidence suggests that EIP services are a cost-effective alternative to standard care.[35] There has been a recent surge in papers calling for early intervention approaches to be broadened to other diagnostic groups, including major depression,[36] OCD,[22] eating disorders[37] and bipolar disorder.[38] Preliminary evidence from services for recent-onset eating and mood disorders demonstrate significant improvements in symptoms, reduced hospital (re)admissions, and most importantly, high levels of patient satisfaction.[39–42]

The utility of focusing exclusively on discrete diagnostic categories in the delivery of early intervention specifically, and mental healthcare more generally has, however, been questioned.[32 43] The early stages of mental disorder are often characterised by fluctuating patterns of specific and non-specific subthreshold symptoms, diagnostic instability and comorbidity.[44 45] A single-disorder focus could result in these earlier presentations of illness being excluded.[46] A transdiagnostic approach, consistent with evidence for pluripotent models of clinical staging, has been put forward as a necessary solution to address this problem.[32 43 47 48] The recognition of the need to broaden the early intervention paradigm has led to the development of several integrated youth mental health hubs.[49 50] These hubs act as entry-level services for young people irrespective of diagnosis, and typically provide a comprehensive package of low-intensity mental, physical and social care support in community settings. Young people tend to rate these services positively and between 52% and 68% experience improvements in symptoms and functioning. However, a proportion of individuals with more severe symptoms do not seem to benefit from these services and rigorous outcome research for youth hubs is limited.[50 51]

Although the role of early intervention in reducing distress and functional impairment seems obvious, the evidence-base for these services is incomplete and much more work needs to be done.[14 22] There is limited prospective evidence evaluating the utility of these services for non-psychotic disorders, it is unclear to what extent the findings from psychosis would translate to other diagnostic groups. There is also a lack of research evaluating the feasibility or the implementation processes of services in clinical settings.[51] Moreover, even within psychosis, further research is needed to determine how long EIP services should be provided, whether it is the reduction in DUI or other components of EIP services that account for the improved outcomes, and whether outcomes would be similar with other service structures and models.[52 53] An ever-growing population, accompanied by reducing health budgets, creates an environment where only services that demonstrate effectiveness, economic viability and sustainability receive funding.[54] It is, therefore, imperative to develop a rigorous evidence base to refine, adapt and evaluate early intervention services for non-psychotic disorders, with a particular focus on identifying the "active ingredients" of such services and the most effective methods for widespread scaling and implementation.

The primary objective of this review is to provide a baseline characterisation of the differing ways in which early intervention services are structured and implemented for non-psychotic mental health disorders. The emerging literature for non-psychotic disorders is heterogeneous and dispersed, with distinct streams of research developing in disciplinary silos. The aim of this review is to draw together these streams to facilitate collaboration and cross-disciplinary learning and discourse. By synthesising the field and highlighting commonalities and differences, we hope that a broad set of common principles for early intervention services will emerge. This review, in conjunction with reviews in psychosis, will help set the stage for a more unified approach to expanding and refining early intervention services for psychiatric disorders. Here, we focus exclusively on disorders that tend to emerge in adolescence and adulthood rather than in childhood. Neurodevelopmental disorders typically use a very different approach to early intervention than adolescent-onset and adult-onset disorders (eg, intervening in infancy).[55] A scoping review methodology was selected for this review as early intervention is an emerging, dispersed and heterogeneous research area and is therefore not amenable to the narrower aims of a traditional systematic review.[56 57] Given that this is a relatively new research area, we sought to map all the available evidence within this field rather than only the best available evidence (eg, randomised controlled trials).[58]

Table 1 MEDLINE search strategy

	Query	Results
#1	exp Early Medical Intervention [MeSH term)/ or (early intervention* or early-intervention*).tw	19623
#2	exp Mood Disorders [MeSH term)/ or Bipolar Disorders [MeSH term)/ or (mood disorder* or affective disorder* or depressi* or dysthymi* or bipolar*).tw	453041
#3	#1 AND #2	1616
#4	exp Anxiety Disorders [MeSH term)/ or (anxiety disorder* or neurotic disorder* or agoraphobi* or obsessive-compulsive disorder* or OCD or panic disorder* or phobic disorder* or post-traumatic stress disorder* or post traumatic stress disorder* or PTSD or generalised anxiety disorder* or social phobia).tw	119604
#5	#1 AND #4	560
#6	exp "Feeding and Eating Disorders" [MeSH term)/ or (eating disorder* or anorexi* or bulimi* or binge-eating* or binge eating* or (eating disorder not otherwise specified) or EDNOS or (other specified feeding or eating disorder) or OSFED).tw	56480
#7	#1 AND #6	199
#8	exp Substance-Related Disorders [MeSH term)/ or exp "Disruptive, Impulse Control, and Conduct Disorders" [MeSH term)/ or (((substance-related or alcohol or opioid or morphine or marijuana or heroin or cocaine or amphetamine or cannabis) adj1 (disorder* or illness* or dependence or abuse or misuse)) or (impulse control disorder*) or conduct disorder* or fire setting behaviour* or gambling or trichotillomania).tw	295108
#9	#1 AND #8	924
#10	exp Somatoform Disorders [MeSH term)/ or (somatoform or somatoform disorder* or somati#ation or body dysmorphi* or conversion disorder* or hypochondri*).tw	25487
#11	#1 AND #10	38
#12	exp Personality Disorders [MeSH terms)/ or (personality disorder* or antisocial personality disorder* or anti-social personality disorder* or borderline personality disorder* or emotionally unstable personality disorder* or obsessive-compulsive personality disorder* or dependent personality disorder* or histrionic personality disorder* or narcissistic personality disorder* or avoidant personality disorder* or paranoid personality disorder* or schizoid personality disorder* OR schizotypal personality disorder*).tw	47019
#13	#1 AND #12	208

RESEARCH QUESTIONS

1. What is the extent, range and nature of the literature on early intervention services for adolescents and adults with non-psychotic mental health disorders?
2. What are the characteristics of early intervention services and care pathways?
   a. Are there any similarities and/or differences across early intervention services provided for each diagnosis and transdiagnostically?
3. Are there any factors that influence the implementation of early intervention services (ie, barriers and facilitators to implementation)?
4. Do early intervention services reduce DUI, improve the course and outcome of mental disorders or minimise the disruption to psychosocial development and function?

METHODS AND ANALYSIS

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews (PRISMA-ScR) checklist,[57] and the scoping review framework outlined in the Joanna Briggs Institute (JBI) Reviewer's Manual[59] were used to guide the development of this protocol.

Eligibility criteria

Documents will be included if they: (1) Describe and/or evaluate an early intervention service for non-psychotic mental health disorders (concept) based in any type of healthcare facility (ie, hospitals, day services and community settings) and in any geographical area (context). Here, early intervention refers to a structured programme of care delivered by a stand-alone team or teams integrated into mental health services that provide treatment for individuals with recent-onset subthreshold or threshold disorders. The level of care can vary from low-intensity techniques of signposting, psychoeducation and self-help resources all the way through to specialised multidisciplinary teams and complex high intensity interventions; (2) Describe and/or evaluate an early intervention service for adolescents (≥10–17 years) or adults (>18 years) with a recent-onset subthreshold or threshold mood disorder, anxiety disorder, eating disorder, personality disorder, impulse control or substance use disorder, and/or somatoform disorder (types of participants).

Table 2 Draft data charting form

Data item	Description of item
Document details	
Type of document	The type of document can include but will not be limited to published or unpublish primary research, any type of review, protocols, theoretical paper, guidelines, opinion pieces, editorials and expert consensus papers.
Author(s)	List of authors
Year of publication	Year of publication
Title	Title of document
Journal	The title of the scientific journal (for published documents only)
Country of origin	Country where the document originates
Aim/purpose of document	Summary of the aim/purpose of the document
Study design	For published or unpublished research papers, the design of the study as reported in the paper. Includes but is not limited to randomised controlled trials, pre–post design, historical controlled trial, prospective or retrospective cohort studies, cross-sectional and case series/study.
Study methodology	The methodological framework: qualitative, quantitative or mixed methods.
Characteristics of early intervention service	
Name of service	The name of the early intervention service/programme.
Year established	The year the early intervention service was established.
Location	The country and region in which the early intervention service was implemented.
Population	The population for which the service was designed for. This item will include details such as age, diagnosis, duration of illness and illness severity.
Setting	The physical setting in which the early intervention service is based. This includes but is not limited to community centres, primary care, outpatient clinics and inpatient wards. Early intervention services can occupy more than one of these settings.
Service providers	A description of who provides the service and their role, includes but is not limited to social workers, youth workers, peer support workers, nurses, clinical or counselling psychologists and psychiatrists.
Service structure/ process	A description of the service structure and administrative processes includes but is not limited to 'service within a service' models, stand-alone multidisciplinary team models, 'hub' and 'spoke' models, and process variables such as specific wait time targets.
Access to service	Methods for accessing the early intervention service, includes but is not limited to active engagement and outreach through schools, colleges and youth clubs, referral from primary care, self-referral and drop-in.
Services and interventions	A description of the types of services and interventions provided, includes but is not limited to psychoeducation, online self-help and self-management support, psychological therapies (eg, CBT, brief therapy), sexual health and family planning, health promotion, social services, peer support, and crisis intervention and management.
Clinical staging	Whether a clinical staging approach was used to inform the design, evaluation or implementation of the service.
Outcome Research	
Participants	Details related to the participants included in the study. This will include information related to sample size, diagnosis, age, sex and inclusion/exclusion criteria.
Comparator data or standard care	Description of comparator data or the care provided to a control group.
Outcomes and time points	Description of the qualitative and quantitative outcomes and the time points of data collection. This will include standardised clinical assessments, and self-report measures as well as implementation outcomes, such as measures of acceptability, feasibility, adoption, fidelity and sustainment.
Key results/findings	An outline of the key results and findings reported in the document. This includes quantitative outcomes such as changes in symptoms, engagement and patient satisfaction, as well as qualitative outcomes, such as, descriptions of barriers and facilitators to implementation.

CBT, cognitive–behavioural therapy.

Table 3 Summary of reach, effectiveness, adoption, implementation and maintenance framework criteria

Reach (participant representativeness)	The representativeness of individuals enrolled in the study to the characteristics of the intended population. 1=Limited generalisability: highly selected subsample that is not typical of the intended population, high number of exclusionary criteria, and/or a recruitment strategy that is likely to result in a biassed sample. 2=Moderately generalisable: participants match intended population on key characteristics (eg, sex/gender, diagnosis, age), but are still a selected subsample due to exclusion criteria and recruitment strategies. 3=Generalisable: participants are typical of the intended population, limited or no exclusion criteria and/or recruitment strategies is not selective and are unlikely to result in a biassed sample.
Effectiveness (outcome representativeness)	Measured outcomes are important and meaningful to all stakeholders involved, including potential negative effects, quality of life and economic outcomes. 1=Limited generalisability: primary outcomes restricted to an estimate of the overall effect of the intervention on a single metric of health, limited attention to process outcomes, quality of life, patient and staff satisfaction, patient engagement, unintended harms, or functional rehabilitation. 2=Moderate generalisability: primary outcomes focus on overall effect of intervention on health, some inclusion of measures that are meaningful to stakeholders or process outcomes. 3=Generalisable outcomes: primary outcomes include mix of impact of intervention on health and outcomes that are meaningful to patients and other stakeholders (including qualitative evaluations), explicit discussion around prevention of harms to participants, process outcomes, patient engagement, acceptability and satisfaction.
Adoption (setting representativeness)	The representativeness of settings and the individuals within those settings who deliver the programme. 1=Limited generalisability: highly selected settings and staff and/or only includes 'best' sites and staff, that is, well-resourced, credentialed or seasoned interventionists, many exclusion criteria; or limited information to determine context of study or intervention. 2=Moderate generalisability: intervention tested in contexts outside of 'best' sites and staff, but adoption is still limited to selected settings that are well resourced with some expertise in intervention trials. 3=Generalisable: sites and staff are randomly selected, few or no exclusion criteria and/or trialled in diverse settings.
Implementation (fidelity/adaptation, and cost/feasibility)	Fidelity to the intervention and adaptations made to intervention during study/programme. 1=Limited information on the implementation: no details on adaptation to local context, no details related to core element of interventions, or an evaluation of the consistency of implementation across settings staff, and patients. 2=Moderate reporting of fidelity/adaptations: core elements described but details missing, or fidelity was monitored but no details on measurement tools. 3=Detailed report of modifications made, adaptations to local context, and rationale for modification, an outline of core elements and evaluation of the fidelity to core elements of the model. The cost of the intervention in terms of time and money. 1=No details on time, cost and resources, no efforts to contain costs, and use of state-of-the-art resources and procedures such that costs of intervention are likely to be high. 2=Details on time, cost and resources is still limited but more than for a rating of 1. The intervention has minimal impact on time, cost and resources. 3=Explicit efforts to contain costs and to make the intervention feasible in low resource settings.
Maintenance (sustainment)	The extent to which an intervention becomes institutionalised or part of the routine organisational practices and policies and the extent to which behaviour is sustained for more than 6 months. 1=Limited sustainability efforts or details of such efforts: no report of efforts to continue an intervention after the completion of study, or no reports of continued use. 2=Moderate sustainment: limited discussion regarding the sustainability of an intervention, some evidence of continued use. 3=Sustainment: long-term outcomes reported, explicit plans for handing off intervention to setting/sites, details of methods to encourage sustainable implementation or embedding within routine organisational practices and policies or evidence of sustained use for 6 months or more.

Transdiagnostic early intervention services and early intervention services for comorbid/concurrent disorders will be included provided that at least one of the diagnoses is listed in the previous sentence; (3) Mixed child and adolescent services will be included, where feasible, only information relevant for the adolescent portion of the services will be charted and (4) All document types and study designs are eligible for inclusion: randomised

controlled trials, non-randomised studies, observational studies, qualitative studies, reviews, ongoing trials, protocols, theoretical papers, grey literature, editorials, opinions pieces and expert consensus statements (types of studies).

Documents will be excluded if they: (1) Describe a primary prevention programme based in educational establishments, high-risk groups (eg, athletes) or in the general population, (2) Describe a parent-only intervention, (3) Describe a specific intervention (eg, type of cognitive–behavioural therapy) that is not attached to a service and (4) Primarily or only focus on early intervention for a physiological or medical condition, schizophrenia spectrum and other psychotic disorders and/or neurodevelopmental disorders.

Search strategy

A comprehensive literature search will be conducted from inception on PsycINFO, MEDLINE, EMBASE and HMIC. ProQuest databases will also be searched for grey literature (ie, conference papers and proceedings, theses, government publications). The search is completed in three stages. First, an initial limited search was conducted in MEDLINE using the terms "early intervention" and "mood disorder" or "anxiety disorder" or "eating disorder" or "personality disorder" or "impulse control disorder" or "substance use disorder" or "somatoform disorder". The initial limited search was conducted by KR in April 2019 to identify keywords and subject headings to generate a search strategy. Different combinations of keywords and subject headings were trialled in MEDLINE, and key papers from the early intervention field were used as indicators for the sensitivity of the search strategy. The preliminary search strategy was developed by KR and reviewed by AA, KA and US. An iterative process was used to balance the sensitivity and specificity. The MEDLINE-specific search strategy returns 3545 documents before deduplication and is outlined in table 1.

In the second stage, all databases will be searched using the MEDLINE search strategy. The search strategy will be tailored to each database. The search for scoping reviews are more iterative than systematic reviews, it is; therefore, feasible that as the reviewers become more familiar with the literature that additional search terms and sources may be identified. The final stage involves identifying additional articles by searching the reference lists of included articles. Studies not reported in English, German, French and Spanish will be excluded from the review during the screening and eligibility assessment. No date limits will be applied to the search. References will be imported to the EndNote X8 reference manager.

Study selection process

The title and abstract screening in the second stage of the search will be completed by one reviewer with a portion of the articles being screened in duplicate to ensure reliability (25%). Retrieved full texts will also be screened by one reviewer with a sample of full-text documents (25%) being screened in duplicate for reliability. The eligibility criteria will be applied to each document on a case-by-case basis to determine eligibility for inclusion. Discrepancies between reviewers will be resolved by discussion and if necessary other members of the review team will be consulted.

Data items and charting

A standardised data charting form developed by the study team will be used to chart the data from eligible studies (see table 2 for a description of each data item). The data charting form was developed using the template from the JBI manual and by drawing on recent reviews of youth service models.[50 51] Each section of the data charting form was developed to address one of the four research questions. The 'Document Details' section which provides descriptive information on document type, author(s), publication date, title and aim/purpose of document will be used to evaluate the extent, nature and range of the literature on early intervention services (question 1). The second section 'Characteristics of Early Intervention Service' will address the second question as key characteristics of the services, namely the population, setting, structure and interventions used in early intervention services will be charted (question 2). The 'Outcome Research' section will be used to answer questions 3 and 4 as any data related to implementation, effectiveness or efficacy will be charted (question 3 and 4). Similar to the full-text screening, one reviewer will chart the majority of the documents with only a portion (25%) of the documents being charted in duplicate to ensure reliability. A small selection of documents will be charted by both reviewers at the outset to ensure that there is clarity and consistency in the use of the data charting form. Where there is more than one paper on the same service model, information will be pooled across the papers to provide the most detailed description of the model and any available evidence.

Critical appraisal

The lack of critical appraisal tools in scoping reviews has been highlighted as one of the primary limitations of this knowledge synthesis method.[60] Critical appraisal can facilitate the interpretation of reviews by identifying the relative strengths and weaknesses of the included articles and identifying gaps in the research field. However, formal evaluations of methodological quality for scoping reviews can be challenging given the diversity of study designs and the volume of included literature.[61] Given the range of study designs, a two-stage assessment of methodological quality will be conducted for this review. First, each study will be ranked using the JBI Levels of Evidence for Effectiveness from high (level 1) to low (level 5) (level 1—Experimental Designs; level 2—Quasi-experimental Designs; level 3—Observational–Analytical; level 4—Observational–Descriptive; level 5—Expert Opinion and Bench Research).[62] Once stratified according to the level of evidence, the quality of the studies within each stratum

will be evaluated using the JBI Critical Appraisal tools.[63] Additionally, the generalisability and real-world applicability (external validity) of the included studies will be evaluated against the domains of the reach, effectiveness, adoption, implementation and maintenance (RE-AIM) framework. A modified version of a RE-AIM framework rating system developed by Gaglio *et al* will be used in the current study.[64] The modified rating system can be seen in table 3. Each document will be given a rating ranging from 1 (limited generalisability or no information) to 3 (generalisable/pragmatic or information to enable generalisation) on six key domains: participant representativeness, setting representativeness, outcome representativeness, fidelity/adaptation, cost/feasibility of intervention and sustainment. A narrative summary of the methodological quality will be provided alongside quantitative values for each domain of the RE-AIM framework. A portion of the included articles will be appraised in duplicate.

Synthesis of results

The search results will be reported using a flow diagram to clearly detail the review decision process, indicating the number of citations screened, duplicates removed, study selection and full texts retrieved. The characteristics of the included studies will be presented in an informative table with a narrative and quantitative (eg, frequencies) summary in text. Figures will be used to display the distribution of documents over time and across diagnoses. Descriptions of the early intervention services will be reported for each diagnostic group and transdiagnostically along with any evidence supporting the services and barriers and facilitators to implementation. An aggregated summary of early intervention services with descriptions of common themes and differences across the services will be provided. An effort will be made to identify gaps in knowledge to inform the direction of future research.

Patient and public involvement

No patients or public were involved in the development of this protocol.

DISSEMINATION

This review contributes to the growing body of research for early intervention initiatives in mental health by mapping the existing literature on early intervention services for non-psychotic mental health disorders. Through the publication of the results and dissemination via social media and conference presentations, the results will hopefully provide a timely foundation for cross-disciplinary discourse and early intervention service development and research. The results of this review may inform the design of new services and policies to support them.

Twitter Katie Richards @krichar25 and Amelia Austin @Ame_Austin

Contributors All authors contributed to the development of this protocol. KR drafted the manuscript and search strategy. AA, KA and US reviewed the search strategy and the draft manuscripts. KR incorporated the feedback from the authors. All authors read and approved the final manuscript.

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10.1.2 Chapter 4: Assessing implementation fidelity in First Episode Rapid Early Intervention for Eating Disorder

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Assessing implementation fidelity in the First Episode Rapid Early Intervention for Eating Disorders service model

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Background

The First Episode Rapid Early Intervention for Eating Disorders (FREED) service model is associated with significant reductions in wait times and improved clinical outcomes for emerging adults with recent-onset eating disorders. An understanding of how FREED is implemented is a necessary precondition to enable an attribution of these findings to key components of the model, namely the wait-time targets and care package.

Aims

This study evaluated fidelity to the FREED service model during the multicentre FREED-Up study.

Method

Participants were 259 emerging adults (aged 16–25 years) with an eating disorder of <3 years duration, offered treatment through the FREED care pathway. Patient journey records documented patient care from screening to end of treatment. Adherence to wait-time targets (engagement call within 48 h, assessment within 2 weeks, treatment within 4 weeks) and care package, and differences in adherence across diagnosis and treatment group were examined.

Results

There were significant increases (16–40%) in adherence to the wait-time targets following the introduction of FREED, irrespective of diagnosis. Receiving FREED under optimal conditions also increased adherence to the targets. Care package use differed by component and diagnosis. The most used care package activities were psychoeducation and dietary change. Attention to transitions was less well used.

Conclusions

This study provides an indication of adherence levels to key components of the FREED model. These adherence rates can tentatively be considered as clinically meaningful thresholds. Results highlight aspects of the model and its implementation that warrant future examination.

Keywords

Eating disorders; early intervention; emerging adults; anorexia nervosa; bulimia nervosa.

Rapid access to early intervention services in psychiatry can result in better outcomes and higher patient satisfaction, compared with treatment-as-usual (TAU) approaches.[1] One such service is First Episode Rapid Early Intervention for Eating Disorders (FREED), designed for emerging adults (aged 16–25 years) with recent-onset eating disorders.[2] Eating disorders are associated with substantial physical and psychosocial morbidity,[3] and over time can become less amenable to change.[4–6] Emerging adulthood is a peak risk period for eating disorder onset, yet evidence suggests that help-seeking and treatment utilisation are particularly low within this group.[7–9] FREED aims to deliver developmentally informed care for emerging adults that reduces service-related delays and barriers to treatment, to maximise the likelihood of recovery and minimise the impact on psychosocial trajectories.

FREED service model

FREED operates as a service within a service, overseen by a FREED Champion (typically a psychologist or nurse) who coordinates and leads a mini-team of clinicians delivering FREED-adapted treatment. Procedurally, the model involves wait-time targets of 2 weeks for assessment and 4 weeks for treatment, an electronic patient tracker to monitor and manage patient throughput, and weekly FREED 'huddles' and clinical supervision. Referrals to the service receive an engagement call within 48 h of referral. This aims to engage patients by validating and praising help-seeking, emphasising the importance of early intervention, and alleviating concerns (e.g. practical concerns, confidentiality concerns and fears about change and not being unwell enough to access treatment). Finally, the content of evidence-based treatment and style of working are adapted to meet the illness stage and developmental needs of emerging adults with recent-onset eating disorders. Treatment is delivered in a person-centred, motivational and flexible style, with a focus on transitions, eating disorder-related brain changes, social media use and significant other involvement.[10]

FREED implementation and evidence base

The implementation and evaluation of FREED has been guided by the RE-AIM (Reach, Effectiveness/Efficacy, Adoption, Implementation, Maintenance) framework.[10,11] This framework highlights five key dimensions that facilitate or hinder the population-based impact of an intervention. These dimensions are (a) the reach to the target population; (b) the effectiveness/efficacy; (c) the adoption of the intervention by organisations or individuals that can deliver it; (d) the implementation fidelity, time and cost and (e) the maintenance of an intervention over time.[12] An overview of the implementation of FREED to date, with reference to the RE-AIM framework, is provided by Allen et al.[10] The effectiveness of

Table 1 FREED care package adaptations in the FREED-Up study

Adaptation	Description
Biological malleability rationale for early intervention	A focus on the malleability of brain changes associated with eating disorders, emphasising the need for early intervention to restore brain changes and enhance the likelihood of recovery.
Psychoeducation on the impact of eating disorders on brain, body and behaviour	Verbal and/or written psychoeducation materials on the impact of eating disorders on the brain, body and behaviour, initiated early at assessment and continued throughout treatment (e.g. the psychological effects of starvation, and the vicious cycle of dieting, bingeing and purging) – even more than in treatment as usual, with tailoring to developmental stage.
Dietary change	A focus on dietary change initiated early at assessment, with initial goal setting and meal planning, and during treatment, with nutritional information, meal planning, goal setting and, where possible, early dietetic involvement.
Family/significant other involvement	Active and ongoing encouragement for family or significant other involvement in care that is developmentally appropriate and collaboratively planned. Where possible, discussions around carer skills training and support should be provided.
Exploration of social media and health-related app use	An exploration of social media and health-related app use as a potential maintaining factor for the eating disorder at assessment and treatment. A 'Social Media and Apps – Friends or Foes?' booklet can be given to patients.
Exploration of transitions	Special attention is given to the experience and management of transitions in care and life. Structured university preparation groups, covering topics such as social and sexual health, budgeting, time management, cooking and developing independence, can also be provided by teams.

FREED, First Episode Rapid Early Intervention for Eating Disorders; FREED-Up, First Episode Rapid Early Intervention for Eating Disorders - Upscaled.

FREED has been demonstrated in a single-site pilot study ($N = 142$) and a larger multi-site study (FREED-Upscaled (FREED-Up) study; $N = 502$). Specifically, FREED increases treatment uptake, and reduces wait times and duration of untreated eating disorder (i.e. time between the onset of an eating disorder and the start of evidence-based treatment). It also improves eating disorder symptoms and reduces the need for costly in-patient/day treatment, compared with TAU.[13–15] The successful and ongoing scaling of FREED to eating disorder services across England and internationally, alongside active outreach with community stakeholders and FREED's online presence, all continue to build toward the reach and adoption of FREED.[10]

Once an effective intervention is adopted across a growing number of settings and organisations, it is important to ensure that it is delivered as intended, i.e. implementation fidelity.[11] Fidelity can mediate treatment effects and explain why an intervention is more successful in one setting than another.[16] Evaluations of fidelity also provide valuable information regarding the feasibility of an intervention and where additional training and support may be needed. To date, there has been limited evaluation of the implementation dimension for FREED. Here, we focus on evaluating one component of this dimension, namely, adherence to key aspects of the model during the multi-site FREED-Up study: the wait-time targets and the FREED care package. The wait-time targets for the engagement call (<48 h), assessment (<2 weeks) and treatment (<4 weeks) are advisory and aspirational rather than obligatory. Although wait-time targets can reduce the wait for care,[17,18] they can have unintended consequences, such as tunnel vision (i.e. a focus on the target to such an extent that other important features of healthcare are neglected).[19] Target implementation requires careful consideration and ongoing evaluation to ensure that they are challenging and clinically meaningful but also achievable.[20] The FREED care package tailors treatment to the needs of emerging adults with recent-onset eating disorders. In evaluations of FREED to date, it is unclear to what extent the care package adaptations were actually used and contributed toward the positive outcomes in the FREED-Up study. The care package adaptations measured in the FREED-Up study are outlined in Table 1.

The present study addressed three questions. First, how closely were the FREED wait-time targets for the engagement call, assessment and treatment adhered to, and did this vary across treatment group (FREED versus TAU) or diagnoses? Second, how frequently were the FREED care package adaptations used at assessment and during treatment, and did this use vary across diagnoses? Third, did the use of the FREED care package adaptations change throughout treatment?

Method

Study design and sample

This study is an analysis of patient journey record (PJR) data collected during the FREED-Up study. In brief, FREED-Up was a multi-site, quasi-experimental, pre–post study evaluating the impact of FREED compared with TAU on wait times, duration of untreated eating disorder and clinical outcomes (study findings are detailed elsewhere[10,13]). The study took place across four large specialist National Health Service (NHS) eating disorder outpatient services in England. Ethical approval was granted by the Camberwell St Giles Research Ethics Committee (16/LO/1882) and NHS Health Research Authority. The study was conducted in accordance with the ethical standards of relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

FREED patients ($n = 278$) were aged 16–25 years, had a primary diagnosis of an eating disorder (according to DSM-5 criteria) and an eating disorder illness duration of <3 years. Diagnosis and illness duration were determined by a structured interview based upon the Eating Disorder Diagnostic Scale[21] and the Eating Disorder Examination.[22] Illness duration was operationalised as the time since the onset of a diagnosable eating disorder. Exclusion criteria were need for immediate in-patient admission, a comorbid physical or mental disorder that should be the primary focus of treatment, and a severe intellectual disability or insufficient English language ability to complete study procedures. Written informed consent was obtained from all participants. The TAU comparison group ($n = 224$) were patients aged 16–25 years with an eating disorder illness duration of <3 years who were referred to the eating disorder services during the 1.5- to 2-year period before the implementation of FREED. Electronic patient records were screened to identify TAU patients that were of comparable age and illness duration to FREED patients. The present study largely focused on data from FREED patients with PJRs. However, wait-time data for TAU were included for comparison purposes.

Outcomes

Sample characteristics

Sociodemographic and Eating Disorder Examination Questionnaire (EDE-Q) data were collected at baseline. The EDE-Q[23] is a 36-item questionnaire measuring attitudinal and behavioural aspects of eating disorders in the past 28 days. Only the EDE-Q global score is reported here. The global score consists of 22-items covering the domains of dietary restraint, eating concerns, and concerns about weight and shape. Each item is rated on a seven-point scale for severity or frequency, with higher scores indicating greater eating disorder psychopathology.

Wait times

Wait times for the engagement call, assessment and treatment were defined as the time from when the referral was received by the service to when the patient received the engagement call, attended the assessment or attended the first treatment session. Estimates of the average wait times are reported elsewhere.[13] Here, count data of the number of patients seen within the FREED timeframes were used: ≤2 working days for the engagement call (i.e. calculation excluded weekends), ≤14 days for assessment and ≤28 days for treatment. Additionally, count data for the number of patients whose engagement call was initially attempted within 2 days (irrespective of whether it was successful or not), and the number of patients initially offered an assessment in ≤14 days or treatment in ≤28 days (regardless of whether the patient accepted the appointment or not), were included. Understanding waits that go beyond the initial timelines could prove informative for understanding any delays and for the development of the FREED model in the future. For this reason, count data for the number of patients seen within extended versions of the wait-time targets were also included, in the form of participants seen within 4 weeks (28 days) for assessment and 8 weeks (56 days) for treatment.

PJRs

Data from PJRs, developed for the study and completed by clinicians, were used here. PJRs documented the care received by FREED patients from referral up to 1 year. The form records service process data such as date of referral, screening call, and assessment and treatment sessions. It also details (a) the type of evidence-based out-patient psychological intervention provided (i.e. cognitive–behavioural therapy for eating disorders, the Maudsley Model of Anorexia Nervosa Treatment for Adults (MANTRA), guided self-help), for how many sessions; and (b) whether and when FREED-related care package adaptations were provided at assessment or treatment (see Table 1). The form also records any other additional out-patient appointments (e.g. dieticians sessions, medical reviews). Only the frequency of these additional appointments was reported, and not their content, as these were assumed to have a specific purpose (e.g. meal planning in dietician sessions or risk assessment in medical reviews).

Analysis

Statistical analyses were conducted with R programming software version 4.0.5 for MacOS.[24] The frequency (percentage) of adherence to the wait-time targets and the overall use of care package components at assessment and treatment are reported. Changes in the use of care package adaptations over time were also evaluated by calculating the frequency of use at different stages of treatment. For this, treatment was categorised into five stages: stage 1, sessions 1–5; stage 2, sessions 6–10; stage 3, sessions 11–15; stage 4, sessions 16–25 and stage 5, session 26 to end of treatment. For wait-time targets, the key focus was on adherence to the set FREED timelines (i.e. 48 h for engagement call, 2 weeks for assessment, 4 weeks for treatment) and adherence to an extended version of this timeline (i.e. 4 weeks for assessment and 8 weeks for treatment).

Chi-squared or Fisher's exact tests were used as appropriate, to evaluate whether there were any significant variations in wait-time adherence and care package use across diagnostic groups and treatment group. Moreover, we conducted an analysis of the differences in wait-time adherence between patients who did and did not receive FREED under optimal conditions. Patients with optimal conditions had minimal external delays (no gatekeeping or patient-related delays, such as patients taking a holiday before commencing treatment), no prior treatment and/or no transitions from another service. *Post hoc* analyses of the adjusted standardised residuals were used to determine which categories had substantially larger or smaller frequencies than expected, in the context of a significant omnibus test. In accordance with statistical conventions, a standardised residual of ±1.96 or more was considered as significant.[25] For continuous variables, a robust alternative to the *t*-test, the Yuen–Welch test T_y, based upon 10% trimmed means and Winsorized variances alongside percentile-t bootstrapping (2000 bootstrap samples), was used.[26]

Results

Sample characteristics

PJRs were available for 259 out of 278 (93%) FREED patients in the FREED-Up study. The demographics and clinical characteristics of the patients with PJRs are presented in Table 2. Patients with PJRs did not significantly differ from those without PJRs in age, gender, ethnicity, baseline EDE-Q global score and wait from referral to assessment or treatment (*P*-values varied from 0.16 to 1). Only data from patients with PJRs were included in the subsequent analyses.

Table 2 Baseline characteristics of FREED patients, with patient journey records

	Anorexia nervosa, *n* = 109	Bulimia nervosa/binge eating disorder, *n* = 69	Other specified feeding or eating disorder, *n* = 81	All, *N* = 259
Age, years, mean (s.d.)	19.88 (2.09)	20.62 (2.31)	20.22 (2.63)	20.19 (2.34)
Gender (female:male)	105:4	66:3	70:11	241:18
Ethnicity, *n* (%)				
White	75 (69)	36 (52)	59 (73)	170 (66)
Asian	10 (9)	8 (12)	7 (9)	25 (10)
Black	3 (3)	4 (6)	3 (4)	10 (4)
Mixed	6 (6)	10 (15)	3 (4)	19 (7)
Other/unknown	15 (14)	11 (16)	9 (11)	35 (14)
EDE-Q, mean (s.d.)	3.69 (1.43)	4.38 (0.90)	4.28 (1.07)	4.06 (1.23)

FREED, First Episode Rapid Early Intervention for Eating Disorders; EDE-Q, Eating Disorder Examination Questionnaire.

Table 3 Adherence to service wait-time targets for all patients and patients with optimal conditions

	FREED, all patients				FREED, patients with optimal conditions			
	Anorexia nervosa	Bulimia nervosa/binge eating disorder	Other specified feeding or eating disorder	All	Anorexia nervosa	Bulimia nervosa/binge eating disorder	Other specified feeding or eating disorder	All
Engagement call, *n* (%)								
Attempted ≤48 h	93/101 (92)	53/59 (90)	63/74 (85)	209/234 (89)	50/54 (93)	42/47 (89)	36/42 (86)	128/143 (90)
Received ≤48 h	53/100 (53)	32/66 (49)	36/75 (48)	121/241 (50)	26/55 (47)	24/50 (48)	20/42 (48)	70/147 (48)
Assessment, *n* (%)								
Offered ≤2 weeks	54/104 (52)	36/63 (57)	36/78 (46)	126/245 (51)	35/55 (64)	31/48 (65)	20/42 (48)	86/145 (59)
Received ≤2 weeks	50/109 (46)	30/69 (44)	30/81 (37)	110/259 (43)	30/55 (55)	28/55 (55)	17/43 (40)	75/149 (50)
Received ≤4 weeks[a]	78/109 (72)	49/69 (71)	61/81 (75)	188/259 (73)	45/55 (82)	43/51 (84)	38/43 (88)	126/149 (85)
Treatment, *n* (%)								
Offered ≤4 weeks	40/100 (40)	20/63 (32)	18/76 (24)	78/239 (33)	23/52 (44)	17/46 (37)	10/42 (24)	50/140 (36)
Received ≤4 weeks	28/108 (26)	15/69 (22)	17/79 (22)	60/256 (23)	17/54 (32)	14/51 (28)	10/41 (24)	41/146 (28)
Received ≤8 weeks[a]	64/108 (59)	41/69 (59)	42/79 (53)	147/256 (57)	40/54 (74)	35/51 (69)	26/41 (63)	101/146 (69)

All comparisons were made across diagnosis for all FREED patients and patients with optimal conditions. FREED, First Episode Rapid Early Intervention for Eating Disorders.
[a] Extended wait-time targets.

Wait-time target adherence

Adherence to FREED wait-time targets is shown in Table 3, along with the percentage of FREED patients who received an assessment and treatment according to extended (4 and 8 weeks, respectively) wait-time targets. The engagement call was initially attempted within 48 h for 89% of patients, with approximately 50% actually receiving the call within this time, irrespective of diagnosis (attempted: $\chi^2(2) = 2.18$, $P = 0.34$; received: $\chi^2(2) = 0.54$, $P = 0.76$) or whether they received FREED under optimal conditions (attempted: $\chi^2(1) = 0.01$, $P = 0.90$; received: $\chi^2(1) = 1.01$, $P = 0.31$).

Overall, 51% of FREED patients were offered an assessment within 2 weeks and 43% of FREED patients actually received their assessment within 2 weeks. This was substantially higher than the TAU patients ($\chi^2(1) = 30.06$, $P < 0.001$). Only 19% of TAU patients were seen for assessment within 2 weeks. Diagnostic group did not affect whether FREED patients were offered or seen within 2 weeks for assessment (offered: $\chi^2(2) = 1.70$, $P = 0.43$; received: $\chi^2(2) = 1.52$, $P = 0.47$). The number of patients waiting <2 weeks increased significantly for offered ($\chi^2(1) = 8.83$, $P < 0.01$) and attended ($\chi^2(1) = 8.88$, $P < 0.01$) assessments if patients were seen under optimal conditions.

A total of 33% of FREED patients were offered treatment within 4 weeks and 22% started treatment within 4 weeks. Again, this was substantially higher than the TAU group, with only 3% of this group starting treatment within 4 weeks ($\chi^2(1) = 30.10$, $P < 0.001$). Slightly more FREED patients with anorexia nervosa were offered treatment within 4 weeks, compared with bulimia nervosa/binge eating disorder and other specified feeding or eating disorder; however, this difference did not reach statistical significance (offered: $\chi^2(2) = 5.26$, $P = 0.07$). Diagnostic group did not affect the number of FREED patients attending treatment within 4 weeks (received: $\chi^2(2) = 0.65$, $P = 0.72$). Receiving FREED under optimal conditions significantly increased the likelihood of being seen within 4 weeks (received: $\chi^2(1) = 4.08$, $P = 0.04$), but did not significantly affect the number of patients offered treatment within this timeframe (offered: $\chi^2(1) = 1.46$, $P = 0.29$).

Extending the wait-time targets for received assessment and treatment to 4 and 8 weeks resulted in a considerable increase in adherence rates, to 73% and 58%, respectively. The increase in adherence was even more striking for offered assessment and treatment appointments (80% and 67%), or if patients with external delays were excluded (85% and 69%).

Care package adherence

Assessment

Assessment data were available for 241 out of 259 (93%) FREED patients with PJRs. As Table 4 shows, most domains of the FREED care package were well used at assessment, with the exception of attention to transitions. Highly used adaptations included a verbal discussion about the impact of eating disorders on brain, body and behaviour, followed by a verbal discussion of social media use, any discussion of or actual involvement of family/significant others, and the biologically malleability rationale for early intervention. The accompanying online or print resources were less frequently used. Any focus on dietary change occurred in approximately half of all assessments. In accordance with the FREED model, the most widely used components of dietary change at assessment were early nutritional goal setting and meal planning. In relation to significant other involvement, a discussion about involvement was the most frequently reported adaptation, followed by a significant other actually attending the assessment. The significant other most frequently attending the assessment were mothers (57%), followed by romantic partners (11%), parents (9%), siblings (7%), friends (7%) and fathers (5%).

There were significant differences in assessment adaptation use across diagnoses, as indicated in Table 4. Specifically, any focus on dietary change was less likely in bulimia nervosa/binge eating disorder relative to anorexia nervosa and other specified feeding or eating disorder ($\chi^2(2) = 5.84$, $P < 0.05$). Compared with patients with bulimia nervosa/binge eating disorder or other specified feeding or eating disorder, patients with anorexia nervosa were substantially more likely to receive the nutritional booklet ($\chi^2(2) = 7.12$, $P < 0.05$) and meal planning ($\chi^2(2) = 7.68$, $P < 0.05$) at assessment. Patients with anorexia nervosa were also more likely to have a significant other attend the assessment than patients with bulimia nervosa/binge eating disorder ($\chi^2(2) = 14.53$, $P < 0.001$). Finally, social media use was more frequently explored in other specified feeding or eating disorder, and less frequently explored in anorexia nervosa ($\chi^2(2) = 7.07$, $P < 0.05$).

Treatment

Treatment data were available for 251 out of 259 (97%) FREED patients with PJRs. The average number of treatment sessions was 18.09 (s.d. 11.70, range 0–57), with anorexia nervosa receiving more sessions (mean 22.83, s.d. 12.74), compared with bulimia nervosa/binge eating disorder (mean 14.10, s.d. 8.34) and other

Table 4 Percentage of patients receiving care package adaptations at assessment and treatment

	Anorexia nervosa		Bulimia nervosa/binge eating disorder		Other specified feeding or eating disorder		All	
Adaptations	Assessment, *n* = 102	Treatment, *n* = 106	Assessment, *n* = 64	Treatment, *n* = 68	Assessment, *n* = 75	Treatment, *n* = 77	Assessment, *n* = 241	Treatment, *n* = 251
Biological malleability rationale for early intervention	80%	49%**	67%	38%	83%	25%**	78%	39%
Psychoeducation on the impact of eating disorders								
Verbal discussion	88%	85%**	88%	96%	87%	96%	88%	91%
Leaflet or online resources given/reviewed	35%	28%	30%	35%	36%	35%	34%	32%
Dietary change								
Any focus on dietary change	58%	98%	41%*	100%	59%	99%	53%	99%
Nutrition booklet given/reviewed	25%**	40%	13%	38%	11%	52%	17%	43%
Meal plan given/reviewed	21%**	82%	6%	85%	11%	74%	14%	81%
Other nutrition information given/reviewed	11%	53%	6%	52%	8%	46%	9%	50%
Nutritional goal set/reviewed	23%	81%	9%	82%	23%	91%	19%	85%
Dietician appointment discussed/made	4%	45%**	2%	25%*	3%	29%	3%	35%
Dietician or dietetic group attended	Not applicable	63%***	Not applicable	25%**	Not applicable	26%***	Not applicable	41%
Family/carer/significant other involvement								
Any focus on significant other involvement	85%	90%***	72%	74%	78%	70%**	80%	79%
Discussed significant other involvement	63%	82%***	48%	63%	55%	56%**	56%	69%
Significant other attended assessment or treatment	40%**	55%***	13%***	25%*	33%	21%***	31%	36%
Discussed carer skills training	27%	39%***	16%	16%*	16%	14%**	20%	25%
Discussed carer support	33%	41%***	17%	21%	24%	12%***	26%	26%
Discussed family therapy	9%	23%	13%	18%	8%	13%	10%	18%
Family session attended	Not applicable	16%	Not applicable	9%	Not applicable	7%	Not applicable	11%
Discussed multi-family therapy	0%	1%	2%	3%	0%	1%	0.4%	2%
Exploration of social media and health-related app use								
Verbal discussion	78%*	53%	86%	62%	92%*	57%	84%	57%
Social media booklet/resources given/reviewed	35%	27%	31%	22%	28%	36%	32%	29%
Exploration of transitions								
Verbal discussion	27%	49%	34%	35%	36%	47%	32%	45%
University preparation group recommended	3%	22%	3%	10%	3%	12%	3%	16%
University preparation group attended	Not applicable	6%	Not applicable	0%	Not applicable	4%	Not applicable	4%

*$P < 0.05$, **$P < 0.01$, ***$P < 0.001$.

specified feeding or eating disorder (mean 15.03, s.d. 10.44). Patients with anorexia nervosa received cognitive–behavioural therapy for eating disorders (49%), MANTRA (48%), cognitive analytic therapy (6%) or family-based therapy (1%). Patients with bulimia nervosa/binge eating disorder received cognitive–behavioural therapy for eating disorders (83%), guided self-help (9%) or cognitive analytic therapy (3%). Patients with other specified feeding or eating disorder received cognitive–behavioural therapy for eating disorders (90%), MANTRA (6%), family-based therapy (3%) or cognitive analytic therapy (2%).

Table 4 shows the overall use of care package adaptations during treatment, and Fig. 1 depicts the change in adaptation use over time. Similar to assessment, psychoeducational discussions on the impact of eating disorders on brain, body and behaviour remained high throughout treatment. In contrast, the biological malleability rationale was less frequently used during treatment, relative to assessment. Social media and health-related app use was also less frequently explored in treatment relative to assessment, with most discussions occurring within the first five sessions of treatment (43% at stage 1 *v.* 21% at stage 5). The use of accompanying online and print resources remained low during treatment, with the exception of the nutrition booklet, which was used more during treatment relative to assessment. The most highly used domain of the care package during treatment was any focus on dietary change. Among the dietary change activities, nutritional goal setting and meal planning were the most frequently used. Approximately 40% of patients saw a dietician individually or in a group setting at some point during treatment.

Overall, any type of significant other involvement remained high during treatment. Discussions about significant other involvement and actual attendance were the most frequently used carer-related activities. Carer support and skills training were less frequently used. Most carer-related activities occurred within the first five sessions of treatment, with the exception of attendance, which peaked at stage 5. There were limited discussions of family and multi-family therapy, and family sessions taking place. Similar to assessment, mothers tended to be the person who most frequently attended the treatment sessions (47%), followed by parents, families or fathers (37%), and others (16%). Attention to transitions increased during treatment relative to assessment; however, discussions of or use of the university preparation groups remained low. Unlike most adaptations, use of attention to

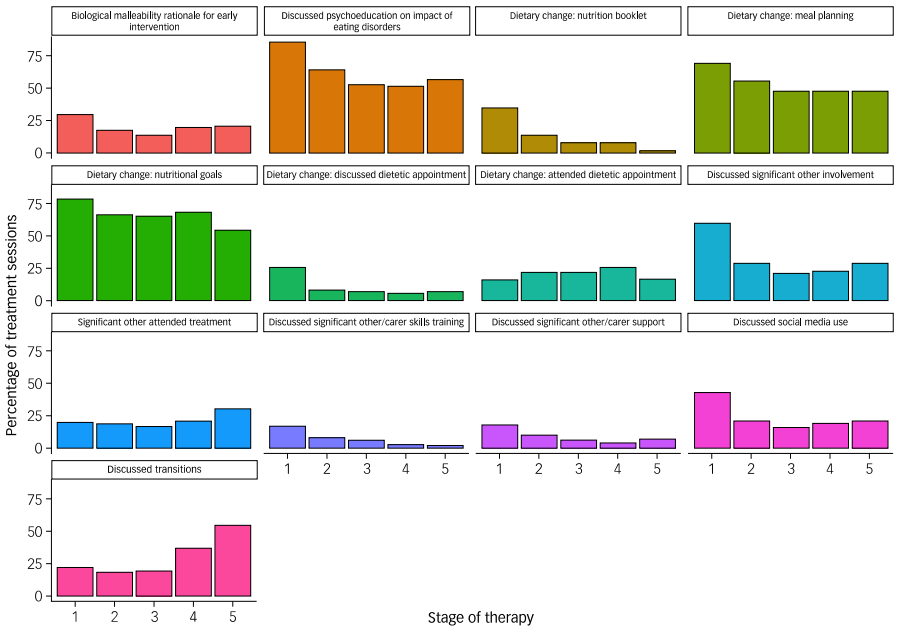

Fig. 1 The frequency (percentage of sessions) of use of FREED treatment adaptations across stages of therapy. Stage 1: sessions 1–5; stage 2: sessions 6–10; stage 3: sessions 11–15; stage 4: sessions 16–25; stage 5: session 26 to end of treatment. All *x*-axes represent stages 1–5 of therapy. FREED, First Episode Rapid Early Intervention for Eating Disorders.

transitions steadily increased over the course of treatment (22% at stage 1 *v.* 55% at stage 5).

As highlighted by the asterisks in Table 4, patients with anorexia nervosa were significantly more likely to have discussions around dietetic involvement ($\chi^2(2) = 9.34$, $P < 0.01$), attendance to dietetic appointments or groups ($\chi^2(2) = 35.86$, $P < 0.001$), any type of significant other involvement ($\chi^2(2) = 12.20$, $P < 0.01$), discussions around significant other involvement ($\chi^2(2) = 15.74$, $P < 0.001$), significant other attendance at treatment ($\chi^2(2) = 27.34$, $P < 0.001$), and discussions around carer skills training ($\chi^2(2) = 18.07$, $P < 0.001$) and support ($\chi^2(2) = 20.76$, $P < 0.001$). Moreover, patients with anorexia nervosa were more likely to receive the biological malleability rationale for early intervention during treatment ($\chi^2(2) = 11.19$, $P < 0.01$). In contrast, patients with bulimia nervosa/binge eating disorder and other specified feeding or eating disorder were significantly more likely to receive psychoeducation on the impact of eating disorders than anorexia nervosa ($\chi^2(2) = 9.20$, $P < 0.01$), but use was high across all groups.

Discussion

The process of translating new interventions into real-world clinical settings is complicated. The RE-AIM framework, a tool for enhancing the implementation and generalisability of interventions, was used to support the translation of FREED from a single-site research project to a wider initiative, with the aim of reaching as many young people as possible.[10] The purpose of this study was to evaluate the implementation dimension of the RE-AIM framework in the multi-site FREED-Up study. Specifically, we evaluated adherence to two key components of the model during the study, the wait-time targets and the care package, and whether adherence varied over time or across diagnostic and treatment group.

Wait-time targets

Most patients, irrespective of diagnosis, had their engagement call attempted within 48 h, with approximately half receiving the call within this timeframe. This suggests that although the 48 h target is a realistic goal for services, actually getting the patient on the telephone can be challenging. Patients frequently require multiple telephone calls, may not feel comfortable talking over the telephone, or may be ambivalent or refuse to engage with clinicians. Ambivalence can be particularly problematic in early-stage illness, where the negative physiological and psychosocial consequences of eating disorders may not be as apparent to the young person.[7] To overcome these barriers, FREED advocates for a flexible and proactive approach when engaging patients via their preferred method of contact (e.g. email, text). Specifically, if initial engagement attempts were unsuccessful, clinicians tried different methods of contact, with a higher number of attempts over a longer period of time than traditionally used in services (i.e. did more 'chasing'). Once contact was established, patients were also asked what method of contact they would prefer. This provides patients with a greater sense of autonomy in how they communicate with the service.

There was moderate adherence to the 2-week wait-time target for assessment, and low adherence to the 4-week wait-time target for treatment. However, the introduction of FREED led to large

increases in the number of patients seen within these timeframes. Double the number of patients were seen within 2 weeks for assessment, and almost ten times as many patients were seen within 4 weeks for treatment. Substantial differences were also evident between offered and attended appointments for those with and without external delays, suggesting that external and patient-related factors require special attention when addressing delays to care. Patient-related delays could be addressed through evidence-based public awareness campaigns[9] and the development of tools, apps and online resources to support emerging adults to seek help earlier. There was also a trend toward patients with anorexia nervosa being more likely to be offered treatment within 4 weeks.

This study provides an indication of the percentage of patients that teams can expect to see within the wait-time targets in real-world clinical settings: approximately 90% for attempted engagement calls in <48 h, approximately 60% for an assessment offered in <2 weeks, and approximately 30% for treatment offered in <4 weeks. This level of adherence was associated with significant reductions in wait times and duration of untreated eating disorder relative to TAU,[13] suggesting that these adherence rates are clinically meaningful irrespective of whether the targets were achieved or not. However, barriers to adherence need to be addressed in the future implementation of FREED. Targets should be challenging, but also realistically achievable with the available skills and resources. Unattainable targets can motivate in the short term, but eventually lead to frustration and stress.[27,28] Additional resources or an extension of the wait-time targets may therefore be warranted for some teams who are using FREED. Extending targets for assessment and treatment to 4 and 8 weeks, respectively, led to vast improvements in adherence rates, and may thus serve as achievable interim targets.

Our findings are timely, given recent commitments by NHS England to introduce access and wait-time standards for mental health services.[29] Wait-time standards of treatment within 4 weeks from referral for routine cases and 1 week for urgent cases have already been introduced in child and adolescent eating disorder services (CAEDS).[30] In the second quarter of 2020/21, 85% of referrals started urgent treatment within a week and 90% started routine treatment within 4 weeks. Approximately 65% were seen within these targets when they were first introduced in 2016.[31] Considerable and continued investment in CAEDS (an additional £30 million funding a year in the first instance, and a further £11 million in 2019/20 and 2020/21), rigorous performance monitoring and a national programme of training and support were vital to enable such vast improvements in target adherences. Our study provides the first evaluation of adherence to wait-time targets in adult eating disorder services, but with very limited government investment to date.[32,33] Of note, the CAEDS waiting time targets use initial assessment as the start of treatment, which is more lenient than our separate assessment and treatment targets. If we apply this more lenient criterion here, around 70% of our FREED-Up patients would have been seen within the target period.[13] These findings must be seen against the wider backdrop of resource constraint within adult eating disorder services in the NHS, something that is only likely to be exacerbated by the ongoing COVID-19 pandemic.[34]

Care package

Overall, the care package adaptations were well used during the FREED-Up study, increasing confidence in the extent to which this aspect of the model facilitates positive outcomes. The overarching domains were highly used at assessment or treatment, with the exception of attention to transitions, which was used in approximately half of all cases at either stage of care. This may be understandable, given that not all patients will experience transitions when in treatment, despite the relevance of transitions to the emerging adult developmental stage. Attention to transitions did, however, increase over the course of treatment, probably owing to the increased likelihood of transitions in later stages of treatment. Most other adaptations had a pattern of decreasing use over time, which is anticipated as once a topic is addressed it may not be necessary or appropriate to continue with it. Moreover, the therapeutic focus often becomes broader in the later stages of eating disorder treatment.[35,36] However, attendance by significant others peaks in the last stage of treatment. This could be because of the type of patients (mainly anorexia nervosa) receiving over 25 sessions of treatment, or because it takes time to persuade young people to involve significant others.

Any focus on dietary change and psychoeducation were the most used adaptations in treatment. This is reassuring, given that nutritional rehabilitation is central to any evidence-based eating disorder treatment. However, dietary change activities were only moderately used at assessment, which is disappointing because early nutritional change is one of the primary principles of FREED. Limited use of dietary change activities at assessment could be because of patient-related ambivalence, clinician reservations and/or time constraints in the assessment session.

Some components of the care package had low-to-moderate use, specifically, accompanying print/online resources, discussions of family or multi-family therapy, carer skills training and support, and the university preparation groups. These components may be considered as more supplementary than other aspects of the care package, or may only have been discussed if the eating disorder service could provide that facility. Increasingly, there is a trend toward not just online, but also app-based or interactive online materials, and revising FREED care package components accordingly may be helpful.

The use of care package adaptations varied across the diagnostic groups. Patients with anorexia nervosa were more likely than other diagnoses to receive a focus on early dietary change at assessment and dietetic involvement during treatment, as well as significant other involvement, particularly significant other attendance, support and skills training. Compared with bulimia nervosa/binge eating disorder, patients with other specified feeding or eating disorder also received a higher focus on early dietary change, possibly because of anorexia nervosa-type presentations within this group. Anorexia nervosa is typically (but not always) a more outwardly visible illness, which may influence the perceived need for early nutritional change and signify to others that the individual is unwell and requires support. In contrast, the shame and secrecy associated with other eating disorders may inhibit their disclosure, and therefore require more effort to encourage significant other involvement. This imbalance in provision of nutritional advice and support, and significant other involvement, needs to be considered further in the future implementation of FREED.

Limitations

There are several limitations to the current study that require consideration when interpreting the results. First, care package adaptation use was only assessed by clinician self-report. Although clinician-reported fidelity is efficient and non-intrusive, there are concerns regarding the accuracy of this method. Some studies find weak-to-moderate agreement between clinician and observer estimates.[37] Further validation of this mode of fidelity monitoring for FREED should be the focus of future research. Second, this study did not evaluate the way in which care package adaptations were used, i.e. the style and quality of delivery. Merely mentioning

social media versus having an in-depth discussion about it as a maintaining factor are likely to have profoundly different effects on patient outcomes, but would be noted down equally on the PJR. Limited information on the quality of delivery also prevented any meaningful evaluation of the impact of these adaptations on outcome. Third, the non-randomised design limits the causal conclusions that can be drawn regarding the impact of FREED on wait-times target adherence.[13] Finally, the data were collected within the context of a research study. It is unclear to what extent these adherence rates will generalise to settings outside of the study, or when FREED becomes 'business as usual'.

In conclusion, this study evaluated the implementation of FREED, with attention to waiting time and care package adherence. To the best of our knowledge, this is the first evaluation of adherence to wait-time targets in adult eating disorder services, providing a benchmark not only for FREED, but for what might be possible in NHS eating disorder services. Our findings suggest that adherence to the FREED wait-time targets can be an achievable goal, but require ongoing monitoring and refinement to ensure that the selected targets closely align with the baseline capacity of each team. This study also sheds light on how much and at what point FREED care package adaptations were used. There was moderate-to-high use of these adaptations that varied over the stages of treatment and between diagnoses. This supports the applicability of FREED, and suggests that care package adaptations are an important part of how FREED improves clinical outcomes. However, further validation of adherence, the quality of delivery and its impact on outcomes is needed. A better understanding of adherence to key components of the FREED model (and evidence-based treatments more generally) is essential for conclusions regarding what is integral to its effectiveness, and what aspects of the model may need to be adapted or refined.

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Data availability

The data that support the findings of this study are available from the corresponding author, U.S., upon reasonable request.

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Author contributions

The study was conceptualised and designed by U.S., K.L.A., V.A.M. and D.G. The authors M.F., A.A., K.L., K.L.A., R.B., G.B., A.B., F.C., M.F.-S., D.G., N.G., W.R.J., K.K., A.K., K.M., V.A.M., N.N., M.S, L.S. and U.S conducted the study, and collected and managed the data. Analysis and drafting of the manuscript was completed by K.L.R., with assistance from U.S. and K.L.A. All authors reviewed and contributed toward the final version of the manuscript.

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Declaration of interest

None.

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10.1.3 Chapter 6: A Delphi study to explore clinician and lived experience perspectives on setting priorities in eating disorder services

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A Delphi study to explore clinician and lived experience perspectives on setting priorities in eating disorder services

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Abstract

Background: Due to scarce resources and high demand, priority setting in mental health services is necessary and inevitable. To date, no study has examined priority setting in eating disorder (ED) services specifically. Here, we evaluate the level of consensus and perceived relative importance of factors used to determine patient prioritisation in ED services, amongst clinicians and individuals with lived experience (LE) of an ED.

Methods: A three round Delphi study and a ranking task were used to determine the level of consensus and importance. Consensus was defined as > 80% agreement or disagreement. Items that reached consensus for agreement were ranked in order of importance from most to least important. Participants were 50 ED clinicians and 60 LE individuals. Participant retention across rounds 2, 3, and 4 were 92%, 85%, and 79%, respectively.

Results: Over three iterative rounds, a total of 87 statements about patient prioritisation were rated on a 5-point Likert-scale of agreement. Twenty-three items reached consensus in the clinician panel and 20 items reached consensus in the LE panel. The pattern of responding was broadly similar across the panels. The three most important items in both panels were medical risk, overall severity, and physical health deteriorating quickly. Clinicians tended to place greater emphasis on physical risk and early intervention whereas the LE panel focused more on mental health and quality of life.

Conclusions: Eating disorder services tend to prioritise patients based upon medical risk and severity, and then by the order in which patients are referred. Our findings align in some respects with what is observed in services, but diverge in others (e.g., prioritising on quality of life), providing important novel insights into clinician and LE opinions on waiting list prioritisation in EDs. More research is warranted to validate these findings using multi-criterion decision techniques and observational methods. We hope these findings provide a foundation for future research and encourage evidence-based conversations around priority setting in ED services.

Keywords: Eating disorders, Priority setting, Delphi study, Waiting lists

Waiting lists and their management are a major issue for publicly funded mental health services [1]. Waiting can increase distress, risk, and negatively impact outcomes and functioning [2–4]. Several initiatives have been proposed to manage waiting lists including wait time targets, and structured prioritisation tools and procedures [5–7]. In England, wait-time targets were introduced in 2016 for early intervention in psychosis and child and adolescent

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eating disorder (ED) services. These targets, alongside additional funding and performance monitoring, led to substantially improvements in rapid access to care [6, 8]. There are now plans to introduce similar targets for all mental health services in England [9].

Despite such efforts, demand continues to exceed supply, making effective priority setting procedures necessary. There are, however, only a limited number of tools for priority setting in mental health, most of which are non-specific and for child and adolescent services [5, 10].

Eating disorders are serious, life-threatening illnesses that cause considerable distress and have long-term implications for physical, social, and occupational functioning [11]. The limited availability of specialist ED services in many countries, alongside the unique challenges presented by EDs (e.g., ambivalence, extreme physical risk), make ED patient prioritisation daunting, even for experienced clinicians. Prioritisation decisions can lead to ethical dilemmas where individuals are required to balance professional considerations and institutional constraints alongside personal and moral judgements about what is "right" [12, 13]. There are no explicit frameworks and limited research to support decision making for ED service prioritisation. A systematic search identified only one relevant study, where patients with either obesity or anorexia nervosa (AN) were prioritised based upon age, social class, and mental health history. Patients were more likely to be prioritised if they were younger, with a comorbid mental health problem and from a low social class [14].

Three ethical principles of distributive justice are frequently used to guide priority setting decisions in healthcare: egalitarianism, utilitarianism, and prioritarianism [15, 16]. Egalitarianism aims to reduce inequalities and equalise lifetime health across the population. It is based on the premise that everyone is equally deserving of a long and healthy life, and is associated with distributive mechanisms such as 'first-come first-served' or lottery allocation. The UK National Health Service (NHS) is fundamentally egalitarian, providing access to all regardless of disadvantage [17]. Utilitarianism aims to maximise the aggregate total benefit to the population by directing care to those that will benefit the most, often quantified using quality-adjusted life years. Finally, prioritarianism, which closely aligns with the 'rule of rescue' (the desire to save those facing death), gives priority to individuals who are the worst-off, sickest, or most in need of care [15, 16].

The National Institute for Health and Care Excellence [18] recommend that patients with EDs should be treated as soon as possible, especially individuals with or at risk of severe emaciation, suggesting a tendency towards prioritarianism. In line with this, ED services typically prioritise patients based upon clinical priority and urgency in the first instance (e.g., body mass index (BMI) < 15 kg/m^2, rapid weight loss) followed by the order in which they were referred. Prioritarianism is widespread within healthcare and even without formal prioritisation policies, patients with more severe and disabling presentations tend to be seen quicker [19–21]. Recent early intervention initiatives in EDs are more utilitarian, as they advocate for prioritising patients in early-stage illness, where treatment can be quicker and more effective [22–26]; however, see [27]. Utility and health gain are consistently valued in priority setting studies, sometimes emerging as the most important attribute (e.g., [28–30]). However, the importance of utilitarianism varies by context and the degree of health gained [31, 32]. Moreover, utilitarian approaches create complex ethical dilemmas where individuals with chronic illnesses and disabilities risk being disadvantaged [33].

Balancing equity, efficiency, and prioritarian goals is a challenge for developing transparent and fair priority setting procedures and policies in healthcare [34]. No single distributive theory is likely to ensure healthcare resources are allocated justly. Multi-allocation systems are often needed alongside evidence of value systems endorsed by the communities affected by such decisions [16]. An evaluation of clinician and patient perspectives, i.e., the people who are most directly involved in and affected by wait list decisions, would provide some much-needed insights and currency for discussion for what is a very challenging issue faced by ED services. To the best of our knowledge, there are no priority setting studies assessing the views of ED clinicians or individuals with lived experience (LE) of an ED. Here, we describe a Delphi study in which the collective opinions of clinicians and individuals with LE were sought to evaluate the level of consensus (agreement/disagreement) and perceived relative importance of factors used to determine patient prioritisation in ED services. The Delphi method is particularly well-suited for areas where there is limited research, no set standard, and for determining collective community-based values to facilitate decision making [35].

Methods

Study design

The Delphi method is a systematic approach for determining the level of consensus or dissensus (widespread dissent) among 'experts' on a given topic. The term 'expert' refers to someone who has professional or personal experience and knowledge on a topic [36]. A Delphi study typically involves multiple iterative rounds of questionnaires whereby feedback on responses is provided and items are re-rated considering this feedback. Participants are anonymous and rate items independently. This technique allows participants to reflect on their own

position, and answer/amend answers without pressure from domineering group members [37, 38].

Participants

Participants were recruited online via social media platforms (Twitter, Facebook, Instagram), and professional organisations and networks (including the British Eating Disorder Society, First Episode Rapid Early Intervention for EDs Network, and Eating Disorder Specialist Interest Groups). Expertise was defined as: (1) a practicing healthcare professional with at least one year's worth of experience in EDs for the clinician panel; or (2) a current or previous diagnosis of Diagnostic and Statistical Manual of Mental Disorders-5 ED for the LE panel. A total of 110 individuals (50 clinicians and 60 individuals with LE) took part in the study. The demographic characteristics are outlined in Table 1.

Table 1 Participant characteristics

	Clinician (*n* = 50)		**Lived experience (*n* = 60)**
Age in years (*M, SD*)	41.24 (10.47)	Age in years (*M, SD*)	29.78 (2.33)
Gender (*n*, %)		Gender (*n*, %)	
Female	41 (82)	Female	53 (88)
Male	9 (18)	Male	6 (10)
Non-binary	0	Non-binary	1 (2)
Ethnicity (*n*, %)		Ethnicity (*n*, %)	
White/White British	47 (94)	White/White British	56 (93)
Asian/Asian British	1 (2)	Asian/Asian British	3 (5)
Black/Black British	1 (2)	Black/Black British	0
Mixed/Multiple or other ethnic background	1 (2)	Mixed/Multiple or other ethnic background	1 (2)
Profession (*n*, %)		Diagnosis[a] (*n*, %)	
Psychiatrist	9 (18)	Anorexia nervosa	48 (80)
Clinical Psychologist	9 (18)	Bulimia nervosa	12 (20)
Psychiatric nurse	14 (28)	Binge eating disorder	7 (12)
Psychotherapist	6 (12)	OSFED/Atypical/Purging disorder	21 (35)
Occupational therapist	4 (8)	ARFID	5 (8)
Dietician	1 (2)	Comorbid neurodevelopmental disorder	8 (13)
Other	7 (14)	Other comorbid disorder (including mood, anxiety, and personality disorder)	46 (77)
Years working in EDs (*n*, %)		Time since ED onset in years (*M, SD*)	11.48 (8.31)
< 4 years	16 (32)	Recovered (*n*, %)	
5–15 years	28 (56)	Yes	18 (30)
> 16 years	6 (12)	Partially	16 (27)
		No	24 (40)
		Unsure	2 (3)
Work settings[a] (*n*, %)		Treatment setting[a] (*n*, %)	
Inpatient	35 (70)	Inpatient	24 (40)
Day patient	20 (40)	Day patient	22 (37)
Outpatient	25 (50)	Outpatient	55 (92)
Public	48 (96)	Public	56 (93)
Private	11 (22)	Private	28 (47)
CAMHS/CAEDS	20 (40)	CAMHS/CAEDS	23 (38)
AMHS/AEDS	45 (90)	AMHS/AEDS	46 (77)
All-age service (0–25 years)	4 (8)	All-age service (0–25 years)	8 (13)

Note. OSFED other specified feeding and eating disorder, *ARFID* avoidant restrictive food intake disorder, *ED* eating disorder, *CAMHS* child and adolescent mental health service, *CAEDS* child and adolescent eating disorder service, *AMHS* adult mental health service, *AEDS* adult eating disorder service

[a] Participants can endorse multiple categories

Procedure

The study involved a three round Delphi (Round 1–3) and a ranking task (Round 4) distributed via the cloud-based online survey platform Qualtrics, Provo, UT, Version April-August 2021 [39]. A modified Delphi method was used for this study, where the first round consisted of structured statements rather than open-ended questions. Modified Delphi methods are frequently used to minimise participant burden or provide a *seed list* derived from the literature [35, 40–42]. For the current study, this approach was selected to ensure that opinions were gathered on specific clinical (e.g., duration of illness) and non-clinical (e.g., socio-economic status) factors identified as important for priority setting in EDs specifically and health care more broadly. This approach was also selected to reduce the number of rounds and therefore time commitment required to take part in the study. The questionnaire for Round 1 was developed by conducting a systematic literature review followed by consultation and pre-testing with ED clinicians and individuals with LE (see Additional File 1 for details). Data collection occurred between April and August 2021. Each round took place over a 4 to 6-week period. Participants remained anonymous to one another throughout the study.

Participants contacted the researchers (KR and IW) by email to express interest in taking part. Once eligibility was confirmed, a link to the consent form and first survey was provided. In Round 1–3, participants were presented with statements about patient prioritisation (e.g., "Patients should be prioritised if they have a diagnosis of anorexia nervosa") and asked to rate each statement on a 5-point Likert scale ranging from 'Strongly disagree' (1) to 'Strongly agree' (5). Participants were asked to rate the items in relation to priority in ED services and for what their answer would be in most situations. The order of the statements was randomised for each participant. An optional comment box was provided alongside each statement where participants could provide feedback on language/wording, difficulties in understanding, or reasons why they gave a specific rating. The number of prioritisation statements per round are outlined in Fig. 1. In Round 1, an additional open-ended question was included at the end of the survey to identify new prioritisation factors. In Rounds 2 and 3, statements that were re-rated from previous rounds were accompanied

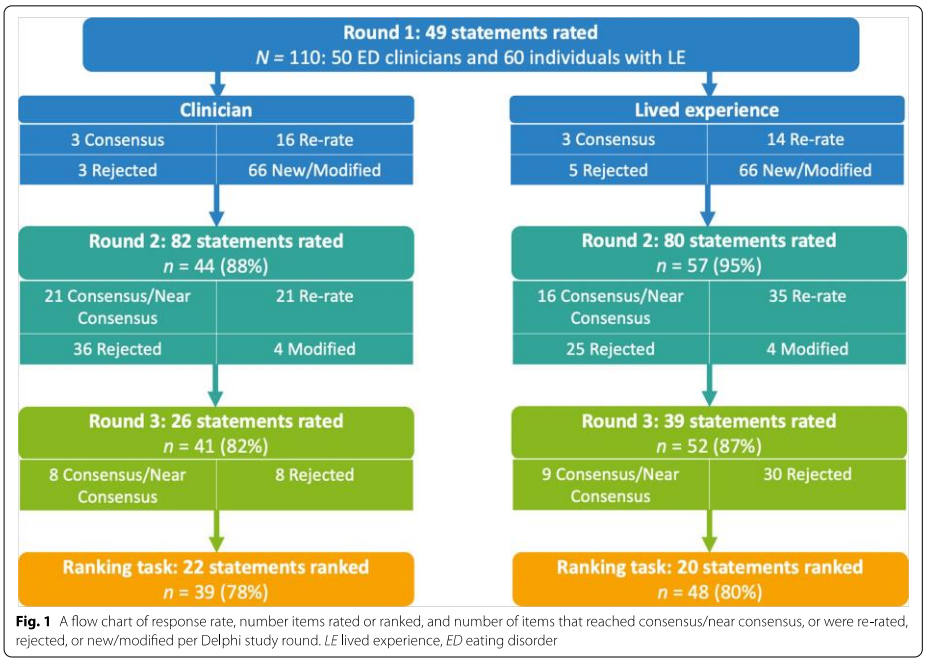

Fig. 1 A flow chart of response rate, number items rated or ranked, and number of items that reached consensus/near consensus, or were re-rated, rejected, or new/modified per Delphi study round. *LE* lived experience, *ED* eating disorder

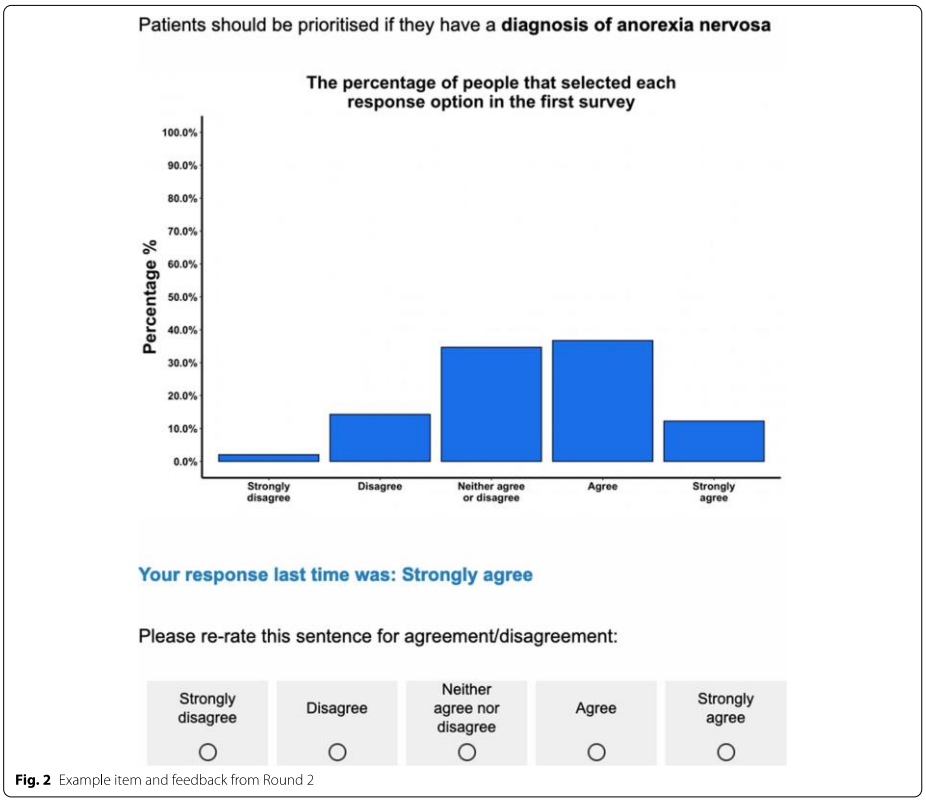

Fig. 2 Example item and feedback from Round 2

by a histogram showing the distribution of responses and the participant's own response from the previous round (see example in Fig. 2). Round 4 involved a ranking task, whereby participants were presented with the list of statements that reached consensus for agreement for their panel. Participants were asked to select the 10 most important items and rank them in order of importance from most to least important. Participants could also provide feedback on the ranking task in an optional comment box.

Analysis

The qualitative responses for each round were independently analysed by two of the study authors (KR and IW) using an inductive content analysis method [43]. Open coding was used to identify new prioritisation factors and issues in questionnaire completion. The coding was completed in NVivo (Version 12) [44]. The results of the independent coding process were discussed by the two researchers who conducted the coding (KR and IW). During these discussions, the coders compared and contrasted codes to identify similarities and differences, and based upon these discussions added, modified, or removed items from each survey accordingly. All modifications and new items were integrated into clinician and LE surveys regardless of which group the qualitative feedback came from. The other study authors (KA and US) provided feedback on proposed changes and resolved discrepancies between the coders. The number of modified or new items per round are outlined in Fig. 1.

Frequencies were calculated in SPSS (version 27) and used to determine the percentage of consensus for each item. Consensus was calculated separately for each panel. In Rounds 1 and 2, items were sorted into three

categories: 'consensus', 're-rate', and 'rejected'. 'Consensus' and 'rejected' items were removed and 're-rate' items were re-administered. Consensus was defined as items that obtained ≥ 80% agreement (or disagreement) [40, 41]. Items were categorised as re-rate if they were: (1) changed due to qualitative feedback; (2) rated once and had 40–79% consensus; (3) rated twice with substantial alterations before the second rating and had a 40–79% consensus; (4) rated twice with minor alterations before the second rating, a 40–79% consensus, and > 5% change towards consensus. In Round 1, there were some inconsistencies between qualitative and quantitative responses (e.g., participants explicitly saying that they did not think the factor should be used and then rating 'neither agree nor disagree'). These items were also re-administered in Round 2 alongside additional guidance to support participants with decision making. Items were categorised as 'rejected' if they: (1) had a consensus < 40%; (2) were rated twice with no alterations and had a consensus < 80%; (3) were rated twice with minor alterations, had a consensus < 80%, and < 5% change towards consensus. Following Round 3, final frequencies and consensus levels were calculated, as well as the mean score and standard deviation for each panel. The items in the final list were categorised as reaching consensus (≥ 80% rated disagree or agree), near-consensus (70–79% rated disagree or agree), or no consensus (< 70% rated disagree or agree). Items were grouped according to broader themes and the qualitative data coded to identify common rationales for ratings.

Analysis for the ranking task involved assigning a value of 10 (most important) to 1 (least important) to the items included in the list and a value of 0 to all other items. Mean rank was calculated for each item and used to signify the overall position of the item in the list. The percentage of participants who mentioned an item in their top 10 was also calculated and used to break ties when mean ranks were equal. Kendall's coefficient of concordance (W) was calculated to evaluate the degree of consensus among respondents on the ranking task. The interpretation of W is as follows: weak < 0.3, moderate < 0.7, and strong ≥ 0.7. W was calculated using the 'irr' package in R programming software [45].

Results

Round 1–3: Delphi

The response rate per round, and the number of items rated/ranked, reached consensus/near consensus, re-rated, rejected, or new/modified per round are depicted in Fig. 1. The items that reached consensus for agreement or disagreement and their mean rating and level of consensus are outlined in Table 2. The full list of 87 statements, and their mean rating, and level of consensus are provided in Additional File 2.

Diagnosis

None of the ED diagnoses nor comorbid diagnoses reached consensus/near consensus in either panel. Common reasons for ratings were the belief that all ED diagnoses are equally serious and disruptive, and other factors, such as, impact on functioning, severity, and risk also needed to be considered. However, AN, bulimia nervosa (BN), and comorbidities were perceived by some respondents as elevating complexity and acute risk and therefore warranting prioritisation. Some perceived comorbidities as the responsibility of other services and/or requiring adapted treatment.

Duration of eating disorder

An illness duration of < 6 months, < 1 year, and < 3 years reached consensus/near consensus for agreement in the clinician panel, but not the LE panel. Despite differences in ratings, qualitative comments were remarkably similar across the panels. There were numerous comments regarding the importance of early intervention for improving outcomes and increasing the likelihood of recovery. However, there were concerns regarding limited resources/capacity and the detrimental impact on individuals with longer illnesses (i.e., this group being deprioritised/excluded/given up on). Severity, risk, and willingness to engage were thought to take precedence over illness duration.

Body weight and behavioural ED symptoms

For weight-related, binge eating, and compensatory ED symptoms, greater frequency/severity were associated with a higher level of agreement. Consensus was reached for very low weight, quickly losing weight (irrespective of starting weight), extreme dietary restriction, low and unstable weight, and if a diabetic patient was purposefully restricting/omitting their insulin. Any ED symptom in isolation, especially weight, was generally perceived as insufficient for priority setting. An understanding of severity, risk, distress, willingness to engage, and functioning were required for decision-making. Many were opposed to weight-based prioritisation as it can result in patients feeling they are 'not sick enough' to 'deserve' treatment.

Illness severity

Overall severity considering psychological, physical, and social aspects reached consensus for agreement in both panels. It was important, particularly for LE experts, that severity incorporated all aspects of severity and not just physical or weight-related metrics. The dissensus for mild ED symptoms stems from the belief that intervening

Table 2 Patient prioritisation statements that reached consensus for agreement or disagreement and their mean rating and level of consensus

Items	Clinician				Lived experience			
Patients should be prioritised	**Mean (*SD*)**	**Disagree (%)**	**Agree (%)**	**Consensus achieved**	**Mean (*SD*)**	**Disagree (%)**	**Agree (%)**	**Consensus achieved**
Duration of Eating Disorder								
…if their eating disorder developed less than 6 months ago	**3.95 (0.83)**	**9%**	**82%**	**Yes**	3.14 (1.05)	22%	34%	No
…if their eating disorder developed less than 1 year ago	**4.00 (0.60)**	**7%**	**80%**	**Yes**	3.32 (0.91)	16%	46%	No
Body Weight and Behavioural Eating Disorder Symptoms								
Weight-related								
…if they are a very low weight	**4.25 (0.72)**	**2%**	**89%**	**Yes**	**3.93 (0.87)**	**9%**	**82%**	**Yes**
…if they are quickly losing weight (irrespective of their starting weight)	**4.30 (0.67)**	**2%**	**93%**	**Yes**	**4.18 (0.83)**	**5%**	**84%**	**Yes**
…if their weight is unstable (changing a lot) and they are underweight	**3.93 (0.70)**	**5%**	**89%**	**Yes**	3.86 (0.78)	8%	78%	Near
Compensatory								
…if they have reduced the amount or type of food they are eating (dietary restriction) at an extreme level (e.g., very little dietary intake almost every day)	**4.25 (0.62)**	**0%**	**91%**	**Yes**	**4.07 (0.76)**	**5%**	**86%**	**Yes**
…if they have diabetes and are purposefully restricting their insulin to lose weight (diabulimia)	**4.36 (0.75)**	**2%**	**89%**	**Yes**	**4.29 (0.80)**	**5%**	**89%**	**Yes**
Illness Severity								
…based upon the severity of their illness (taking into account psychological, physical, and social severity)	**4.50 (0.76)**	**2%**	**95%**	**Yes**	**4.13 (0.79)**	**5%**	**86%**	**Yes**
Individual Treatment Factors								
…if they have recently had treatment (within the last 6 months) but are now relapsing	**3.77 (0.57)**	**5%**	**80%**	**Yes**	3.84 (0.90)	11%	73%	Near
…if they are transitioning between child and adult services	**4.25 (0.69)**	**2%**	**91%**	**Yes**	3.68 (0.89)	10%	60%	No
…if they are transitioning between inpatient and community services	**4.27 (0.76)**	**5%**	**91%**	**Yes**	**4.20 (0.88)**	**4%**	**84%**	**Yes**
Service-related Factors								
….on a 'first-come first-serve' basis (people will receive treatment in the order in which they are referred, i.e., if Patient X's referral arrived before Patient Y's, Patient X will be seen first)	**2.05 (0.94)**	**80%**	**9%**	**Yes**[a]	2.61 (1.14)	55%	29%	No
…if their treatment was inappropriate, limited, or of poor quality (e.g., only re-feeding with limited therapeutic input)	3.63 (0.48)	0%	63%	No	**4.02 (0.87)**	**8%**	**80%**	**Yes**
…if they have been waiting a long time for treatment	**3.90 (0.59)**	**3%**	**83%**	**Yes**	**4.14 (0.73)**	**2%**	**84%**	**Yes**
Physical Health Factors								
…if they are at significant medical risk (e.g., very slow or irregular heartbeat, abnormal blood results)	**4.73 (0.49)**	**0%**	**98%**	**Yes**	**4.72 (0.64)**	**2%**	**93%**	**Yes**
…if their physical health is getting worse quickly (any metric of physical health)	**4.47 (0.74)**	**2%**	**98%**	**Yes**	**4.23 (0.81)**	**5%**	**93%**	**Yes**
…if they are experiencing medical problems because of their eating disorder (e.g., osteoporosis, fertility problems, bowel problems, problems with their heart or circulation)	**4.14 (0.79)**	**4%**	**84%**	**Yes**	**4.40 (0.72)**	**3%**	**93%**	**Yes**

Table 2 (continued)

Items	Clinician				Lived experience			
Patients should be prioritised	**Mean (*SD*)**	**Disagree (%)**	**Agree (%)**	**Consensus achieved**	**Mean (*SD*)**	**Disagree (%)**	**Agree (%)**	**Consensus achieved**
…if they have a major physical disorder (e.g., cardiovascular disease, diabetes, cancer) that is made worse by their eating disorder	**4.20 (0.59)**	**0%**	**91%**	**Yes**	**4.07 (0.71)**	**5%**	**89%**	**Yes**
…if they are pregnant	**4.52 (0.58)**	**0%**	**96%**	**Yes**	**4.25 (0.82)**	**5%**	**87%**	**Yes**
…if they are experiencing malnutrition (as indicated by blood tests and irrespective of weight)	**4.27 (0.66)**	**0%**	**89%**	**Yes**	**4.18 (0.81)**	**5%**	**86%**	**Yes**
Mental Health Factors								
…if they are constantly having intrusive eating disorder related thoughts and feelings (e.g., thoughts about their body shape and weight, fear of putting on weight)	3.20 (0.88)	2%	48%	No	**4.14 (0.73)**	**2%**	**84%**	**Yes**
…if they are thinking or planning to end their life (suicide risk)	3.60 (1.05)	11%	55%	No	**4.30 (1.08)**	**9%**	**88%**	**Yes**
…if their mental health and well-being is getting worse quickly (any metric of mental health)	**4.09 (0.64)**	**0%**	**84%**	**Yes**	**4.29 (0.76)**	**4%**	**95%**	**Yes**
…if they have impaired or poor mental capacity/decision making because of their eating disorder	**4.23 (0.64)**	**0%**	**89%**	**Yes**	**4.11 (0.76)**	**4%**	**84%**	**Yes**
Life and Social Factors								
Individual Characteristics and Circumstances								
…if they are less than 12 years old	**4.23 (0.71)**	**2%**	**89%**	**Yes**	**4.30 (0.85)**	**5%**	**88%**	**Yes**
…if they are less than 18 years old	**3.98 (0.70)**	**5%**	**84%**	**Yes**	3.55 (0.89)	13%	59%	No
…if their eating disorder is negatively impacting their quality of life (e.g., stops them from doing leisure activities, impacts how they interact with other people or makes it difficult to work/study, financial problems)	3.68 (0.92)	15%	75%	Near	**4.14 (0.72)**	**4%**	**88%**	**Yes**

Note. Items in bold reached consensus. *SD* standard deviation

[a] Consensus for disagreement

early will prevent worsening, but services do not have the capacity to do this and need to prioritise higher severity patients.

Individual treatment factors

For items related to patients' treatment history and responsiveness, consensus/near consensus was reached for prioritising patients who were relapsing after recent treatment or transitioning between inpatient and community, child and adult services, or to services in a different area. These were perceived as critical points in treatment where continuity of care is needed to prevent relapse and promote sustained recovery. Although the panels tended to disagree with prioritising those who had several rounds of previous treatment, there were comments on the need to not give up on this patient group. One item was removed after Round 1, as there were many comments about benefit from treatment being difficult, if not, impossible to objectively define, measure, or predict.

Service-related factors

Service-related factors that reached consensus for agreement were waiting a long time for treatment in both panels and if the patient had received inappropriate, limited, or poor-quality care in the LE panel. Waiting a long time for treatment was perceived as detrimental for engagement and outcomes. Clinicians reached consensus for disagreement (i.e., to not use) for a 'first-come first-served' approach with a trend towards disagreeing in the LE panel. Participants felt that with resource constraints, patients should be prioritised according to severity, risk, and clinical need. Dissensus in prioritising patients who found it difficult to get a referral was due to the rating depending upon why the patient found it difficult.

Physical health factors

All physical health-related items reached consensus for agreement across both panels. The items in this category had some of the highest levels of consensus. The high consensus was due to the imminent threat to health and life associated with these items and in the case of pregnancy, the risk to mother and baby.

Mental health factors

Mental health getting worse quickly, impaired/poor cognitive capacity and decision-making, and high distress reached consensus/near consensus in both panels. Constantly having intrusive ED thoughts, suicide risk, and escalating non-suicidal self-injury reached consensus/near consensus in the LE panel. Some perceived intrusive ED thoughts as something experienced by all patients, and suicide risk and self-harm as the responsibility of other services. There were also frequent comments for the need to ensure that the mental health aspects of the ED should be considered equally important, if not more, than physical health. Motivation reached near consensus in the clinician panel as treatment can be more successful and shorter for motivated patients. However, others felt that lack of motivation is an indicator of severity, and that developing motivation is a key part of the treatment process.

Life and social factors

Both panels reached consensus for agreement for prioritising patients < 12 years old, and clinicians reached consensus for patients < 18 years old. Early intervention to prevent the ED becoming entrenched/chronic/persistent and minimising the impact on the person's development were the most frequently cited reasons for ratings. However, some felt that early intervention should be based on illness duration rather than age, and that younger patients already had separate services and better support systems. The ED negatively impacting quality of life reached consensus/near consensus for agreement in both panels. However, some felt that this item would apply to all patients and would therefore be difficult to prioritise. There was a trend towards disagreeing with prioritising based upon income, ethnicity, and if the patient was starting university soon, or had a small window of time before they moved. Having or living in a household with a high income reached near consensus for disagreement in both panels and only having a small window of time before they move somewhere else reached near consensus for disagreement in the LE panel. There were numerous comments on how ethnicity and income should not impact priority, and many felt that it was more important to support the patient in establishing care in the new area for university or a small window before they moved. Moreover, many felt that housing issues (e.g., homelessness) would need to be addressed before ED treatment. Of the social context items, having very little social support was the only item that reached near consensus for agreement. Social issues were perceived as increasing stress, but outside the remit of ED services.

Round 4: Ranking

The results of the ranking task and W are outlined in Table 3 in rank order from most to least important. The ranks align closely with final consensus ratings. Medical risk, overall severity, and rapid physical deterioration were unanimously identified as the most important factors for priority setting in both panels. For clinicians, most of the other 'top 10' items were associated with heightened physiological risk (e.g., very low weight, rapidly losing weight), except for being < 12 years old and transitioning between inpatient and community. Clinicians commented on how physical risk needs to be addressed before psychological work can begin. Although physical risk items were prominent in the LE panel 'top 10', there was a greater emphasis on mental health factors, with items such as rapid mental deterioration, quality of life, suicide risk, and intrusive ED thoughts included. Participants with LE indicated that they felt uncomfortable placing physical risk items high on the list because mental health/emotional components are such an important and often neglected aspect of care that drives the ED, but also recognised that with limited resources physical risk needs to be a priority.

Discussion

The aim of this study was to evaluate the degree of consensus and perceived relative importance of factors for priority setting decisions in ED services for two key stakeholder groups: clinicians and individuals with LE of an ED. To our knowledge, this is the first evaluation of clinician and LE opinions on priority setting in ED services. Despite differences in 'expertise', the pattern of responding was similar across the panels, with some notable differences. This is in accordance with previous Delphi studies in EDs and mental health more broadly, whereby consumers and professionals converge in their consensus [35, 40].

Medical risk, overall severity, and rapid physical deterioration were ranked as the top three factors for determining priority in clinician and LE panels. There was a strong view, particularly amongst LE participants, that severity should incorporate social and psychological aspects, not only physical. Most of the other items included in the 'top 10' for both panels were associated with a high degree of physical or mental risk (e.g., pregnancy, diabulimia, suicide). Clinicians included more

Table 3 Rank order of the top 10 items from most to least important

Clinician				Lived experience			
Rank and item	**Mean rank (*SD*)**	**% Rated in top 10**	**% Consensus**	**Rank and item**	**Mean rank (*SD*)**	**% Rated in top 10**	**% Consensus**
1.**if they are at significant medical risk (e.g., very slow or irregular heartbeat, abnormal blood results)**	**6.13 (3.96)**	**80%**	**98%**	1.**if they are at significant medical risk (e.g., very slow or irregular heartbeat, abnormal blood results)**	**6.17 (3.66)**	**81%**	**93%**
2.**based upon the severity of their illness (taking into account psychological, physical, and social severity)**	**4.13 (4.42)**	**56%**	**95%**	2.**based upon the severity of their illness (taking into account psychological, physical, and social severity)**	**5.98 (3.68)**	**83%**	**86%**
3.**if their physical health is getting worse quickly (any metric of physical health)**	**3.95 (4.08)**	**51%**	**98%**	3.**if their physical health is getting worse quickly (any metric of physical health)**	**3.38 (3.47)**	**63%**	**93%**
4.if they are pregnant	3.54 (3.24)	64%	96%	4.if their mental health and well-being is getting worse quickly (any metric of mental health)	3.31 (3.42)	60%	95%
5.if they have diabetes and are purposefully restricting their insulin to lose weight (diabulimia)	2.97 (3.20)	59%	89%	5.if they have a major physical disorder (e.g., cardiovascular disease, diabetes, cancer) that is made worse by their eating disorder	3.00 (3.31)	54%	89%
6.if they are transitioning between inpatient and community services	2.97 (3.50)	56%	91%	6.if their eating disorder is negatively impacting their quality of life (e.g., stops them from doing leisure activities, impacts how they interact with other people or makes it difficult to work/study, financial problems)	3.00 (3.59)	52%	88%
7.if they are quickly losing weight (irrespective of their starting weight)	2.69 (3.29)	46%	93%	7.if they are less than 12 years old	2.98 (3.52)	52%	88%
8.if they have reduced the amount or type of food they are eating (dietary restriction) at an extreme level (e.g., very little dietary intake almost every day)	2.54 (3.32)	41%	91%	8.if they are pregnant	2.90 (3.81)	44%	87%
9.if they are a very low weight	2.41 (3.27)	44%	89%	9.if they are thinking or planning to end their life (suicide risk)	2.85 (3.80)	42%	88%
10.if they are less than 12 years old	1.97 (3.07)	41%	89%	10.if they are constantly having intrusive eating disorder related thoughts and feelings (e.g., thoughts about their body shape and weight, fear of putting on weight)	2.69 (3.52)	54%	84%
	W	.14		*W*	.11		

Note. Items in bold obtained the same rank across participant groups. *SD* standard deviation, *W* Kendall's coefficient or concordance

physical risk and weight-related items, whereas the LE panel included mental health-related items, which were absent from the clinician's 'top 10'. Severity, physical health factors, and mental health risk items also obtained some of the highest levels of consensus across both panels. Moreover, consensus for weight and behavioural ED symptoms was greatest for the most severe/frequent and risky symptoms (e.g., vomiting 5 or more times per week). Qualitative comments also suggest that judgements throughout the study were largely influenced by the degree of risk or severity. Severity and acute risk are consistently identified as important for priority setting decisions in physical and mental healthcare and align with prioritarian principles of distributive justice. There appears to be a drive to treat those who are suffering the most or facing death [20, 32, 46]. These findings are consistent with ED clinical guidelines (i.e., 18) and practice, where the urgency of the patient's condition tends to take precedence.

Some authors argue that preferentially allocating resources to those who are most unwell unjustly ignores those who will be worse later if left untreated, particularly when the most unwell will only benefit slightly [16]. The use of utilitarian principles such as this to justify choices were evident in the current study, albeit to a lesser extent than prioritarian (e.g., "*Early intervention is key, however, if another patient is deemed at greater physical & mental risk then this needs to be evaluated*"). This is in line with evidence demonstrating that people are generally willing to sacrifice some aggregate health gains to give priority to the most severely ill [20]. Utilitarian rationales were provided for many items, including transitions, age, illness duration, mild ED symptoms, and motivation.

Participants described transitions as poorly managed and crucial points where priority and continuity of care could promote sustained recovery and prevent relapse. The transition between inpatient and community services reached consensus in both panels and was included in the clinician's 'top 10', underscoring its importance in priority setting. The transition between child and adult services and different areas reached consensus/near consensus in the clinician panel. Transitions have long been perceived as particularly challenging in EDs requiring careful coordination [47, 48]. The dangers of poorly managed transitions are evident in high profile cases, such as the death of 19-year-old Averil Hart in the UK [49].

An age of < 12 years old reached consensus and was included in the 'top 10' for both panels, suggesting a strong preference for prioritising the very young. Clinicians also reached consensus for patients < 18 years old. Comments suggest that younger patients were prioritised because of the belief that early intervention can lead to better outcomes and minimise the impact on development. This rationale did not hold as strongly for adolescents and emerging adults, despite evidence suggesting that a similar rationale may also be applicable to these age groups (e.g., [50, 51]). These findings largely align with recent efforts to ensure early access to ED treatment for children and young people [52] and broader healthcare priority setting literature, where younger patients tend to be prioritised for treatment [31, 32].

The consensus for illness duration items was notably different in clinician and LE panels. Only the clinician panel reached consensus/near consensus for prioritising patients with an illness duration of < 6 months, < 1 year, and < 3 years. The lack of endorsement of these items in the LE panel is likely due to concerns regarding the exclusion and neglect of patients with longer illness durations. Personal experiences of exclusion or difficulties accessing appropriate treatment may increase the strength of this concern in the LE panel. Indeed, clinical and research observations suggest that individuals with severe and enduring EDs are less likely to be in active ED treatment (for a myriad of reasons) [53]. Moreover, despite evidence in support of early intervention, predicting who will respond to what treatment and when, remains limited in EDs [54, 55]. Predictive uncertainty such as this makes the application of utilitarian principles difficult, leading to more egalitarian responses [56]. The LE panel appear to have a stronger preference for equity over utility in these circumstances. Conversely, clinical experience and observing the impact of early intervention on patients could strengthen ratings in the opposite direction. First Episode Rapid Early Intervention for EDs (FREED) is an early intervention service for emerging adults (16–25 years old) with recent onset EDs (< 3 years duration). FREED functions as a 'service-within-a-service', i.e., a smaller sub-group of clinicians in an evidence-based ED service are responsible for delivering FREED. FREED aims to reduce service-related delays to care and adapts evidence-based ED treatments to the needs of emerging adults in early-stage illness [23, 57]. Qualitative data gathered during the national scaling of FREED in England generally did not find that early intervention had a detrimental impact on non-FREED patients, if anything, the benefits were perceived as extending beyond FREED patients. Specifically, increased service efficiencies and the rapid response to treatment observed in FREED patients were seen as freeing up resources for non-FREED patients. Some of the materials and principles of FREED (e.g., attention to social media use) were also beneficial to non-FREED patients. Observing the impact of FREED on patients was noted as a key driver for using the model [Richards, Allen, & Schmidt, unpublished data]. Clinical experience of rationing treatment and considering the long-term implications of prioritisation decisions

may also contribute towards the clinician preference for utility over equity.

The notably higher consensus for mental health and quality of life items in the LE panel and the inclusion of these items in the 'top 10' as well as the exclusion of weight-related items could, in part, stem from a drive to promote equity and parity of esteem between physical and mental health in ED services. There were numerous qualitative comments to support this: "*there needs to be equivalence of physical and mental symptoms*" or "*it should be based on the distress the person is experiencing and the impact it has on their life—NOT their weight*". Mental health impacts were also described as the most problematic for patients and as the main driver of the ED. Physical health metrics, especially weight, have historically been used as one of the defining features of gaining access to ED services [58–60]. In recent years, there have been widespread campaigns (e.g., dump the scales [61]) and explicit instructions in clinical guidelines to not use weight or BMI as the only means of determining access treatment [18]. However, as this study and others demonstrate, the disparity between the physical and mental health components of the ED remains. More work is needed to consider the mental health and quality of life aspects of the ED in service access and priority setting.

Egalitarian principles were evident for diagnosis and broader life and social context. Many perceived all ED diagnoses as equally serious and debilitating, and that priority should be based on severity/risk/distress/impact on life rather than diagnosis. There was also limited endorsement of items related to the patient's life and social context. Age, the impact of the ED on quality of life, and very limited social support were considered as pertinent factors. However, ethnicity, income, going to university, and a small window of time before moving somewhere else were deemed less relevant. Egalitarian rationales were provided for these items (i.e., individuals should not be disadvantaged by personal circumstances) and parallel findings in the wider priority setting literature [31, 32]. However, a "pure" equity approach was not sought. The 'first-come first-served' method was the only item to reach consensus for disagreement (i.e., should not be used). The blindness of this approach to factors that would be inappropriate to ignore (e.g., medical risk) led to the rejection of this item. Participants did however comment on how they wished that priority could be determined in this way (e.g., "*Whilst I would like this to be the case there will be some people who are more urgently in need*").

Clinical implications

One of the key findings of this study is the greater emphasis on mental health symptoms and quality of life in the LE panel. There were strong opinions against prioritising solely based upon physical metrics, especially weight-related criteria. Physical risk is currently one of the main prioritisation factors used in services, and as pressure escalates, the focus on physical risk becomes greater. It is important to raise awareness of and address this over-reliance on physical metrics within ED services. Given current pressures on services, prioritising based upon anything else can feel like a luxury, however, these findings indicate that this is not a luxury and that the whole person needs to be kept in mind as much as possible. The development of an ED prioritisation tool to facilitate discussions around priority setting and to ensure that all aspects of the person are considered could help address this imbalance. Prioritisation tools incorporating measures of risk, symptoms, psychosocial functioning, and the impact on the person's life have been used to promote transparent and equitable priority setting in other areas of healthcare (e.g., [62]). There will be a degree of subjectivity in quantifying certain metrics (e.g., quality of life), as every patient is different, and some may lack insight into their ED symptoms and the impact of these on their daily functioning. However, this does not necessarily mean that these features cannot be meaningfully considered alongside other metrics to inform patient priority decisions. Such prioritisation tools could also be used as an indicator for the condition of services (e.g., the discrepancy between demand and capacity) and stimulate discussions with service commissioners and policy makers around adequately funding services.

Another important discrepancy between clinician and LE opinions was the greater endorsement of prioritising patients in early-stage illness in the clinician panel. Participants with LE did not perceive patients in early-stage illness as a priority, largely because they did not want other patient groups to be disadvantaged. To be considered as a priority, early intervention therefore needs to be adequately resourced to ensure that it does not negatively impact the care of others. In addition to effective priority setting procedures, there is also a pressing need to address capacity issues and pressures on specialist ED services. Promising avenues to relieve pressure on services include increasing the reach of effective prevention programs [63], implementing task-sharing interventions (e.g., peer support, guided self-help) [64], and more initiatives for the early identification and treatment of EDs in educational and primary care settings [65, 66].

Strengths and limitations

A major strength of this study was that we were able to recruit a large sample with high retention across the rounds. Participants also provided detailed responses to the optional comment boxes and open-ended questions,

which provided insights into why people gave specific ratings and increased the validity of our conclusions. The inclusion of both clinician and LE opinions from across the UK was another strength of this study. However, there are several limitations that need to be considered. First, the recruitment method, i.e., self-selection and largely through social media, may have introduced a bias in the sample. Only those who were motivated and active on social media would have the opportunity to participate. Participant motivation for taking part was not assessed and may have biased the results. Diagnoses and recovery/illness status were also not verified with standardised criteria or clinical interviews and may have impacted how participants responded to the questionnaires. Additionally, while the inclusion criteria were deliberately broad to increase diversity of experiences, one year's worth of experience in EDs may not have been sufficient to develop clinical 'expertise' in this area. Moreover, although the sample was diverse in some respects (e.g., profession), it was not in others (e.g., ethnicity). Caution is therefore needed when generalising these findings, particularly for items that relate to under-represented characteristics. Second, as comment boxes and open-ended questions were optional, not everyone provided a rationale for their choice. This makes the qualitative data on why participants chose certain options "incomplete". Finally, participants expressed difficulties in rating and ranking items. Prioritisation decisions are highly complex and difficult, and single item ratings vastly underestimate this complexity. In practice, decisions are rarely made on a single factor and dimensions of the decision-making process were not included in this study. For example, one issue, which was raised by participants in their qualitative feedback, was the lack of specification on precisely what type of intervention or care the patient was being prioritised for. Decision making is likely to differ for prioritising patients for physical monitoring/observations/care versus psychosocial interventions. There was also overlap between factors which complicated the decision making in the ranking task. While this study provides an important starting point for discussions around priority setting in EDs, more research is needed utilising more ecologically valid techniques. Additionally, an in-depth ethnographic study using observations of priority setting behaviour alongside interviews with clinicians and patients would be a useful addition to this evidence-base.

Conclusions

Priority setting decisions are ethically complex, difficult, and can have considerable consequences for those involved. Yet, research to guide discussions and support clinical decision making in ED services is absent. EDs are unique as they carry considerable physical and psychological risks that need to be considered during priority setting decisions. Our findings demonstrate that clinicians and individuals with LE place physical and psychological risk and severity (prioritarianism) at the top of determining priority in ED services. Followed by a mix of utilitarian and egalitarian approaches with clinicians placing greater emphasis on the former and individuals with LE on the latter. While further testing of these findings is warranted in more heterogenous samples and with more ecologically valid designs, we hope that this paper will stimulate discussion for this important topic. Now more than ever, there is a pressing need for research to support conversations regarding fair, just, and transparent priority setting in EDs.

Abbreviations

AEDS: Adult eating disorder service; AMHS: Adult mental health service; AN: Anorexia nervosa; ARFID: Avoidant/restrictive food intake disorder; BMI: Body mass index; BN: Bulimia nervosa; CAEDS: Child and adolescent eating disorder service; CAMHS: Child and adolescent mental health service; ED: Eating disorder; FREED: First Episode Rapid Early Intervention for Eating Disorders; LE: Lived experience; NHS: National Health Service; OCD: Obsessive compulsive disorder.

Supplementary Information

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Additional file 1. Round 1 questionnaire development.

Additional file 2: Table 1. Fulllist of all patient prioritisation statements and their mean rating and levelof consensus.

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Authors' contributions

KR contributed towards the conception and design, acquisition of the data, analysis and interpretation of the data, and drafted the manuscript. IW contributed to the acquisition of the data, and analysis and interpretation of the data. KA contributed towards the conception and design, and interpretation of the data. US contributed towards the conception and design, and interpretation of the data. All authors read, substantially revised, and approved the manuscript.

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Availability of data and materials

The datasets generated and/or analysed during the current study are not publicly available due to the conditions of consent and to protect the anonymity of participants but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was conducted in accordance with ethical standards of relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. The study received ethical approval from King's College London Research Ethics Committee for Psychiatry, Nursing and Midwifery (reference: HR/DP-20/21–21302). Informed consent was obtained from all participants using an electronic information sheet and consent form.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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10.1.4 Chapter 7: National roll-out of early intervention for eating disorders: Process and clinical outcomes from first episode rapid early intervention for eating disorders

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EARLY INTERVENTION IN THE REAL WORLD

WILEY

National roll-out of early intervention for eating disorders: Process and clinical outcomes from first episode rapid early intervention for eating disorders

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Abstract

Aim: First Episode Rapid Early Intervention for Eating Disorders (FREED) is an early intervention model for young people with recent-onset eating disorders (ED). Promising results from a previous single-centre study and a four-centre study (FREED-Up) have led to the rapid national scaling of FREED to ED services in England (FREED-4-All). Our aim was to evaluate duration of an untreated ED (DUED), wait time target adherence, and clinical outcomes in FREED-4-All and compare these to the (benchmark) findings of the earlier FREED-Up study.

Method: FREED services submit de-identified data to the central FREED team quarterly. The current study covers the period between September 2018 and September 2021. This FREED-4-All dataset includes 2473 patients. These were compared to 278 patients from the FREED-Up study.

Results: DUED was substantially shorter in the FREED-4-All dataset relative to the FREED-Up study (15 vs. 18 months). Adherence to the wait time targets was comparable in both cohorts (~85% of engagement calls attempted in <2 days, ~50%–60% of assessments offered in <14 days, ~40% of treatment offered in <28 days). Patients in the FREED-4-All dataset experienced significant improvements in ED and general psychological symptoms from pre- to post-treatment that were comparable to the FREED-Up study. These findings should be interpreted cautiously as only 6% of FREED-4-All patients had post-treatment data.

Conclusions: Data from the FREED-4-All evaluation suggest that FREED is replicating at scale. However, these data are flawed, uncertain, proximate, and sparse and should therefore be used carefully alongside other evidence and clinical experience to inform decision making.

KEYWORDS
early medical intervention, feeding and eating disorders, mental health services, National Health Services, young adult

1 | INTRODUCTION

Eating disorders (ED) are costly and complex illnesses with serious physical, psychiatric, and psychosocial consequences (Treasure et al., 2020). Adolescence and emerging adulthood are a peak risk period for the onset of EDs as well as a key developmental phase where people acquire the skills, knowledge, and confidence to flourish in adult roles (Potterton et al., 2020; Solmi et al., 2021). Evidence suggests that earlier, faster, and easier access to specialist ED services can improve outcomes and limit the deleterious effects of EDs on health, quality of life and functioning (Ambwani et al., 2020; Treasure et al., 2015).

Despite evidence in support of early intervention, there is typically a protracted period before patients start treatment. The average duration of an untreated ED (DUED) is alarmingly long, ranging from 2.5 years in anorexia nervosa (AN) to 6 years in binge eating disorder (BED) (Austin et al., 2020). First Episode Rapid Early Intervention for EDs (FREED) is one of few evidence-based initiatives aimed at facilitating early intervention and reducing DUED.

FREED is an early intervention service for emerging adults (16–25-year-olds) with recent onset EDs (<3 years duration) (Schmidt et al., 2016). The central aims of the model are to reduce wait times and DUED and provide treatment which is tailored to illness stage and developmental needs. The FREED service model and care package have been described in detail elsewhere (Allen et al., 2020; Brown et al., 2018; Richards et al., 2021). Of relevance to the current study, the service model includes an engagement call provided within 48-hours of referral, wait time targets of 2-weeks for assessment and 4-weeks for treatment, and a 'FREED Tracker' to monitor and manage patient throughput.

The FREED model has been evaluated in a single-centre pilot study and a multi-site FREED-Upscaled (FREED-Up) study (Austin et al., 2021; Brown et al., 2018; Flynn et al., 2020; McClelland et al., 2018). Both studies employed quasi-experimental pre-post designs comparing FREED patients to a historical treatment-as-usual (TAU) group. The TAU group were patients of a similar age and illness duration seen in the services immediately before FREED was introduced. FREED-Up took place across four ED services in England. Compared to TAU, FREED patients waited significantly less time for assessment (3–3.5 weeks less) and treatment (10–12 weeks less) and had a notably shorter DUED (2–3 months shorter). FREED also led to significant improvements in treatment uptake and clinical outcomes. Weight recovery for patients with AN was substantially higher in FREED compared to TAU (17%–18% vs. 53%–59%). The proportion of FREED patients requiring day- or in-patient treatment was also lower than TAU, which resulted in cost savings (FREED: £8781 vs. TAU: £13 604).

FREED therefore has demonstrated utility in improving outcomes and reducing wait times, DUED, and treatment costs in settings beyond where it was initially developed. Assessing the impact of an intervention at scale and comparing it to results from earlier research studies is essential to determine whether the intervention can replicate desired effects and warrants further scaling, or whether more refinement is needed. Since the FREED-Up study, the aim has been to continue to scale and implement FREED to reach as many young people as possible (Allen et al., 2020). The term FREED-4-All has been used to describe this implementation phase. In April 2020, FREED became part of the Academic Health Sciences Network's national adoption and spread programme (Academic Health Science Network, 2020). To date, FREED has been scaled to 32 ED services in England (64% of all eligible services) with more interested or preparing to launch in 2022. Most of this scaling has occurred during the COVID-19 pandemic, which had a profound effect on the normal functioning of ED services. Decreases in capacity, coupled with a marked increase in the acuity and volume of referrals, pushed already underfunded ED teams to their limits and continue to provide major challenges (Solmi et al., 2021).

The ongoing evaluation of FREED was built into the model's operational processes. Specifically, the data collected on the FREED Tracker are used locally and nationally for monitoring and evaluation purposes (Allen et al., 2020). Routinely collected data such as this are invariably flawed (missing or incorrectly entered), uncertain (differences in how items are understood and rated), proximate (proxy for what is of interest), and sparse (low volumes of data for subgroups) (FUPS; Wolpert et al., 2016). Caution is therefore needed when using this type of data because the missingness and uncertainty around the data introduce unknown and unmeasurable biases. Nonetheless, FUPS data remain valuable and are, in many circumstances, all that is available. Three key principles have been proposed for analysing and working with FUPS data: (1) acknowledgement of their limited validity, reliability, and generalisability; (2) transparency and simplicity in analytical procedure; (3) considering the data in the context of all other available information (Wolpert & Rutter, 2018). The FUPS framework was used to guide the analysis and interpretation in the current study.

The aim of this study was to evaluate DUED, adherence to FREED wait time targets, and clinical outcomes in the FREED-4-All cohort and compare these to the FREED-Up study to examine whether the findings are replicated at scale.

2 | METHOD

2.1 | Study design and sample

This study involved a descriptive, pre-post, and comparative evaluation of routinely collected data (FREED-4-All) gathered from 30 ED services implementing FREED in the National Health Service (NHS) in England. The data cover the period between September 2018 and September 2021. At the outset, there were three services providing data, this increased to five in 2019, eight in 2020, and 30 in 2021. The sample consists of 2473 FREED patients (16–25-year-olds with an ED diagnosis of less than 3 years duration) referred to the pathway during this period. The FREED-4-All data were compared to data collected during the FREED-Up study. Only data from the FREED (not TAU) patients and demographic and clinical outcomes at baseline, and 6- and 12-months

from the FREED-Up study were used. Diagnostic information was also taken from clinician rather than researcher estimates (unlike previous FREED-Up papers [Austin et al., 2021; Flynn et al., 2020]).

2.2 | FREED-4-All: Data collection procedure

An Excel spreadsheet (the "FREED Tracker") was used to collect FREED-4-All data at each site. ED and psychological outcomes were gathered pre-treatment and post-treatment, but the precise timing was flexible so that sites could fit the data collection into their local processes. On average, the post-treatment measures were collected 6-months after the referral was received. De-identified Trackers were submitted quarterly to the central FREED team who provided performance and data quality feedback.

All sites sign an Operational Agreement prior to data collection and sharing. Written informed consent is not required. Instead, patients are informed about the data sharing via an information sheet and/or other fair processing notices and given the opportunity to opt out of the data sharing, without any implications for treatment. The justification is that the data offers significant benefits to the evaluation of FREED without requiring personal patient information, and complies with the General Data Protection Regulation (Information Commissioner's Office, 2018).

2.3 | Outcomes

2.3.1 | Engagement call, assessment, and treatment wait times and target adherence

Wait times for the engagement call, assessment, and treatment were defined as the time in days (including/excluding weekends) from when the referral was received to when the engagement call was first attempted (regardless of whether it was successful) and completed, the assessment was first offered (regardless of whether it took place) and attended, and when the first treatment session was offered (regardless of whether it took place) and attended. Adherence to FREED wait time targets was calculated as the number of patients who had their engagement call attempted and completed in ≤2 days, were offered or received an assessment in ≤14 days and were offered or received treatment in ≤28 days.

2.3.2 | Eating disorder examination questionnaire (EDE-Q; Fairburn & Beglin, 2008)

A 28-item self-report questionnaire measuring ED symptomatology in the past 28 days. Only the global score is reported and consists of 22-items measuring attitudinal and behavioural aspects of EDs. Each item is rated on a 7-point scale (0–6) for severity/frequency, with higher scores indicating greater severity/frequency. A global score of ≥2.8 is suggestive of clinically significant ED symptoms (Mond et al., 2008).

2.3.3 | Binge eating, vomiting, and laxative episodes per month

Within the FREED-Up study, binge eating, vomiting, and laxative episodes per month were measured using the behavioural items on the EDE-Q. For the FREED-4-All dataset, clinicians were able to decide how they collected this information locally.

2.3.4 | Body mass index (BMI)

BMI was calculated by dividing the patient's weight by the square of their height (kg/m^2). A BMI of >18.5 kg/m^2 is considered as not underweight in current ED classifications.

2.3.5 | Clinical outcomes in routine Evaluation-10/outcome measure (CORE-10/OM; Barkham et al., 2013)

CORE-OM and CORE-10 are global measures of psychological distress. CORE-10 is made up of 10-items drawn from the CORE-OM, which is a 34-item measure. Each item is rated on a 5-point scale ranging from 0 (*not at all*) to 4 (*most of the time*).

2.4 | Data analysis

The analysis was conducted using R programming software version 4.0.5 (R Core Team, 2021). The primary focus of the analysis was descriptive. Means and standard deviations were calculated for continuous variables, including age at referral, DUED, wait in days (including and excluding weekends) for the engagement call, assessment, and treatment, and the EDE-Q, binge eating/vomiting/laxative episodes per month, BMI, and CORE-10/OM at pre-treatment and post-treatment for FREED-4-All and pre-treatment, 6-months, and 12-months for FREED-Up. Frequencies were calculated for count data, namely, diagnosis, adherence to FREED wait time targets, and the proportion of patients above the EDE-Q clinical cut-off (≥2.8) and above the underweight BMI criteria (>18.5 kg/m^2) at pre- and post-treatment, 6-months, and 12-months. Missing cases were omitted from percentage calculations to enable a comparison of proportions between FREED-Up and FREED-4-All.

Secondary to this descriptive evaluation, differences between FREED-Up and FREED-4-All were tested using robust statistical procedures. For continuous variables, a robust *t*-test (Yuen-Welch test; T_y) using 20% trimmed means, Winsorized variances, and percentile *t*-bootstrapping (2000 bootstrapped samples) from 'WRS2' package were used (Mair & Wilcox, 2020). A robust explanatory measure of effect size (ξ) was also used for continuous variables. Values of .15, .35, and .50 correspond to small, medium, and large effects, respectively (Wilcox & Tian, 2011). Chi-squared or Fisher's exact tests were used to investigate differences in categorical variables and adjusted

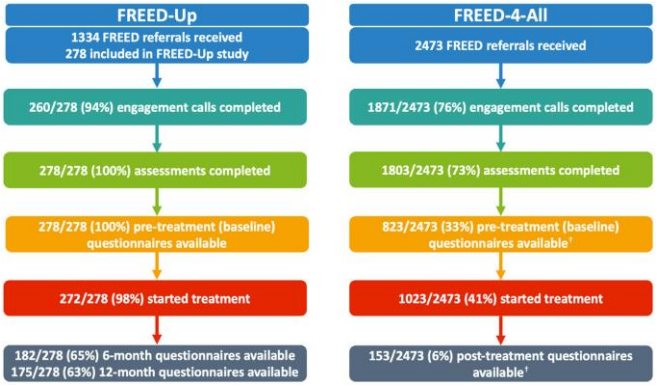

FIGURE 1 Flow diagram of patients that completed/started each component of the FREED pathway and the number of pre- and post-treatment questionnaires in FREED-Up and FREED-4-All cohort. †The number of pre- and post-treatment questionnaires in the FREED-4-All cohort varied by questionnaire. The value in the diagram is the highest estimate. A detailed overview of the missing data per questionnaire is available in the Appendix

TABLE 1 Baseline patient characteristics of FREED-Up and FREED-4-All cohorts

	FREED-Up ($N = 278$)	FREED-4-All ($N = 2473$)	T_y or χ^2	p	ξ
Age: *M* (*SD*)	20.19 (2.39) [$n = 278$]	19.87 (2.29) [$n = 2458$]	−2.00	.04*	.09
Diagnosis: % (*n*)			33.76	<.001***	
Anorexia nervosa	35% (96/278)*	46% (819/1779)			
Bulimia nervosa	27% (75/278)	25% (450/1779)			
Binge eating disorder	1% (3/278)*	4% (67/1779)			
Avoidant/restrictive food intake disorder	0% (0/278)	1% (22/1779)			
Other specified feeding or eating disorder	37% (104/278)***	24% (421/1779)			
Duration of untreated eating disorder: *M* (*SD*)	17.85 (10.38) [$n = 267$]	14.86 (9.73) [$n = 1136$]	−3.96	< .001***	.22

Note: Missing data cases were not included in the percentage calculations. The asterixis denoting significance for each diagnosis relate to the degree to which the observed frequencies significantly differed from expected frequency for each cell as indicated by the adjusted standardized residuals.
Abbreviations: FREED, first episode rapid early intervention for eating disorders.
*$p < .05$. ***$p < .001$.

standardized residuals were used to determine which categories had substantially larger or smaller frequencies than expected.

Two sets of multi-level models were used to evaluate change in clinical outcomes from pre- to post-treatment. The first set evaluated changes in clinical outcomes in each FREED cohort separately. For FREED-Up, changes between baseline and 6-months, and baseline and 12-months were tested. For FREED-4-All, changes between pre- and post-treatment were tested. The second set of models evaluated differences in change between FREED-Up and FREED-4-All. The FREED-4-All post-treatment time point was compared to the 6-month (Time 2) and 12-month (Time 3) time points in FREED-Up. The models were fit using 'nlme' package and Bliese's procedure (Bliese, 2016; Pinheiro et al., 2021).

2.5 | Missing data

An analysis of missing data was conducted to understand patterns of missingness. A detailed overview of missing data per variable is available in the Appendix (Table A1). Numerous reasons for missingness were identified, including patients not returning questionnaires and insufficient capacity. The missing data are unlikely to be missing at completely random, although some might be. Given the missing data, it was deemed inappropriate to use baseline variables to evaluate or control for missingness.

3 | RESULTS

3.1 | Patient characteristics

A flow diagram of the number of patients from intake to start of treatment and the amount of questionnaire data available at each time point are provided in Figure 1. Demographic and clinical characteristics are presented in Table 1. Only 20% ($n = 503$) of FREED-4-All patients were referred before the onset of COVID-19 in the UK. On average, FREED-4-All patients were significantly younger and had a shorter DUED than FREED-Up patients. They were substantially more likely to be diagnosed with AN or BED and less likely to be diagnosed with Other Specified Feeding and Eating Disorder (OSFED). Closer

inspection of the FREED-4-All data over time suggests that the proportion of AN cases increased from 34% in September 2018–February 2020 (before the pandemic) to 46% in March 2020–September 2021 (during the pandemic).

3.2 | Waiting times

Adherence to the wait time targets and the average wait for the engagement call, assessment, and treatment are outlined in Table 2. Adherence to the targets were similar in FREED-Up and FREED-4-All, except for offered assessment, which was moderately higher in FREED-Up. The average wait for receiving an engagement call was significantly shorter for FREED-4-All patients, whereas the average wait for offered and attended assessment and offered treatment were substantially shorter for FREED-Up patients.

3.3 | Clinical outcomes

Only about a third of FREED-4-All patients had baseline clinical outcomes (n = 823/2473; 33%) and only 6% (n = 153/2473) had post-treatment data (see Figure 1). These findings must therefore be regarded as preliminary and used alongside other information. The mean scores and difference in clinical outcomes pre- and post-treatment are outlined in Table 3, and multi-level models evaluating the impact of time and FREED cohort on clinical outcomes are outlined in Table 4. FREED led to significant improvements in all clinical outcomes from Time 1 to Time 2 and Time 1 to Time 3 in both cohorts, except for laxative episodes in FREED-4-All. The only significant time by FREED cohort interaction effect was for EDE-Q for the Time 1 versus Time 2 contrast, suggesting significantly higher reductions in EDE-Q for FREED-4-All patients at Time 2. The proportion of patients scoring above the EDE-Q clinical cut-off (≥2.8) and BMI threshold

TABLE 2 Adherence to the wait time targets and mean wait in days for the 48-hour engagement call, assessment, and treatment for FREED-Up and FREED-4-All cohorts

		FREED-Up		FREED-4-All				
		Adherence to target: % (n)	Mean wait in days (SD)	Adherence to target: % (n)	Mean wait in days (SD)	T_y	p	ξ
Engagement call								
Attempted <48-hours	Excluding weekends	86% (216/251)	2.23 (6.33)	85% (1650/1953)	1.87 (5.18)	1.06	.27	.05
	Including weekends	75% (188/251)	3.09 (8.86)	75% (1474/1953)	2.55 (7.28)	0.52	.62	.03
Completed <48-hours	Excluding weekends	65% (170/260)	4.02 (7.17)	73% (1373/1870)	2.69 (5.81)	−3.61	< .001***	.19
	Including weekends	56% (145/260)	5.54 (10.06)	64% (1199/1870)	3.68 (8.14)	−3.55	< .001***	.18
Assessment								
Offered <2-weeks	Excluding weekends	63% (168/265)*	16.40 (16.53)	51% (1005/1970)	21.72 (21.98)	5.32	< .001***	.21
	Including weekends	46% (123/265)*	23.07 (23.09)	39% (760/1970)	30.54 (30.75)	5.29	< .001***	.21
Completed <2-weeks	Excluding weekends	56% (155/277)	18.38 (17.45)	48% (871/1799)	23.09 (23.76)	3.59	< .001***	.15
	Including weekends	40% (111/277)	25.83 (24.38)	36% (644/1799)	32.46 (33.23)	3.68	< .001***	.16
Treatment								
Offered <4-weeks	Excluding weekends	44% (114/257)	38.02 (26.73)	42% (475/1120)	46.58 (40.84)	2.09	.02*	.10
	Including weekends	26% (66/257)	53.25 (57.13)	26% (294/1120)	65.15 (57.13)	2.06	.04*	.11
Started <4-weeks	Excluding weekends	38% (103/271)	41.13 (28.38)	39% (402/1021)	47.71 (39.88)	1.48	.14	.07
	Including weekends	22% (59/271)	57.61 (39.69)	24% (244/1021)	66.72 (55.82)	1.46	.15	.07

Note: Missing data cases were not included in the percentage calculations. The asterixis denoting significance for the percentage adherence estimates relate to the degree to which the observed frequencies significantly differed from expected frequency for that cell as indicated by the adjusted standardized residuals.

Abbreviations: FREED, first episode rapid early intervention for eating disorders.

*p < .05. ***p < .001.

TABLE 3 Mean and mean difference in clinical outcomes before and after treatment in FREED-Up and FREED-4-All cohorts

	FREED-Up					FREED-4-All		
	T1: Baseline *M* (*SD*)	T2: 6-month *M* (*SD*)	T3: 12-month *M* (*SD*)	T1-T2[a] *MD*	T1-T3[a] *MD*	T1: Baseline *M* (*SD*)	T2: Post-treatment *M* (*SD*)	T1-T2[a] *MD*
EDE-Q	4.08 (1.21) [*n* = 278]	2.85 (1.57) [*n* = 182]	2.31 (1.55) [*n* = 175]	1.23***	1.77***	4.06 (1.29) [*n* = 793]	2.04 (1.39) [*n* = 135]	2.02***
Binge episodes per month	6.41 (8.39) [*n* = 278]	3.70 (8.17) [*n* = 182]	2.39 (4.60) [*n* = 175]	2.71***	4.02***	4.83 (10.17) [*n* = 820]	2.19 (4.84) [*n* = 151]	2.64***
Vomit episodes per month	6.97 (11.76) [*n* = 278]	3.27 (9.73) [*n* = 182]	2.18 (6.80) [*n* = 175]	3.70***	4.79***	5.84 (15.07) [*n* = 821]	1.43 (3.98) [*n* = 150]	4.41***
Laxative episodes per month	2.03 (6.52) [*n* = 278]	1.13 (4.22) [*n* = 182]	0.55 (2.93) [*n* = 175]	0.90*	1.48***	1.30 (5.71) [*n* = 823]	0.46 (2.83) [*n* = 153]	0.84
BMI (AN only)	16.42 (1.19) [*n* = 96]	17.67 (1.77) [*n* = 76]	18.43 (2.23) [*n* = 66]	−1.25***	−2.01***	17.41 (2.24) [*n* = 429]	19.08 (2.55) [*n* = 88]	−1.67***
CORE-10/OM	1.97 (0.75) [*n* = 277]	1.45 (0.74) [*n* = 182]	1.39 (0.85) [*n* = 175]	0.52***	0.58***	1.93 (0.72) [*n* = 577]	1.42 (0.83) [*n* = 76]	0.51***

Abbreviations: AN, anorexia nervosa; BMI, body mass index; CORE-10/OM, clinical outcomes in routine evaluation-10/outcome measure; EDE-Q, eating disorder examination questionnaire; FREED, first episode rapid early intervention for eating disorders; MD, mean difference.
[a]Significance values calculated using multi-level models for each FREED cohort separately.
*$p < .05$. ***$p < .001$.

(>18.5 kg/m^2) are presented in Table 5. The cohorts were significantly different in BMI at pre-treatment ($\chi^2(1) = 25.29$, $p < .001$) and in BMI and EDE-Q when comparing FREED-Up at 6-months to FREED-4-All at post-treatment (EDE-Q: $\chi^2(1) = 12.89$, $p < .001$; BMI: $\chi^2(1) = 11.23$, $p < .001$).

4 | DISCUSSION

This study used routinely collected data to evaluate DUED, adherence to the wait time targets, and clinical outcomes in 30 FREED services in NHS England. Data from the FREED-Up study were used as a benchmark to assess whether FREED is replicating at scale. DUED, adherence to the wait time targets, and the impact on clinical outcomes were comparable, if not superior, in FREED-4-All relative to FREED-Up. This provides encouraging, albeit tentative, evidence that FREED can be successfully scaled into routine clinical practice. There was, however, a small but significant increase in the average wait for assessment (by 5–8 days) and treatment (by 7–12 days) for FREED-4-All patients. The wait for assessment was 20–30 days and for treatment was 45–65 days. To put these numbers into context, a survey conducted in 2017 found the average wait for adults with EDs in the UK was 70 days for assessment and 147 days for treatment (Beat, 2017). Most patients were referred during the pandemic, which may account for the longer wait times. Preliminary analysis of the impact of COVID-19 on FREED is underway and suggests that this might be the case. However, more data is needed to confirm or refute these conclusions.

The FREED-4-All cohort were slightly younger, had a higher proportion of patients with a diagnosis of AN relative to OSFED, and a shorter DUED. The increased proportion of patients with AN appears to be largely driven by the onset of COVID-19, which is in keeping with other reports of increased rates of AN presentations during the pandemic (Haripersad et al., 2021; Taquet et al., 2021). This relative increase in AN is likely to put greater pressure on already stretched teams due to the higher medical risk associated with AN compared to other EDs. Patients with AN often require more intensive and multidisciplinary input.

The average DUED of FREED-4-All patients was shorter than FREED-Up patients' by approximately 3 months. This finding is encouraging as it suggests that FREED is not only replicating but doing better at scale, and the 15 months DUED in FREED-4-All is substantially shorter than the 30–60 months reported in the literature (Austin et al., 2020). However, with the current data it is challenging to attribute the shorter DUED directly to FREED, especially as the waits for assessment and treatment were not substantially shorter. The shorter DUED could be due to newer sites having a shorter DUED at the outset, the rapid deterioration of patients during the pandemic, or increased awareness of EDs.

The clinical outcomes in the FREED-4-All cohort are in line with the FREED-Up study and previously reported estimates of symptom change (e.g., Byrne et al., 2011; Turner et al., 2015). The only difference was the substantially greater improvements in EDE-Q and BMI weight recovery when comparing FREED-4-All at post-treatment to FREED-Up at 6-months. However, it is important not to overinterpret these findings due to the FUPS characteristics of the data. The missing data are particularly problematic for post-treatment clinical outcomes, which limits the validity and generalisability of these results. Outcome data in FREED-Up were collected via an online portal, where participants directly entered their data and with dedicated researchers reminding participants to complete questionnaires. In contrast, outcome data collection in FREED-4-All relied on busy clinicians

TABLE 4 Multi-level models evaluating the impact of time and FREED cohort on clinical outcomes

Outcome	ICC	Predictors	*b* (*SE*)	*β* (*SE*)	*t*	df	*p*
EDE-Q	0.37	Time (1 vs. 2)[a]	−1.23 (0.10)	−0.77 (0.06)	−12.23	604	< .001***
		Time (1 vs. 3)[b]	−1.74 (0.11)	−1.08 (0.07)	−16.45	604	< .001***
		FREED cohort[c]	−0.06 (0.09)	−0.03 (0.06)	−0.61	1094	.54
		Time (1 vs. 2)*FREED cohort[c]	−0.69 (0.16)	−0.43 (0.10)	−4.45	604	< .001***
		Time (1 vs. 3)*FREED cohort[c]	−0.19 (0.16)	−0.12 (0.10)	−1.17	604	.24
Binge eating episodes per month	0.62	Time (1 vs. 2)[a]	−2.41 (0.58)	−0.28 (0.07)	−4.16	634	<.001***
		Time (1 vs. 3)[b]	−3.90 (0.57)	−0.45 (0.07)	−6.86	634	<.001***
		FREED cohort[c]	−1.60 (0.67)	−0.19 (0.08)	−2.37	1123	.02*
		Time (1 vs. 2)*FREED cohort[c]	−0.45 (0.81)	−0.05 (0.09)	−0.56	634	.58
		Time (1 vs. 3)*FREED cohort[c]	1.16 (0.73)	0.13 (0.08)	1.59	634	.11
Vomit episodes per month	0.86	Time (1 vs. 2)[a]	−3.20 (0.62)	−0.26 (0.05)	−5.12	631	<.001***
		Time (1 vs. 3)[b]	−4.40 (0.67)	−0.36 (0.05)	−6.58	631	<.001***
		FREED cohort[c]	−1.18 (0.98)	−0.10 (0.08)	−1.20	1126	.23
		Time (1 vs. 2)*FREED cohort[c]	−0.46 (0.86)	−0.04 (0.07)	−0.54	631	.59
		Time (1 vs. 3)*FREED cohort[c]	0.51 (0.85)	0.04 (0.07)	0.60	631	.55
Laxative episodes per month	0.47	Time (1 vs. 2)[a]	−0.88 (0.37)	−0.17 (0.07)	−2.36	637	.02*
		Time (1 vs. 3)[b]	−1.48 (0.38)	−0.29 (0.08)	−3.85	637	< .001***
		FREED cohort[c]	−0.74 (0.41)	−0.15 (0.08)	−1.79	1127	.07
		Time (1 vs. 2)*FREED cohort[c]	0.10 (0.49)	0.02 (0.10)	0.20	637	.84
		Time (1 vs. 3)*FREED cohort[c]	0.67 (0.49)	0.13 (0.10)	1.38	637	.17
BMI (AN only)	0.48	Time (1 vs. 2)[a]	1.17 (0.25)	−0.05 (0.12)	4.75	314	<.001***
		Time (1 vs. 3)[b]	2.18 (0.26)	−0.10 (0.10)	8.33	314	<.001***
		FREED cohort[c]	0.99 (0.24)	0.01 (0.12)	4.18	523	<.001***
		Time (1 vs. 2)*FREED cohort[c]	0.53 (0.33)	−0.03 (0.16)	1.62	314	.11
		Time (1 vs. 3)*FREED cohort[c]	−0.47 (0.35)	0.06 (0.14)	−1.35	314	.18
CORE-10/OM	0.47	Time (1 vs. 2)[a]	−0.51 (0.05)	−0.63 (0.07)	−9.66	517	<.001***
		Time (1 vs 3)[b]	−0.56 (0.06)	−0.69 (0.07)	−9.66	517	<.001***
		FREED cohort[c]	−0.06 (0.05)	−0.07 (0.07)	−1.03	868	.30
		Time (1 vs. 2)*FREED cohort[c]	0.03 (0.09)	0.04 (0.11)	0.35	517	.73
		Time (1 vs. 3)*FREED cohort[c]	0.08 (0.10)	0.10 (0.12)	0.77	517	.44

Abbreviations: AN, anorexia nervosa; BMI, body mass index; CORE-10/OM, clinical outcomes in routine evaluation-10/outcome measure; EDE-Q, eating disorder examination questionnaire; FREED, first episode rapid early intervention for eating disorders; ICC, intraclass correlation coefficient.
[a]Time 2 for the FREED-Up cohort is the 6-month follow-up and for the FREED-4-All cohort is the post-treatment time point.
[b]Time 3 for the FREED-Up cohort is the 12-month follow-up and for the FREED-4-All cohort is the post-treatment time point.
[c]The FREED-Up cohort served as the statistical reference group.
*$p < .05$. ***$p < .001$.

TABLE 5 Percentage of patients above the EDE-Q clinical cut-off and BMI threshold pre- and post-treatment in FREED-Up and FREED-4-All cohorts

	FREED-Up			FREED-4-All	
	T1: Baseline	T2: 6-month	T3: 12-month	T1: Baseline	T2: Post-treatment
% (*n*) above EDE-Q clinical cut-off (≥2.8)	84% (233/278)	49% (89/182)	35% (61/175)	84% (663/793)	29% (39/135)
% (*n*) of patients with AN above the BMI threshold (>18.5 kg/m^2)	0% (0/96)	33% (25/76)	52% (34/66)	22% (93/429)	59% (52/88)

Abbreviations: AN, anorexia nervosa; BMI, body mass index; FREED, first episode rapid early intervention for eating disorders.

and their local processes and procedures. Reasons for missingness included patients not returning questionnaires, clinicians not being accustomed to or invested in collecting outcome measures, limited IT support, staff changes, pausing FREED due to COVID-19, and insufficient capacity. This provides important insights into the difficulties of gathering FREED data alongside clinical work and the need for additional support and innovation to improve data quality and quantity.

Despite the pandemic, FREED appears to be largely replicating at scale with DUED, wait time target adherence, and clinical improvements comparable to earlier FREED studies and estimates in the literature. We hope that over time and with improvements in data quality that we can have greater confidence in the findings derived from the FREED-4-All dataset and ultimately make progress towards reducing the impact of EDs.

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CONFLICT OF INTEREST

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The datasets analysed during the current study are not publicly available due to privacy and legal reasons outlined in the operational agreement, namely that the data should be exclusively used for the purpose of evaluating FREED and that the data will not be shared with any external parties without express permission of the original owners of the data.

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APPENDIX A

TABLE A1 Missing data per variable for all participants, participants who had an assessment, and participants who started treatment for FREED-Up and FREED-4-All cohorts

Outcome: time point(s)	FREED-Up			FREED-4-All		
	All $n = 278$	Assessment completed $n = 278$	Treatment started $n = 272$	All $n = 2473$	Assessment completed $n = 1803$	Treatment started $n = 1023$
Age: baseline % (*n*)	0% (0)	0% (0)	0% (0)	1% (15)	1% (7)	0% (0)
Diagnosis: baseline % (*n*)	0% (0)	0% (0)	0% (0)	28% (694)	13% (248)	5% (55)
DUED: baseline % (*n*)	4% (11)	4% (11)	3% (7)	54% (1337)	39% (708)	31% (313)
Attempted engagement call % (*n*)	10% (27)	10% (27)	9% (25)	21% (520)	11% (204)	12% (123)
Completed engagement call % (*n*)	6% (18)	6% (18)	6% (17)	24% (603)	12% (223)	13% (129)
Offered assessment % (*n*)	5% (14)	5% (14)	5% (13)	20% (503)	1% (16)	3% (27)
Completed assessment % (*n*)	1% (1)	1% (1)	1% (1)	27% (674)	1% (4)	2% (21)
Offered treatment % (*n*)	8% (21)	8% (21)	7% (19)	55% (1353)	39% (707)	2% (20)
Completed treatment % (*n*)	3% (7)	3% (7)	1% (1)	59% (1452)	44% (800)	1% (2)
EDE-Q: baseline % (*n*)	0% (0)	0% (0)	0% (0)	68% (1680)	57% (1029)	39% (395)
EDE-Q: 6-month or post-treatment % (*n*)	35% (96)	35% (96)	33% (91)	95% (2338)	93% (1670)	87% (892)
EDE-Q: 12-month % (*n*)	37% (103)	37% (103)	36% (98)	N/A	N/A	N/A
EDE-Q: pre- and post/6-month % (*n*)	35% (96)	35% (96)	33% (91)	95% (2357)	94% (1687)	89% (910)
EDE-Q: pre- and 12-month % (*n*)	37% (103)	37% (103)	36% (98)	N/A	N/A	N/A
Binge episodes: baseline % (*n*)	0% (0)	0% (0)	0% (0)	67% (1653)	55% (1006)	36% (367)
Binge episodes: 6-month or post-treatment % (*n*)	35% (96)	35% (96)	33% (91)	94% (2322)	92% (1656)	86% (876)
Binge episodes: 12-month % (*n*)	37% (103)	37% (103)	36% (98)	N/A	N/A	N/A
Binge episodes: pre- and post/6-month % (*n*)	35% (96)	35% (96)	33% (91)	95% (2343)	93% (1675)	87% (895)
Binge episodes: pre- and 12-month % (*n*)	37% (103)	37% (103)	36% (98)	N/A	N/A	N/A
Vomit episodes: baseline % (*n*)	0% (0)	0% (0)	0% (0)	66% (1652)	56% (1005)	36% (369)
Vomit episodes: 6-month or post-treatment % (*n*)	35% (96)	35% (96)	33% (91)	94% (2323)	91% (1657)	86% (877)
Vomit episodes: 12-month % (*n*)	37% (103)	37% (103)	36% (98)	N/A	N/A	N/A
Vomit episodes: pre- and post/6-month % (*n*)	35% (96)	35% (96)	33% (91)	95% (2345)	93% (1677)	88% (897)
Vomit episodes: pre- and 12-month % (*n*)	37% (103)	37% (103)	36% (98)	N/A	N/A	N/A
Laxative episodes: baseline % (*n*)	0% (0)	0% (0)	0% (0)	67% (1650)	55% (1003)	36% (366)
Laxative episodes: 6-month or post-treatment % (*n*)	34% (96)	34% (96)	33% (91)	94% (2320)	92% (1654)	86% (875)
Laxative episodes: 12-month % (*n*)	37% (103)	37% (103)	36% (98)	N/A	N/A	N/A
Laxative episodes: pre- and post/6-month % (*n*)	35% (96)	35% (96)	33% (91)	95% (2342)	93% (1674)	87% (895)
Laxative episodes: pre- and 12-month % (*n*)	37% (103)	37% (103)	36% (98)	N/A	N/A	N/A
BMI (AN only): baseline % (*n*)[a]	0% (0/96)	0% (0/96)	0% (0/96)	48% (390/819)	42% (305/730)	23% (110/476)
BMI (AN only): 6-month or post-treatment % (*n*)[a]	21% (20/96)	21% (20/96)	21% (20/96)	89% (731/819)	88% (644/730)	82% (389/476)
BMI (AN only): 12-month % (*n*)[a]	31% (30/96)	31% (30/96)	31% (30/96)	N/A	N/A	N/A
BMI (AN only): pre- and post/6-month % (*n*)[a]	21% (20/96)	21% (20/96)	21% (20/96)	89% (731/819)	88% (644/730)	82% (389/476)
BMI (AN only): pre- and 12-month % (*n*)[a]	31% (30/96)	31% (30/96)	31% (30/96)	N/A	N/A	N/A
CORE-10/OM: baseline % (*n*)	1% (1)	1% (1)	1% (1)	77% (1896)	69% (1240)	58% (591)
CORE-10/OM: 6-month or post-treatment % (*n*)	34% (96)	34% (96)	33% (91)	96% (2385)	95% (1718)	92% (939)
CORE-10/OM: 12-month % (*n*)	37% (103)	37% (103)	36% (98)	N/A	N/A	N/A
CORE-10/OM: pre- and post/6-month % (*n*)	35% (96)	35% (96)	33% (91)	97% (2397)	96% (1728)	93% (950)
CORE-10/OM: pre- and 12-month % (*n*)	37% (103)	37% (103)	36% (98)	N/A	N/A	N/A

Abbreviations: AN, anorexia nervosa; BMI, body mass index; CORE-10/OM, clinical outcomes in routine evaluation-10/outcome measure; DUED, duration of untreated eating disorder; EDE-Q, eating disorder examination questionnaire; N/A, not applicable; FREED, First Episode Rapid Early Intervention for Eating Disorders.
[a]The denominator (included in the parenthesis) differs for BMI as this calculation includes only patients with anorexia nervosa.

10.2 Appendix B: Ethical approval letters and documents

10.2.1 Ethical approval letters for the clinician perspective study (Chapter 5)

Research Ethics
Office

Franklin Wilkins Building
5.9 Waterloo Bridge Wing
Waterloo Road
London SE1 9NH
Telephone 020 7848 4020/4070/4077
rec@kcl.ac.uk

KING'S College LONDON

Katie Richards

19/07/2019

Dear Katie,

LRS-18/19-13005 The clinicians' perspective of the First Episode Rapid Early Intervention Service for Eating Disorders

Thank you for submitting your application for the above project. I am pleased to inform you that full approval has been granted by the PNM Research Ethics Panel

Ethical approval has been granted for a period of **three years** from 19 July 2019. You will not be sent a reminder when your approval has lapsed and if you require an extension you should complete a modification request, details of which can be found here:

https://internal.kcl.ac.uk/innovation/research/ethics/applications/modifications.aspx

Please ensure that you follow the guidelines for good research practice as laid out in UKRIO's Code of Practice for research: https://www.kcl.ac.uk/research/support/integrity-good-conduct/index.aspx

Any unforeseen ethical problems arising during the course of the project should be reported to the panel Chair, via the Research Ethics Office.

Please note that we may, for the purposes of audit, contact you to ascertain the status of your research.

We wish you every success with your research.

Yours sincerely,

Mr James Patterson

Senior Research Ethics Officer

For and on behalf of:

PNM Research Ethics Panel

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Prof Ulrike Schmidt
Eating Disorders Unit
103 Denmark Hill
London
SE5 8AZ

Email: hra.approval@nhs.net
HCRW.approvals@wales.nhs.uk

26 September 2019
Reissued 10 October 2019

Dear Prof Schmidt

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**The clinicians' perspective of the First Episode Rapid Early Intervention Service for Eating Disorders (FREED)**
IRAS project ID:	**268938**
Protocol number:	**N/A**
REC reference:	**19/HRA/5347**
Sponsor	**King's College London**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The "*After HRA Approval – guidance for sponsors and investigators*" document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **268938**. Please quote this on all correspondence.

Yours sincerely,
Catherine Adams

Approvals Manager

Email: hra.approval@nhs.net

Copy to: *Professor Reza Razavi*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Qualitative Study_Flyer_29082019_v2]	2.0	29 August 2019
Covering letter on headed paper [Quantitative study_CoveringLetter_29082019_v2]	2.0	29 August 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		02 August 2019
Interview schedules or topic guides for participants [Qualitative study_TopicGuide_31052019_v1]	1.0	31 May 2019
IRAS Application Form [IRAS_Form_10092019]		10 September 2019
Letter from funder [The Health Foundation Funding Award Letter]		08 November 2018
Letter from sponsor [Sponsorship Confirmation_03092019]		03 September 2019
Letters of invitation to participant [Qualitative Study_EmailInvitation_29082019_v2]	2.0	29 August 2019
Non-validated questionnaire [Staff Survey (Demographics_NoMAD_AttitudesQuestionnaire)_31052019_1.0]	1.0	31 May 2019
Participant consent form [Qualitative Study_CF_10092019_v5]	5.0	10 September 2019
Participant consent form [Quantitative_Survey_CF_10092019_v4.0]	4.0	10 September 2019
Participant information sheet (PIS) [Qualitative Study_PIS_10092019_v4.0]	4.0	10 September 2019
Participant information sheet (PIS) [Quantitative_Survey PIS_10092019_v4.0]	4.0	10 September 2019
Participant information sheet (PIS) [Quantitative_Online_PIS&CF_10092019_v4.0]	4.0	10 September 2019
Research protocol or project proposal [Protocol_FREEDstudy2_29082019_V3]	3.0	29 August 2019
Summary CV for Chief Investigator (CI) [BriefCVCI-US2019]	1.0	28 September 2019
Summary CV for student [Student CV_18042019]	1.0	18 April 2019
Summary CV for supervisor (student research) [Primary Supervisor CV]	1.0	29 August 2019
Summary CV for supervisor (student research) [Second Supervisor]		
Validated questionnaire [Team Climate Inventory]	1.0	31 May 2019

IRAS project ID	268938

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
This is a single site study sponsored by the participating NHS organisations partner University. Therefore there is only one site type.	This is a single site study sponsored by the participating NHS organisations partner University. You should work with the participating sites R&D office to make arrangements to set up the study and confirm local capacity and capability. This R&D office will confirm to you when the study can start following issue of HRA and HCRW Approval.	This is a single site study sponsored by that organisations partner University. Therefore no study agreements are expected.	No comments	The CI is responsible for research activities at the participating organisation.	This research is limited to the involvement of staff (with no involvement of patients/service users as participants), who will participate in interviews held in non-clinical areas. Therefore no research specific access arrangements are required and no additional pre-engagement checks are necessary

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant intends to apply for the portfolio

10.2.2 Ethical approval letter for the Delphi study (Chapter 6)

Research Ethics Office

Franklin Wilkins Building
5.9 Waterloo Bridge Wing
Waterloo Road
London SE1 9NH
Telephone 020 7848 4020/4070/4077
rec@kcl.ac.uk

KING'S College LONDON

Isabel Woolrych

15 April 2021

Dear Isabel,

Study Title: A Delphi Study of Priority Setting in Eating Disorder Services

Study Reference: HR/DP-20/21-21302

Ethical Clearance

I am pleased to inform you that full approval for your project has been granted by the PNM Research Ethics Subcommittee

Important coronavirus update: In light of the COVID-19 pandemic, the College Research Ethics Committee has temporarily suspended all primary data collection involving face to face participant interactions until further notice. **Ethical clearance for this project is granted. However, the clearance outlined in the attached letter is contingent on your adherence to the latest College measures when conducting your research.** Please do not commence data collection until you have carefully reviewed the update and made any necessary project changes:

https://internal.kcl.ac.uk/innovation/research/ethics/applications/COVID-19-Update-for-Researchers

For your information, ethical approval has been granted for 1 year from 15 April 2021. If you need approval beyond this point, you will need to apply for an extension at least two weeks before this. You will be required to explain the reasons for the extension. However, you will not need to submit a full re-application unless the protocol has changed.

Ethical approval is required to cover the data-collection phase of the study. This will be until the date specified in this letter. However, you do not need ethical approval to cover subsequent data analysis or publication of the results. For secondary data-analysis, ethical approval is applicable to the data that is sensitive or identifies participants.

Please ensure that you follow the guidelines for good research practice as laid out in UKRIO's Code of Practice for research: http://ukrio.org/publications/code-of-practice-for-research/

If you do not start the project within three months of this letter, please contact the Research Ethics Office.

Please note that you will be required to obtain approval to modify the study. This also encompasses extensions to periods of approval. Please refer to the URL below for further guidance about the process:

https://internal.kcl.ac.uk/innovation/research/ethics/applications/modifications.aspx

If you have any query about any aspect of this ethical approval, please contact the Research Ethics Office

https://internal.kcl.ac.uk/innovation/research/ethics/contact.aspx

Data Protection Registration

As you have indicated in Section E that personal data will be processed as part of this research project, this letter also confirms that you have also met your requirements for registering this processing activity with King's College London. This is required in line with the College's role as a Data Controller, in accordance with the General Data Protection Regulation (GDPR).

Please note it is the responsibility of the researcher(s) to ensure compliance with other aspects of the GDPR, more information about this can be found here: https://internal.kcl.ac.uk/innovation/research/Research-Governance/how-does-GDPR-affect-research/How-does-GDPR-affect-research

You are required to adhere to all research data/records management and storage procedures agreed to as part of your application. This will be expected even after the completion of the study.

If there are any changes to the project that will impact on how you will you collect, manage or otherwise use your data, these must also be reflected in a modification request as outlined above.

Please note that we may, for the purposes of audit, contact you from time to time to ascertain the status of your research.

We wish you every success with this work.

Yours sincerely,

Mr James Patterson
Senior Research Ethics Officer

For and on behalf of the PNM Research Ethics Subcommittee

Cc:Prof Ulrike Schmidt

10.3 Appendix C: Participant information sheets

10.3.1 Participant information sheet for clinician perspective study (Chapter 5)

IRAS Project ID: 268938

Participant Information Sheet: Face-to-face interviews

Study Title: The clinicians' perspective of First Episode Rapid Early Intervention Service for Eating Disorders

You are being invited to take part in a study about staff views on, and experience with early intervention for eating disorders generally and First Episode Rapid Early Intervention for Eating Disorders (FREED) specifically. Please read the following information carefully and feel free to ask any questions if anything is unclear. You are welcome to talk to other people about this research.

Why are we doing this research study?

We are interested in getting a better understanding of staff views on and experience with early intervention for eating disorders generally and FREED more specifically. We would like to gain insights into how FREED is implemented and integrated into different teams across the UK. Our aim is to use this information to further develop and refine FREED and progress early intervention for eating disorders in the UK and beyond. This study is being conducted as part of a PhD project at King's College London.

Why have I been asked to take part?

You have been invited to take part because you are a staff member (e.g. psychologist, psychotherapist, doctor, nurse, or allied health professional) working within a service using FREED.

Do I have to take part?

No. It is up to you to decide whether to take part. If you do not wish to take part, it will not impact your work or your involvement with FREED. If you do decide to take part, you are able to change your mind at any time and withdraw from the study, without giving a reason. If you decide to take part, we will ask you to sign a consent form and you will be given a copy of this consent form to keep.

What will happen if I decide to take part in the study?

You will be asked to take part in a face-to-face or telephone interview with a researcher lasting approximately 30-45 minutes. You will be asked questions about your role in your service and FREED, your understanding of the FREED model, your thoughts on early intervention and with FREED, and your experience of working with FREED.

We will also be asking for your permission to audio-record and transcribe the interviews. This is so we can get an accurate record of the discussion. Access to the audio-recordings and transcripts will be restricted to authorised members of the research team. Direct quotes may be used from the interviews in publications. Interview content and direct quotes from the interviews will be anonymised (personal information will be replaced by numbers/codes) so you cannot be identified, and care will be taken to ensure that no other information in the interview can identify you. The audio-recordings will be destroyed after publication.

A copy of the transcript can also be requested so that you may make edits you feel are necessary to ensure that it is an accurate representation of your opinion.

What are the possible disadvantages or risks of taking part?

We do not anticipate there being any risks in taking part. However, the study will take up some of your time, which might be an inconvenience but should not disadvantage you.

What are the benefits of taking part?

There are no payments for taking part in this study and you are unlikely to benefit directly from taking part. We hope that the information from the study will be used to further develop and improve the FREED service model.

Will my taking part be kept confidential?

Yes. All the information we collect will remain strictly confidential and will be anonymised to protect your confidentiality. The information will only be looked at by authorised members of the research team. All the information we collect will be stored securely in locked filing cabinets or in password protected files on King's College London premises. Information you provide will not allow you to be identified in any research outputs/publications. All information will be handled in accordance with King's College London's Data Protection Policy, the Data Protection Act (2018), and the General Data Protection Regulation 2016 (GDPR). The support from GDPR compliant transcription services will be sought to help transcribe the audio-recordings. Documents with identifiable information (e.g. your name) will be retained for up to one year after data collection is completed.

Data Protection Statement: King's College London (KCL) is the lead sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. KCL will keep identifiable information about you for up to 3 years after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible. You can find out more about how we use your information by contacting the Chief Investigator (Professor Ulrike Schmidt, ulrike.schmidt@kcl.ac.uk) or visiting the KCL website: https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research.aspx.

South London and Maudsley NHS Trust (SLaM) will collect information from you for this research study in accordance with our instructions. SLaM will use your name and contact details to contact you about the research study, and make sure that relevant information about the study is recorded, and to oversee the quality of the study. Individuals from KCL and regulatory organisations may look at your research records to check the accuracy of the research study. SLaM will pass these details to KCL along with the information collected from you. The only people in KCL who will have access to information that identifies you will be people who need to contact you regarding your participation or audit the data collection process. KCL will keep identifiable information about you from this study for 3 years after the study has finished.

What will happen to the results of the study?

We hope to publish the results of this study in a scientific journal, and to present the results at conferences. The report will not include any personal details and individuals who took part will not be identified.

Who has reviewed the study?

This study has been reviewed by the King's College London's Psychiatry, Nursing, and Midwifery ethics board. This is to make sure that the research is being conducted to ethical standards and to protect your safety, rights, wellbeing and dignity. Ethical Clearance Reference Number: LRS-18/19-13005. IRAS Project ID: 268938.

Contact:
If you have any questions about this study, or would like to take part, please get in contact. My contact details are: Katie Richards, Eating Disorders, Department of Psychological Medicine, IoPPN, King's College London, 103 Denmark Hill London, SE5 8AZ. Email: katie.richard@kcl.ac.uk

If you want to speak to the supervisors of the study, please contact Professor Ulrike Schmidt: ulrike.schmidt@kcl.ac.uk (0207 848 0181) or Dr Karina Allen: Karina.Allen@slam.nhs.uk

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information: Professor Ulrike Schmidt: ulrike.schmidt@kcl.ac.uk (0207 848 0181)

Thank you for reading this information sheet and for considering taking part in this research.

10.3.2 Participant information sheets for the Delphi study (Chapter 6)

10.3.2.1 Participant information sheet for clinicians

Participant Information Sheet: Clinicians

Study Title: Priority Setting in Eating Disorder Services

You are being invited to take part in a study about clinicians' perspectives on priority setting in eating disorder services. Please read the following information carefully and feel free to ask any questions if anything is unclear. You are welcome to talk to other people about this research.

Why are we doing this research study?

Waiting lists are common in publicly funded eating disorder services, such as the National Health Service (NHS). This is because there are usually not enough resources for the number of people that need to be treated. Deciding how to organise these waiting lists and who is seen more quickly (i.e., given priority), is a difficult task, especially when waiting lists are long. There are many different things that need to be thought about when making these decisions. The main aim of this study is to look at the degree of consensus (agreement or disagreement) amongst clinicians on what factors should be used to decide how patients are prioritised on waiting lists in eating disorder services, and the relative importance of the factors that reach consensus. This study is being conducted as part of a PhD and MSc project at King's College London.

Why have I been asked to take part?

You have been invited to take part because you are a clinician (e.g. psychologist, psychotherapist, doctor, nurse, or allied health professional) who has had experience working in an eating disorder service for at least a year.

Do I have to take part?

No. It is up to you to decide whether to take part. If you do decide to take part, you are able to change your mind at any time and withdraw from the study, without giving a reason. If you decide to take part, we will ask you to sign a consent form.

What will happen if I decide to take part in the study?

Over three and half months, you will be asked to complete four rounds of questionnaires. Each questionnaire should take no longer than 30 minutes to complete. The first questionnaire will ask about background information (e.g. age, profession), then you will be presented with a list of sentences about ways in which people should be prioritised in eating disorder services and asked to rate how much you agree or disagree with each sentence. You

will also be invited to provide feedback or ideas about each sentence alongside your response and there will also be an open-ended question at the end of the list to identify any additional factors.

The second questionnaire will be given to you 2-4 weeks after you completed the first. This questionnaire will be very similar to the first one. You will be asked to rate your agreement or disagreement with sentences about patient prioritisation. Some of these sentences will be the same as the ones from the first questionnaire, some will be different. You will also be given the average rating of the sentence (i.e., how much everyone agreed or disagreed with it) from the first round alongside your own rating in the first round (only you will see your own rating). This is so you can see what other people think about the sentence. You may or may not want to change your answer because of this feedback.

The third questionnaire will be very similar to the second questionnaire. You will be given the third questionnaire about 2-3 weeks after you complete the second one. You will again be given feedback on the average ratings from the second round and will be asked to re-rate the sentences following this feedback.

The fourth questionnaire will be given about 2-3 weeks after you complete the third questionnaire. The fourth questionnaire will be different from the first three. In this questionnaire you will be asked to rank some of the sentences in order of importance from most important to the least important. This is so we can get an understanding of the order of importance of these sentences when making decisions about patient prioritisation.

What are the possible disadvantages or risks of taking part?

We do not anticipate there being any risks in taking part. However, the study will take up some of your time, which might be an inconvenience but should not disadvantage you.

What are the benefits of taking part?

There are no payments for taking part in this study and you are unlikely to benefit directly from taking part. We hope that the information from the study will be used to inform decision-making and prioritisation in eating disorder services.

Will my taking part be kept confidential?

Yes. Your data will be processed under the terms of UK data protection law (including the UK General Data Protection Regulation (UKGDPR) and the Data Protection Act 2018), and King's College London's Data Protection Policy. All the information we collect will remain strictly confidential and will be pseudonymised to protect your confidentiality. The information will only be looked at by authorised members of the research team. All the information we collect will be stored electronically in password-protected folders on King's College London network server. Information you provide will not allow you to be identified in any research outputs/publications. The documents with identifiable information (e.g. your name) will be retained for up to one year after data collection is completed.

Data Protection Statement: This study is a King's College London (KCL) research project. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your

information and using it properly. KCL will keep identifiable information about you for up to 1 year after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. You may withdraw from the study at any time. If you withdraw from the study, you will also be able to withdraw your data for 2 weeks after from submission of the first questionnaire. After this, we will keep the information about you that we have already obtained, since data from each questionnaire will be collated, analysed and used to inform the content that will be included in the following questionnaires. To safeguard your rights, we will use the minimum personally identifiable information possible.
You can find out more about how we use your information by contacting the Chief Investigator (Professor Ulrike Schmidt, ulrike.schmidt@kcl.ac.uk). If you would like more information about how your data will be processed under the terms of UK data protection laws, please visit this link on the KCL website: https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research

What will happen to the results of the study?

We hope to publish the results of this study in a scientific journal, and to present the results at conferences. The report will not include any personal details and individuals who took part will not be identified. Once the information from the study has been analysed, we can provide you with a written report of the results. We welcome any comments, feedback, or thoughts on the final results. We want to make sure that our results accurately reflect your opinions.

Who has reviewed the study?

This study has been reviewed by the King's College London's Psychiatry, Nursing, and Midwifery ethics board. This is to make sure that the research is being conducted to ethical standards and to protect your safety, rights, wellbeing and dignity. Ethical Clearance Reference Number: HR/DP-20/21-21302.

Contact:
If you have any questions about this study, or would like to take part, please get in contact. My contact details are: Katie Richards, Eating Disorders, Department of Psychological Medicine, IoPPN, King's College London, 103 Denmark Hill London, SE5 8AZ. Email: katie.richards@kcl.ac.uk

If you want to speak to the supervisors of the study, please contact Professor Ulrike Schmidt: ulrike.schmidt@kcl.ac.uk (0207 848 0181) or Dr Karina Allen: Karina.Allen@slam.nhs.uk

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information: Professor Ulrike Schmidt: ulrike.schmidt@kcl.ac.uk (0207 848 0181).

Thank you for reading this information sheet and for considering taking part in this research.

10.3.2.2 Participant information sheet for participants with lived experience

Participant Information Sheet: Lived Experience of an Eating Disorder

Study Title: Priority Setting in Eating Disorder Services

You are being invited to take part in a study about perspectives on priority setting in eating disorder services from people who have lived experience of an eating disorder. Please read the following information carefully and feel free to ask any questions if anything is unclear. You are welcome to talk to other people about this research.

Why are we doing this research study?

Waiting lists are common in publicly funded eating disorder services, such as the National Health Service (NHS). This is because there are usually not enough resources for the number of people that need to be treated. Deciding how to organise these waiting lists and who is seen more quickly (i.e., given priority), is a difficult task, especially when waiting lists are long. There are many different things that need to be thought about when making these decisions. The main aim of this study is to look at the degree of consensus (agreement or disagreement) amongst people with a lived experience of an eating disorder on what factors should be used to decide how patients are prioritised in eating disorder services, and the relative importance of the factors that reach consensus. This study is being conducted as part of a PhD and MSc project at King's College London.

Why have I been asked to take part?

You have been invited to take part because you have lived experience of an eating disorder.

Do I have to take part?

No. It is up to you to decide whether to take part. If you do decide to take part, you are able to change your mind at any time and withdraw from the study, without giving a reason. If you decide to take part, we will ask you to sign a consent form.

What will happen if I decide to take part in the study?

Over three and half months, you will be asked to complete four rounds of questionnaires. Each questionnaire will take no longer than 30 minutes to complete. The first questionnaire will ask about background information (e.g. age, profession), then you will be presented with a list of sentences about ways in which people should be prioritised in eating disorder services and asked to rate how much you agree or disagree with each sentence. You will also be invited to provide feedback or ideas about each sentence alongside your response and there will also be an open-ended question at the end of the list to identify any additional factors.

The second questionnaire will be given to you 2-4 weeks after you completed the first. This questionnaire will be very similar to the first one. You will be asked to rate your agreement or disagreement with sentences about patient prioritisation. Some of these sentences will be the same as the ones from the first questionnaire, some will be different. You will also be given the average rating of the sentence (i.e., how much everyone agreed or disagreed with it) from the first round alongside your own rating in the first round (only you will see your own rating). This is so you can see what other people think about the sentence. You may or may not want to change your answer because of this feedback.

The third questionnaire will be very similar to the second questionnaire. You will be given the third questionnaire about 2-3 weeks after you complete the second one. You will again be given feedback on the average ratings from the second round and will be asked to re-rate the sentences following this feedback.

The fourth questionnaire will be given about 2-3 weeks after you complete the third questionnaire. The fourth questionnaire will be different from the first three. In this questionnaire you will be asked to rank some of the sentences in order of importance from most important to the least important. This is so we can get an understanding of the order of importance of these sentences when making decisions about patient prioritisation

What are the possible disadvantages or risks of taking part?

The risks associated with taking part are minimal, as the questionnaires are considered non-invasive. However, some people may find it challenging to disclose diagnoses or prioritise waiting list variables. You do not have to answer any question if you do not want and if you do not feel comfortable to continue, you can withdraw from the study at any time without giving a reason. You are also encouraged to contact the researchers at any point during the study if you have any questions, or concerns. The study will take up some of your time, which might be an inconvenience but should not disadvantage you.

What are the benefits of taking part?

There are no payments for taking part in this study and you are unlikely to benefit directly from taking part. We hope that the information from the study will be used to inform decision-making and prioritisation in eating disorder services.

Will my taking part be kept confidential?

Yes. Your data will be processed under the terms of UK data protection law (including the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act (2018)), and King's College London's Data Protection Policy. All the information we collect will remain strictly confidential and will be pseudonymised to protect your confidentiality. The information will only be looked at by authorised members of the research team. All the information we collect will be stored electronically in password-protected folders on King's College London network server. Information you provide will not allow you to be identified in any research outputs/publications. The documents with identifiable information (e.g. your name) will be retained for up to one year after data collection is completed.

Data Protection Statement: This study is a King's College London (KCL) research project. We will be using information from you in order to undertake this study and will act

as the data controller for this study. This means that we are responsible for looking after your information and using it properly. KCL will keep identifiable information about you for up to 1 year after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. You may withdraw from the study at any time. If you withdraw from the study, you will also be able to withdraw your data for 2 weeks after from submission of the first questionnaire. After this, we will keep the information about you that we have already obtained, since data from each questionnaire will be collated, analysed and used to inform the content that will be included in the following questionnaires. To safeguard your rights, we will use the minimum personally identifiable information possible.
You can find out more about how we use your information by contacting the Chief Investigator (Professor Ulrike Schmidt, ulrike.schmidt@kcl.ac.uk). If you would like more information about how your data will be processed under the terms of UK data protection laws, please visit this link on the KCL website: https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research

What will happen to the results of the study?

We hope to publish the results of this study in a scientific journal, and to present the results at conferences. The report will not include any personal details and individuals who took part will not be identified. Once the information from the study has been analysed, we can provide you with a written report of the results. We welcome any comments, feedback, or thoughts on the final results. We want to make sure that our results accurately reflect your opinions.

Who has reviewed the study?

This study has been reviewed by the King's College London's Psychiatry, Nursing, and Midwifery ethics board. This is to make sure that the research is being conducted to ethical standards and to protect your safety, rights, wellbeing and dignity. Ethical Clearance Reference Number: XXXX.

Contact:
If you have any questions about this study, or would like to take part, please get in contact. My contact details are: Isabel Woolrych, Department of Child and Adolescent Psychiatry, IoPPN, King's College London, 103 Denmark Hill London, SE5 8AZ. Email: isabel.woolrych@kcl.ac.uk.

If you want to speak to the supervisors of the study, please contact Professor Ulrike Schmidt: ulrike.schmidt@kcl.ac.uk (0207 848 0181; Eating Disorders, Department of Psychological Medicine, IoPPN, King's College London, 103 Denmark Hill London, SE5 8AZ) or Miss Katie Richards: katie.richards@kcl.ac.uk.

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information: Professor Ulrike Schmidt: ulrike.schmidt@kcl.ac.uk (0207 848 0181)

Thank you for reading this information sheet and for considering taking part in this research.

10.4 Appendix D: Consent forms

10.4.1 Consent form for clinician perspective study (Chapter 5)

Participant ID:

Consent Form: Face-to-face interviews

Study Titles: The clinician's perspective of the First Episode and Rapid Early Intervention Service for Eating Disorders
IRAS Project ID: 268938
Researcher: Katie Richards, Eating Disorders, Department of Psychological Medicine, IoPPN, King's College London, 103 Denmark Hill London, SE5 8AZ. Email: katie.richard@kcl.ac.uk

By signing this consent form I agree that: **Please Initial Box**

1. **I have read and understood the information sheet dated 10/09/2019 (Version 4.0). I confirm that I have had the opportunity to consider the information and ask questions.**
2. **I understand that I am voluntarily taking part in the study and I am free to withdraw at any time, without giving any reason, and without it influencing my work. I can also refuse to answer questions.**
3. **I understand that I will be asked to complete a 30-45 minute interview about my views on, and experience with FREED.**
4. **I consent to the processing of my personal information for the purposes explained to me in the Information Sheet. I understand that such information will be handled in accordance with the terms of the General Data Protection Regulation.**
5. **I understand that my information may be subject to review by responsible individuals from the College for monitoring and audit purposes.**
6. **I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any research outputs.**
7. **I agree to the interview being audio-recorded and a transcript being produced. The support of a GDPR compliant trancription service will be sought to trancribe the recordings.**
8. **I understand that my words might be quoted directly and will be anonymised so I cannot be identified in any publications.**
9. **I can request a copy of my interview transcript and may make edits I feel are necessary to ensure the effectiveness of any agreement made about confidentiality.**

Participant ID:

10. I consent to my audio-recordings being shared with GDPR compliant transcription services as outlined in the participant information sheet.

11. I agree to participate in the above study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	
Participant Email Address	NHS Trust	
_____	_____	_____
Name of Person taking consent	Date	Signature

10.4.2 Consent forms for the Delphi study (Chapter 6)

10.4.2.1 Consent form for clinicians

Participant ID:

Consent Form: Clinicians

Study Titles: Priority Setting in Eating Disorder Services

Researcher: Katie Richards, Eating Disorders, Department of Psychological Medicine, IoPPN, King's College London, 103 Denmark Hill London, SE5 8AZ. Email: katie.richards@kcl.ac.uk

By signing this consent form I agree that: **Please Initial Box**

1. **I have read and understood the information sheet dated 24/03/2021 (Version 2.0). I confirm that I have had the opportunity to consider the information and ask questions.**
2. **I understand that I am voluntarily taking part in the study and I am free to withdraw at any time, without giving any reason, and without it influencing my work. I can also refuse to answer questions.**
3. **I understand that I will be asked to complete four questionnaires at different time points about factors that can be used as the basis of prioritisation in eating disorder services.**
4. **I consent to the processing of my personal information for the purposes explained to me in the Information Sheet. I understand that such information will be handled in accordance with the terms of the General Data Protection Regulation (GDPR) and the Data Protection Act (2018).**
5. **I understand that my information may be subject to review by responsible individuals from King's College London for monitoring and audit purposes.**
6. **I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any research outputs.**
7. **I agree to participate in the above study.**

Name of Participant	Date	Signature
Participant Email Address	NHS Trust	
Name of Person taking consent	Date	Signature

10.4.2.2 Consent form for participants with lived experience

Participant ID:

Consent Form: Lived Experience

Study Titles: Priority Setting in Eating Disorder Services

Researcher: Isabel Woolrych, Department of Child Psychiatry, IoPPN, King's College London, 103 Denmark Hill London, SE5 8AZ. Email: isabel.woolrych@kcl.ac.uk

By signing this consent form I agree that: **Please Initial Box**

1. **I have read and understood the information sheet dated 24/03/2021 (Version 2.0). I confirm that I have had the opportunity to consider the information and ask questions.**
2. **I understand that I am voluntarily taking part in the study and I am free to withdraw at any time, without giving any reason. I can also refuse to answer questions.**
3. **I understand that I will be asked to complete four questionnaires at different time points about factors that can be used as the basis of prioritisation in eating disorder services.**
4. **I consent to the processing of my personal information for the purposes explained to me in the Information Sheet. I understand that such information will be handled in accordance with the terms of the General Data Protection Regulation (GDPR) and the Data Protection Act (2018).**
5. **I understand that my information may be subject to review by responsible individuals from King's College London for monitoring and audit purposes.**
6. **I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any research outputs.**
7. **I agree to participate in the above study.**

_____	_____	_____
Name of Participant	Date	Signature

_____

Participant Email Address

_____	_____	_____
Name of Person taking consent	Date	Signature

10.5 Appendix E: Recruitment materials

10.5.1 Recruitment documents for the clinician perspective study (Chapter 5)

10.5.1.1 Email invitation for interview

Dear all,

We would like to invite you to take part in a study about staff views on, and experience with early intervention for eating disorders and the First Episode Rapid Early Intervention for Eating Disorders (FREED) service. We are looking for staff members (e.g. doctors, psychologists, nurses, or allied health professionals) working with or alongside FREED.

Taking part involves a 30 to 45-minute interview about your experience of working with FREED. This interview can be done over the phone or in-person. If you would like more information or are interested in taking part please contact Katie Richards, katie.richards@kcl.ac.uk.

This study has been reviewed by the King's College London's Psychiatry, Nursing, and Midwifery ethics board.

Best regards,

Katie

Katie Richards
PhD Student, FREED Network
Eating Disorders Unit, Psychological Medicine
Institute of Psychiatry, Psychology & Neuroscience, King's College London
Ground floor, 103 Denmark Hill, London SE5 8AZ
Email: katie.richards@kcl.ac.uk

www.kcl.ac.uk/eatingdisordersunit | @KingsEDResearch
www.FREEDfromED.co.uk | @FREEDfromED

10.5.1.2 Poster advertisement for clinician perspective study

FREED

KING'S College LONDON

NHS
South London and Maudsley
NHS Foundation Trust

Staff Research Volunteers Needed

Overview

- We are aiming to get a better understanding of staff views on, and experience with, early intervention for eating disorder and the First Episode Rapid Early Intervention for Eating Disorder (FREED) service model

Are you eligible?

- 18 years or older
- Working within an eating disorder team using the FREED service model
- A psychologist, nurse, doctor, or allied health professional

Participation involves

- A 30-40 minute interview completed over the phone or face-to-face

Interested in taking part? Want more information?

Please email Katie Richards on Katie.Richards@kcl.ac.uk

FREED: the clinician's perspective,
Flyer, V2.0 29th August 2019

10.5.2 Recruitment documents for the Delphi study (Chapter 6)

10.5.2.1 Poster advertisement for clinicians

SPEED:
Setting Priorities in Eating Disorder Services

Clinician Research Volunteers Working in Eating Disorder Services Needed

We are aiming to look at the level of agreement or disagreement amongst clinicians working in eating disorder services on what factors should be used to prioritise people in services

AM I ELIGIBLE?

Clinicians from any professional background working in an eating disorder service for at least 1 year

TAKING PART INVOLVES

Four online questionnaires:

- Given every 2-4 weeks
- Taking 20-30 minutes to complete

Interested in taking part?
Want more information?

Please email Katie Richards on katie.richards@kcl.ac.uk

KING'S College LONDON

10.5.2.2 Poster advertisement for participants with lived experience

SPEED:
Setting Priorities in Eating Disorder Services

Volunteers with Lived Experience of an Eating Disorder Needed

We are aiming to look at the level of agreement or disagreement amongst people with lived experience of an eating disorder on what factors should be used to prioritise people in services

AM I ELIGIBLE?

- 18 +
- Lived experience of any eating disorder

TAKING PART INVOLVES

Four online questionnaires:

- Given every 2-4 weeks
- Taking 20-30 minutes to complete

Interested in taking part?
Want more information?

Please email Izzy Woolrych on isabel.woolrych@kcl.ac.uk

KING'S College LONDON

10.6 Appendix F: Interviews and questionnaires

10.6.1 Topic guide for clinician interviews (Chapter 5)

Section 1: Participant background and general views and experience of early intervention for eating disorders (coherence)

1. Can you tell me a little bit about your role within the team?
    a. how long have you been in this position?

2. Could you give me a brief description of your understanding of early intervention?

3. Have you had any experience working in early intervention before FREED?

4. What are your views on early intervention for eating disorders?
    a. does the importance of early intervention differ for different eating disorders?
    b. are there any benefits or downsides of early intervention for eating disorders?

Section 2: FREED initiation, coherence, and cognitive participation

1. How and when were you first introduced to FREED?
    a. Was there anyone driving it forward in your team?

2. Could you give me a brief description of your understanding of the FREED model?

3. What are your views on the model? (e.g., age range, duration criterion, intervention tweaks)

4. In the NHS patients are usually prioritised based upon clinical need. In eating disorders teams this typically means that patients are prioritised according to medical urgency (e.g., low weight). In contrast, FREED patients are also prioritised due to early stage of illness. What is your opinion on this difference?
    a. Does this difference cause any tension in the team?
    b. If so, how is this tension managed?

5. Have you received any FREED training?
    a. What was your experience of the training?
        i. Did you find it helpful?
        ii. Was there anything missing?
        iii. Could anything have been differently?

6. Did you have any hopes and/or concerns about FREED before using it?

Section 3: Implementing FREED, collective action, and reflexive monitoring

1. How have you found the FREED model so far?

2. How, if at all, has working with FREED or having FREED in your team changed the way you work?
    a. How easy or difficult was it to integrate FREED into your existing work?
    b. Were any changes made to the FREED model to make it fit within your team?
    c. Has it influenced your approach and/or relationship to FREED and non-FREED patients?
    d. Has it influenced how you work with other people in your team?

3. Do you feel that your experience of FREED has been similar or different to other members of your team?
    a. What do other people in your team think about FREED?
    b. Is there a shared understanding of FREED?
    c. Are you confident in other people's ability to use FREED?

4. Do you think that FREED has affected treatment uptake, engagement, or satisfaction?

5. Thinking about FREED as whole, what do you think were the most significant barriers and facilitators to using it?

6. How easy or difficult has it been to provide the 48-hour engagement call?

7. How easy or difficult has it been to meet the wait time targets?

8. How easy or difficult has it been to use the FREED treatment adaptations, such as increasing attention on social media and emerging adulthood?

9. How important is it or has it been to have a FREED Champion in the team?
    a. What is the most important aspect of their role?
    b. Is there anything that could or should be done differently?

10. How important is it or has it been to have and be part of the FREED Network?

11. What are the 3 best and 3 most challenging aspects of FREED?

Section 4: Looking ahead

12. What factors do you think might influence the team's ability to continue to support FREED?

13. Do you have any thoughts about how early intervention for eating disorder or FREED could be improved in the future?

14. Is there anything you wish you had known before FREED was introduced in your team?

15. I think that's basically everything I had to ask you, is there anything else you'd like to say, or any further thoughts?

Additional COVID-19 questions

1. How has COVID-19 impacted your work and FREED?
2. Has COVID-19 impacted how important you think early intervention is?

10.6.2 Round 1 questionnaire development for Delphi study (Chapter 6)

The Round 1 questionnaire was developed by conducting a systematic literature review followed by consultation and pre-testing with eating disorder (ED) clinicians and individuals with lived experience (LE). For the literature review, PsychInfo and Medline databases were searched on 24th August 2020 using the following search terms: (eating disorder OR anorexi* OR bulimi* OR binge eat*) AND ((allocation AND resource*) OR priorit*). The search yielded 288 unique articles with only one article being relevant for the current study. The included article was a study conducted by Gajre, McClelland, and Furnham (2018). This study involved a survey in which 361 participants were given a list of eight hypothetical patients with either obesity or anorexia nervosa (AN). The patients varied on three factors: age, social class, and mental health history. Participants were required to choose which patient should receive treatment and then rank patients in order of priority. Age, social class, and comorbid mental health diagnoses were all found to impact priority. Patients with obesity or AN were more likely to be prioritised if they were younger, with a comorbid mental health problem and from a low social class. Following the literature search, KR (lead author) drafted a list of clinical and non-clinical factors for patient prioritisation. This list was then distributed amongst clinicians and researchers in the ED unit at the King's College London/South London and Maudsley Hospital for feedback on appropriateness and wording, and for suggested new items. Clinician and LE versions of the questionnaire were then drafted. These draft questionnaires were given to five clinicians and five individuals with LE for additional feedback on content, formatting, and language, and suggested new items. The final questionnaire for Round 1 consisted of demographic questions (e.g., age, gender, profession), 49 items for prioritising patients within ED services, and open-ended questions for feedback and suggested new items.

10.6.3 Round 1 questionnaires for Delphi study (Chapter 6)

10.6.3.1 Round 1 questionnaire for clinicians

Part A: Background Information

Part A asks some general questions about you.

1. What is your age?

2. What is your gender?
   - ☐ Female
   - ☐ Male
   - ☐ Non-binary
   - ☐ Prefer not to say
   - ☐ Other
     Please specify:

3. Which best describes your ethnic group?
   - ☐ Prefer not to say
   - ☐ White Scottish/English/Welsh/Northern Irish/British
   - ☐ White Irish
   - ☐ White Gypsy or Irish Traveller
   - ☐ Any other White background
     Please specify:
   - ☐ White and Black Caribbean
   - ☐ White and Black African
   - ☐ White and Asian
   - ☐ Any other Mixed/Multiple ethnic background
     Please specify:

- ☐ Asian/Asian British – Indian
- ☐ Asian/Asian British – Pakistani
- ☐ Asian/Asian British – Bangladeshi
- ☐ Asian/Asian British – Chinese
- ☐ Any other Asian background
  Please specify:
- ☐ Black/Black British – African
- ☐ Black/Black British – Caribbean
- ☐ Any other Black/African/Caribbean background
  Please specify:
- ☐ Arab
- ☐ Any other ethnic group
  Please specify:

4. What is your professional job category?

- ☐ Psychiatrist
- ☐ Clinical Psychologist
- ☐ Counselling Psychologist
- ☐ Psychiatric Nurse
- ☐ Counsellor
- ☐ Psychotherapist
- ☐ Occupational Therapist
- ☐ Dietician
- ☐ Social Worker
- ☐ Other, please specify:

5. How many years have you worked in this professional job category?

- ☐ Less than 1 year
- ☐ 1-4 years

- [ ] 5-10 years
- [ ] 11-15 years
- [ ] 16-20 years
- [ ] More than 20 years

6. How many years have you worked in eating disorders?

- [ ] 1-4 years
- [ ] 5-10 years
- [ ] 11-15 years
- [ ] 16-20 years
- [ ] More than 20 years

7. What types of eating disorder services have you worked in?
   [Please choose as many as apply.]

- [ ] Inpatient services
- [ ] Outpatient services
- [ ] Day patient services
- [ ] Community services
- [ ] Other, please specify:

8. Which of the following types of eating disorder services have you worked in?
   [Please choose as many as apply.]

- [ ] Child and Adolescent Mental Health (CAMHS) and/or CAMHS eating disorder services
- [ ] Adult Mental Health (AMH) and/or AMH eating disorder services
- [ ] All age mental health services (for 0-25 years old)
- [ ] Unsure
- [ ] None of the above

9. Since qualifying, where have you worked in eating disorder services?
   [Please choose as many as apply.]

☐ UK - NHS
☐ UK – Private Sector
☐ Other country – Public Sector, please specify:
☐ Other country – Private Sector, please specify:

Part B: Patient Prioritisation in Eating Disorder Services

Part B contains sentences about patient prioritisation in eating disorder services. Read each sentence carefully and decide how much you agree or disagree with it. We want you to think about what your answer would be in most situations and encourage you to try to make a decision of whether you agree or disagree.

You can also leave a comment in the box next to each sentence if you have any ideas or feedback about the sentence. This can include comments on the language/wording of the sentence, difficulties in understanding or rating it, or reasons why you gave a specific rating. This comment box is optional.

Note: it is important for you to think about these sentences for eating disorder services specifically and not for healthcare services more generally.

People should be prioritised…	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree	If you had any thoughts/ideas about the sentence, please provide a comment in the box. This can include language, difficulties in rating, or reasons why you gave a specific rating. [OPTIONAL]

1.	if they have a diagnosis of anorexia nervosa	○	○	○	○	○	
2.	if they have a diagnosis of bulimia nervosa	○	○	○	○	○	
3.	if they have a diagnosis of binge eating disorder	○	○	○	○	○	
4.	if they have a diagnosis of other specified feeding or eating disorder	○	○	○	○	○	
5.	if they are underweight	○	○	○	○	○	
6.	if they are experiencing obesity	○	○	○	○	○	
7.	if they are binge eating (Eating what others would class as a very large amount of food in a short space of time (within 2 hours) and a feeling of losing control over eating)	○	○	○	○	○	
8.	if they have reduced the amount and type of food they are eating (dietary restriction)	○	○	○	○	○	

9.	if they are vomiting, taking laxatives or diuretics, or exercising excessively (purging/compensating)	○	○	○	○	○	
10.	if they are constantly having eating disorder related thoughts and feelings (e.g., thoughts about their body shape and weight, fear of putting on weight)	○	○	○	○	○	
11.	if they are thinking or planning to end their life (suicide risk)	○	○	○	○	○	
12.	if they are injuring themself through behaviours like scratching, burning, and pinching without the intention of ending their life (non-suicidal self-injury)	○	○	○	○	○	
13.	if they are at significant medical risk (e.g., very slow or irregular heartbeat, abnormal blood results)	○	○	○	○	○	
14.	if they are getting worse quickly	○	○	○	○	○	
15.	if they are experiencing medical problems because of their eating disorder (e.g., osteoporosis, fertility problems, bowel problems, problems with their heart and circulation)	○	○	○	○	○	

16.	if they are experiencing mild eating disorder symptoms (e.g., weight/shape concerns, infrequent binge eating or fasting)	○	○	○	○	○	
17.	if they are very upset by their eating disorder	○	○	○	○	○	
18.	if their eating disorder is negatively impacting their life (e.g., stops them from doing leisure activities, impacts how they interact with other people or makes it difficult to work/study)	○	○	○	○	○	
19.	if their eating disorder has only recently developed	○	○	○	○	○	
20.	if they have had an eating disorder for a long time	○	○	○	○	○	
21.	if they are less than 12 years old	○	○	○	○	○	
22.	if they are less than 18 years old	○	○	○	○	○	
23.	if they are less than 25 years old	○	○	○	○	○	
24.	on a ‘first-come first-serve’ basis (people will receive treatment in the order in which their referral arrives, i.e., so if Patient X’s referral arrived before Patient Y’s, Patient X will be seen first)	○	○	○	○	○	

25.	if they have had several rounds of previous treatments	○	○	○	○	○	
26.	if they have not accessed eating disorder services before	○	○	○	○	○	
27.	if they have recently had treatment (within the last 6 months) but are now relapsing	○	○	○	○	○	
28.	if they are motivated for treatment or to get better	○	○	○	○	○	
29.	if they only have a small window of time before they move somewhere else	○	○	○	○	○	
30.	if they are a carer or someone depends on them (e.g., a child)	○	○	○	○	○	
31.	if they have very little social support	○	○	○	○	○	
32.	if they are at risk of harm from others	○	○	○	○	○	
33.	if they have or do live in a household with a low income	○	○	○	○	○	
34.	if they are homeless or do not have secure housing	○	○	○	○	○	

35.	if they have or do live in a household with a high income	○	○	○	○	○	
36.	if they also have a major physical disorder (e.g., cardiovascular disease, diabetes, cancer)	○	○	○	○	○	
37.	if they are pregnant	○	○	○	○	○	
38.	if they have a learning disability	○	○	○	○	○	
39.	if they are also experiencing a mood, anxiety, or stress-related disorder (e.g., major depression, bipolar disorder, generalised anxiety disorder, social phobia, panic disorder, post-traumatic stress disorder)	○	○	○	○	○	
40.	if they are also abusing or are dependent on alcohol or other drugs (substance use disorder)	○	○	○	○	○	
41.	if they also have an autism spectrum disorder	○	○	○	○	○	
42.	if they also have a personality disorder	○	○	○	○	○	
43.	if they are also experiencing an obsessive-compulsive or related disorder (e.g., body dysmorphic disorder)	○	○	○	○	○	
44.	based upon the overall severity of their illness	○	○	○	○	○	

45.	based upon how much they are likely to benefit from treatment	○	○	○	○	○	
46.	if they have been waiting for a long time for treatment (e.g., they moved areas so had to be put on a new waiting list, it took them a long time to talk to their GP or get a GP referral)	○	○	○	○	○	
47.	if they are receiving treatment from another mental health service	○	○	○	○	○	
48.	if there is another member of their family who is receiving treatment for a mental health problem	○	○	○	○	○	
49.	if they found it difficult to get a GP referral	○	○	○	○	○	

Part C: Additional Ideas or Feedback

We want to make sure we include all the factors that you think are important in for prioritising people in eating disorder services. Are there any other factors that have not been listed that you think are important for prioritising patients in eating disorder services? If yes, please specify.

10.6.3.2 Round 1 questionnaire for individuals with lived experience of an eating disorder

Part A: Background Information

Part A asks some general questions about you.

10. What is your age?

    ☐

11. What is your gender?
    - ☐ Female
    - ☐ Male
    - ☐ Non-binary
    - ☐ Prefer not to say
    - ☐ Other
      Please specify:

12. Which best describes your ethnic group?
    - ☐ Prefer not to say
    - ☐ White Scottish/English/Welsh/Northern Irish/British
    - ☐ White Irish
    - ☐ White Gypsy or Irish Traveller
    - ☐ Any other White background
      Please specify:
    - ☐ White and Black Caribbean
    - ☐ White and Black African
    - ☐ White and Asian
    - ☐ Any other Mixed/Multiple ethnic background
      Please specify:
    - ☐ Asian/Asian British – Indian

- ☐ Asian/Asian British – Pakistani
- ☐ Asian/Asian British – Bangladeshi
- ☐ Asian/Asian British – Chinese
- ☐ Any other Asian background
  Please specify:
- ☐ Black/Black British – African
- ☐ Black/Black British – Caribbean
- ☐ Any other Black/African/Caribbean background
  Please specify:
- ☐ Arab
- ☐ Any other ethnic group
  Please specify:

13. Which best describes your employment/work status?
    - ☐ Student
    - ☐ Full-time employment
    - ☐ Part-time employment
    - ☐ Homemaker
    - ☐ Self-employed
    - ☐ Unemployed, currently looking for work
    - ☐ Unemployed, not looking for work
    - ☐ Retired
    - ☐ Unable to work due to illness or disability

14. Has a doctor or health professional ever told you that you have any of the following?

	Yes	No	Unsure
Anorexia Nervosa			
Atypical Anorexia Nervosa			

Bulimia Nervosa			
Binge Eating Disorder			
Other Specified Eating Disorder/Eating Disorder Not Otherwise Specified			
Purging Disorder			
Avoidant/Restrictive Food Intake Disorder			
Mood Disorder (e.g. major depression, bipolar disorder)			
Anxiety Disorder or Stress-related Disorder (e.g. generalise anxiety, panic disorder, post-traumatic stress disorder)			
Personality Disorder (e.g. emotionally unstable personality disorder, anti-social personality disorder)			
Substance Use Disorder			
Neurodevelopmental Disorder (e.g. autism, ADHD)			

15. Approximately, how long have you had your eating disorder (in months)?

16. Would you consider yourself as recovered from your eating disorder?

- ☐ Yes
- ☐ Yes, but I still experience some symptoms
- ☐ Unsure
- ☐ Partially
- ☐ No

If yes, how long have you been recovered or partially recovered from your eating disorder (in months)?

☐

17. Have you ever received specialist inpatient care for your eating disorder? [Inpatient care involves staying in a hospital for a certain length of time to undergo eating disorder treatment. This treatment can include medical monitoring, talking therapies, supervised meals, and other activities that contribute towards recovery.]
    - ☐ Yes
    - ☐ No
    - ☐ Unsure

    If yes, how many times have you received a course of inpatient care?

    ☐

Please rate your experience of your last inpatient admission (i.e., the most recent time):

Very poor				Okay					Excellent
1	2	3	4	5	6	7	8	9	10

18. Have you ever received day patient care for your eating disorder? [Day patient care involves attending a clinic, hospital, or centre for a set number of full- or half-days per week to undergo treatment. Day patient care can now also be delivered virtually via telephone and video

calls. This treatment can include support around meals, talking therapies, and learning skills and activities that contribute towards recovery.]

- ☐ Yes
- ☐ No
- ☐ Unsure

If yes, how many times have you received a course of day patient care?

Please rate your experience of your last course of day patient care (i.e., the most recent time):

Very poor				Okay					Excellent
1	2	3	4	5	6	7	8	9	10

19. Have you ever received outpatient psychological therapy for your eating disorder? [Outpatient psychological therapy consist of attending a clinic, hospital, or centre for treatment, usually weekly for about 1-2 hours for psychological therapy, such as cognitive behavioural therapy or interpersonal therapy. Outpatient care can now also be delivered virtually via telephone or video calls.]

- ☐ Yes
- ☐ No
- ☐ Unsure

If yes, how many times have you received a course of outpatient care?

Please rate your experience of your last course of outpatient care (i.e., the most recent time):

Very poor				Okay					Excellent
1	2	3	4	5	6	7	8	9	10

20. Which of the following types of eating disorder services have you received treatment from?
[Please choose as many as apply.]

- ☐ Child and Adolescent Mental Health (CAMHS) and/or CAMHS eating disorder services
- ☐ Adult Mental Health (AMH) and/or AMH eating disorder services
- ☐ All age mental health services (for 0-25 years old)
- ☐ Unsure
- ☐ None of the above

21. Where have you received treatment?
[Please choose as many as apply.]

- ☐ UK – NHS
- ☐ UK – Private Sector
- ☐ Other country – Public Sector, please specify:
- ☐ Other Country – Private Sector, please specify:

Part B: Patient Prioritisation in Eating Disorder Services

Part B contains sentences about patient prioritisation in eating disorder services. Read each sentence carefully and decide how much you agree or disagree with it. We want you to think about what your answer would be in most situations and encourage you to try to make a decision of whether you agree or disagree.

You can also leave a comment in the box next to each sentence if you have any ideas or feedback about the sentence. This can include comments on the language/wording of the sentence, difficulties in understanding or rating it, or reasons why you gave a specific rating. This comment box is optional.

Note: it is important for you to think about these sentences for eating disorder services specifically and not for healthcare services more generally.

People should be prioritised…	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree	If you had any thoughts/ideas about the sentence, please provide a comment in the box. This can include language, difficulties in rating, or reasons why you gave a specific rating. [OPTIONAL]

1.	if they have a diagnosis of anorexia nervosa	○	○	○	○	○	
2.	if they have a diagnosis of bulimia nervosa	○	○	○	○	○	
3.	if they have a diagnosis of binge eating disorder	○	○	○	○	○	
4.	if they have a diagnosis of other specified feeding or eating disorder	○	○	○	○	○	
5.	if they are underweight	○	○	○	○	○	
6.	if they are experiencing obesity	○	○	○	○	○	
7.	if they are binge eating (Eating what others would class as a very large amount of food in a short space of time (within 2 hours) and a feeling of losing control over eating)	○	○	○	○	○	
8.	if they have reduced the amount and type of food they are eating (dietary restriction)	○	○	○	○	○	

9.	if they are vomiting, taking laxatives or diuretics, or exercising excessively (purging/compensating)	○	○	○	○	○	
10.	if they are constantly having eating disorder related thoughts and feelings (e.g., thoughts about their body shape and weight, fear of putting on weight)	○	○	○	○	○	
11.	if they are thinking or planning to end their life (suicide risk)	○	○	○	○	○	
12.	if they are injuring themself through behaviours like scratching, burning, and pinching without the intention of ending their life (non-suicidal self-injury)	○	○	○	○	○	
13.	if they are at significant medical risk (e.g., very slow or irregular heartbeat, abnormal blood results)	○	○	○	○	○	
14.	if they are getting worse quickly	○	○	○	○	○	
15.	if they are experiencing medical problems because of their eating disorder (e.g., osteoporosis, fertility problems, bowel problems, problems with their heart and circulation)	○	○	○	○	○	

16.	if they are experiencing mild eating disorder symptoms (e.g., weight/shape concerns, infrequent binge eating or fasting)	○	○	○	○	○	
17.	if they are very upset by their eating disorder	○	○	○	○	○	
18.	if their eating disorder is negatively impacting their life (e.g. stops them from doing leisure activities, impacts how they interact with other people or makes it difficult to work/study)	○	○	○	○	○	
19.	if their eating disorder has only recently developed	○	○	○	○	○	
20.	if they have had an eating disorder for a long time	○	○	○	○	○	
21.	if they are less than 12 years old	○	○	○	○	○	
22.	if they are less than 18 years old	○	○	○	○	○	
23.	if they are less than 25 years old	○	○	○	○	○	
24.	on a ‘first-come first-serve’ basis (people will receive treatment in the order in which their referral arrives, i.e.,	○	○	○	○	○	

	so if Patient X's referral arrived before Patient Y's, Patient X will be seen first)						
25.	if they have had several rounds of previous treatments	○	○	○	○	○	
26.	if they have not accessed eating disorder services before	○	○	○	○	○	
27.	if they have recently had treatment (within the last 6 months) but are now relapsing	○	○	○	○	○	
28.	if they are motivated for treatment or to get better	○	○	○	○	○	
29.	if they only have a small window of time before they move somewhere else	○	○	○	○	○	
30.	if they are a carer or someone depends on them (e.g., a child)	○	○	○	○	○	
31.	if they have very little social support	○	○	○	○	○	
32.	if they are at risk of harm from others	○	○	○	○	○	
33.	if they have or do live in a household with a low income	○	○	○	○	○	

34.	if they are homeless or do not have secure housing	○	○	○	○	○	
35.	if they have or do live in a household with a high income	○	○	○	○	○	
36.	if they also have a major physical disorder (e.g., cardiovascular disease, diabetes, cancer)	○	○	○	○	○	
37.	if they are pregnant	○	○	○	○	○	
38.	if they have a learning disability	○	○	○	○	○	
39.	if they are also experiencing a mood, anxiety, or stress-related disorder (e.g., major depression, bipolar disorder, generalised anxiety disorder, social phobia, panic disorder, post-traumatic stress disorder)	○	○	○	○	○	
40.	if they are also abusing or are dependent on alcohol or other drugs (substance use disorder)	○	○	○	○	○	
41.	if they also have an autism spectrum disorder	○	○	○	○	○	
42.	if they also have a personality disorder	○	○	○	○	○	

43.	if they are also experiencing an obsessive-compulsive or related disorder (e.g., body dysmorphic disorder)	○	○	○	○	○	
44.	based upon the overall severity of their illness	○	○	○	○	○	
45.	based upon how much they are likely to benefit from treatment	○	○	○	○	○	
46.	if they have been waiting for a long time for treatment (e.g., they moved areas so had to be put on a new waiting list, it took them a long time to talk to their GP or get a GP referral)	○	○	○	○	○	
47.	if they are receiving treatment from another mental health service	○	○	○	○	○	
48.	if there is another member of their family who is receiving treatment for a mental health problem	○	○	○	○	○	
49.	if they found it difficult to get a GP referral	○	○	○	○	○	

Part C: Additional Ideas or Feedback

We want to make sure we include all the factors that you think are important in for prioritising people in eating disorder services. Are there any other factors that have not been listed that you think are important for prioritising patients in eating disorder services? If yes, please specify.

10.7 Appendix G: Supplementary results

10.7.1 Chapter 3: Early intervention service for non-psychotic disorders: A scoping review

10.7.1.1 Reach, implementation, and clinical and psychosocial outcomes for included studies.

Table 24. Reach, implementation, and clinical and psychosocial outcomes for included studies.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
Youth Wellness Centre (YWC)					
Wang et al., 2020	Cross-sectional.	1520 youth presenting at YWC.	Age: *M* = 19.3 years (*SD* = 2.4). Gender: 59% female, 35% male, 4% transgender, 1% non-binary, 1% gender queer, 1% other.	Demographic, service use data, and clinical information abstracted from an electronic database. Questionnaires collected at initial orientation: GAIN-SS, DERS, K10,	*Reach/Intake* Referrals sources: 47% self-referral, 38% health care provider, and 15% community agency YWC reached at-risk youth (e.g., visible minorities, LGBTQ+, and street-involved) with very high emotional dysregulation, suicidal ideation, and psychological distress, substance use, and some difficulty in social/occupational functioning. However, indigenous youth were under-represented.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			Primary presenting problem: 26% mood, 25% anxiety, 16% coping difficulties, 9% substance use, 7% suicidal.	SOFAS, and OPOC.	*Implementation/Process/Resources* Most were engaged with the early intervention stream (55%). High rates of attendance at initial orientation (91%) and assessment (87%). The average wait from referral to orientation (*M* = 46.6 days, *SD* = 25) and assessment (*M* = 72.7, *SD* = 95.9) were greater than the provincial average (~50 days for assessment). *Outcomes* Compared to the provincial average, satisfaction scores were higher for two items (quality of care and recommending the service to a friend) but not for one (the service helped the young person deal more effectively with life's challenges).
First Episode Mood and					

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
Anxiety Program (FEMAP)					
Ross et al., 2012	Cross-sectional.	93 youth presenting at FEMAP.	Age: *M* = 19.8 years (*SD* = 2.8) Gender/sex: 68% female, 32% male. Primary presenting problem: 39% depression and anxiety, 28% primary depression, 16% primary anxiety, 9% bipolar disorder	Semi-structured clinical interview and questionnaire pack at intake assessment included: SCID-I Screening Questionnaire, BDI-II, STAI, SDS, and questionnaire to identify emotional concerns, psychiatric history, and demographics.	*Reach/Intake* Outreach activities for 22 centres/services included presentations, Q&A sessions, telephone meetings, attendance at drop-in sessions, a school-based art campaign, and community partnerships. Referral sources: 23% educational institutions, 22% family or friends, 20% family doctors, 13% hospital programmes, 13% mental health services, 5% from the internet, and 2% from local papers or public talks. At intake, most (61-95%) had severe/high scores for depression and anxiety and functional impairments (58-66%). 68% reported suicidal

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			symptoms, 7% PTSD, 2% indeterminate category.		thoughts and 15% endorsed wanting to kill themselves. 71% reported some previous mental health care. Parental educational achievement was higher for FEMAP patients than the general population. Barriers: Difficulties identifying locations to engage older FEMAP patients (i.e., 20-26 years).
Osuch et al., 2015	Prospective cohort without control.	548 youth presenting at FEMAP (399 accepted; 149 referred to appropriate service or reassured	Age: Accepted - *M* = 19.2 (*SD* = 2.7); Referred/reassured - *M* = 19.2 (*SD* = 2.6). Sex: Accepted - 61% female, 39% male/other; Referred/reassur	Questionnaires administered at assessment: BDI-II, STAI, SDS, SCID-IV screening questionnaire, ERQ, NIDA ASSIST, ASRS, and YRBS.	*Reach/Intake* Most participants accessed the service without a physician referral (61%), and had received prior treatment (62%), and medication (52%). Accepted and referred/reassured did not differ in referral route (physician vs non-physician). Youth who access the service through a non-physician route had significantly higher anxiety, and higher risk drug and alcohol use.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		that no treatment was needed)	ed - 67% female, 35% male/other. Presenting problem: Accepted - 34% depression and anxiety, 30% depression, 16% anxiety, 10% bipolar disorder, 4% substance use disorder, 3% life stress, 3% trauma/PTSD, 1% other; Referred/Reassured - 15%	Questionnaires administered at 3-month follow-up assessed original mental health concern(s), changes in mental health and addiction problems, experiences of treatment, and SDS.	At baseline, both accepted and referred/reassured had high depression, moderate anxiety, and disability scores that indicated clinical concern. Compared to referred/reassured, accepted youth had higher depression, emotional regulation difficulties, and greater functional impairment. *Implementation/Process/Resources* Accepted youth were more likely to follow through with recommendations made at intake assessment. *Outcome* Disability scores improved over time in both accepted and referred/reassessed patients (no significant difference).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			depression and anxiety, 8% depression, 18% anxiety, 3% bipolar disorder, 4% substance use disorder, 22% life stress, 12% trauma/PTSD, 13% other.		
Osuch et al., 2016	Mixed method including cross-sectional, pre-test – post-test, and	Samples varied by analysis.	No data.	Measures administered at assessment (baseline) and 4-month follow-up:	*Reach/Intake* Most referrals were from non-physician sources (63% of 1332). 95% of 897 assessed youth were accepted by FEMAP or re-referred to another service (i.e., in clinical need).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
	qualitative interviews.			MADRS, ASI, SDS, and QLESQ. Chart review to calculate treatment cost.	60-70% of youth had received prior treatment for mood/anxiety concerns. *Implementation/Process/Resources* 4-months of FEMAP treatment ($1634) costs considerably less than an emergency department psychiatric evaluation ($2188) and 4-months of disability support ($4392). Challenges: assumed care for patient groups the service was not designed for, not able to provide rapid response due to increased referrals and no additional funding (wait times moved from 2 weeks to 5 months), and long-term treatment of some youth (difficulties discharging). Facilitators: FEMAP telephone screening highly effective to minimise clinician time, and empathetic and caring treatment providers. *Outcomes*

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					Qualitative data suggest that FEMAP increased accessibility to treatment, and youth were positive about their experience and FEMAP clinicians. 88 FEMAP patient experienced significant improvements in depression, anxiety, functional impairment, and quality of life from baseline to follow-up.
Arcaro et al., 2017	Mixed method survey.	548 youth presenting at FEMAP.	Age: *M* = 19.25 years (*SD* = 2.65). Sex/gender: 62% female, 38% male. Presenting problem: 29% depression plus	Measures administered at intake assessment: questions asking for patient's top life concerns, BDI-II, STAI, ASRS, ERQ, and SDS.	*Referral/Intake* Most frequent referral source was self-referral (28%), and males were significantly more likely to self-refer than females (35% vs 24%). Other referral sources included GPs (17%), hospitals (21%), educational settings (26%), community agencies (6%), and private professionals (1%).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			anxiety, 25% depression, and 17% anxiety.		At presentation, the most frequently mentioned concerns were interpersonal and academic with mental health symptoms infrequently mentioned as a top concern. At presentation, participants had moderate to severe depression and significant dysfunction in school/work, social life, and family life/home responsibilities.
John-Baptiste et al., 2019	Retrospective cohort with control.	490 matched FEMAP users. 967 propensity-score matched non-user controls.	Age: FEMAP user - *M* = 19.3 years (*SD* = 2.4); Non-users - *M* = 19.2 years (*SD* = 2.4). Gender: FEMAP users - 68% female/other,	Utilization and cost of physician services, ambulatory care, and inpatient services, and drug benefit claim cost over 1 year following FEMAP	*Implementation/Process/Resources* FEMAP users had significantly higher use of physician services and lower use of ambulatory care compared to non-user, there was no difference in inpatient care. Compared to non-users, FEMAP users incurred significantly lower costs for inpatient services (−$784), ambulatory care services (−$90) and drug benefit claims (−$47), but significantly

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			32% male; Non-users - 67% female/other, 33% male. Diagnosis: FEMAP user - 43% mood disorder, 57% anxiety disorder; Non-user - 38% mood disorder, 62% anxiety disorder.	index admission from linked administrative databases.	higher physician services costs ($435) over 1 year. The overall cost was not significantly lower for FEMAP patients in unadjusted and adjusted models (-$853 to -$914).
Arcaro et al., 2019	Mixed method evaluation including interviews	22 youth engaged in FEMAP treatment.	Age: *M* = 22.45 years (*SD* = 2.96).	12-months after first clinical consultation patients were	Eight themes were organised into three overarching phases: (1) Help-seeking, (2) Treatment engagement, and (3) Long-term treatment outcomes.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
	and pre-test - post-test measures.		Gender: 68% female, 32% male.	invited to complete a semi-structured interview covering mental health history and treatment before FEMAP, and experience and impact of FEMAP treatment. Questionnaires administered at intake and follow-up: MADRAS, ASI, and SDS.	*Reach/Intake* Help-seeking: Initially, there was a lack of perceived need for help, a desire to self-manage, and stigma associated with mental illness acted as barriers. Participants only recognised the need for help when it had a marked impact on functioning and/or they reached crisis. Loved ones were facilitators to help-seeking. Participants also had to identify services in the community and satisfaction and trust with the service provider was barrier/facilitator. *Implementation/Process/Resources* The average length of treatment at FEMAP was 13.41 months (*SD* = 8.16) and number of treatment contacts was 21.6 appointments (*SD* = 15.8).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					Treatment engagement: Facilitators for engagement were multidisciplinary and comprehensive treatment under “one roof”, goal-oriented, collaborative, and change focused treatment, personal choice, and consistent support during and between appointments. Barriers included wait times and transitions between services. There was also a phase of unrealistic treatment expectations, and it took time to find what worked. *Outcomes* Depression, anxiety, and disability scores significantly improved from intake to interview, depression scores dropped from above to below a level of clinical concern. Long-term treatment outcomes: Participants reported notable improvements in coping,

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					resilience, symptoms, and all aspects of functioning, and perspective changes throughout treatment, including that they are not alone, self-acceptance, self-compassion, and self-efficacy and empowerment to take responsibility for life decisions.
Osuch et al., 2019	Prospective cohort with control.	676 youth presenting at FEMAP. 210 youth wait list control group (on FEMAP wait list).	Age of patients accepted by FEMAP: *M* = 19.2 years (*SD* = 2.6). Gender of patients accepted by FEMAP: 67% female, 33% male.	Questionnaires administered at intake and follow-up: MADRS, ASI, SDS, THQ, EQ-5D-VAS, ICSRLE, and AADIS-screener. Satisfaction questionnaire only	*Reach/Intake* 81% contacted the service without a physician referral and were just as likely to be accepted by the service than physician referrals. 95% had attempted to seek help previously. Of 676 contacts, 622 met phone screening criteria, 402 attended an intake appointment, 370 were accepted into FEMAP, and 322 attended an assessment.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
				administered at follow-up.	20% disengaged early from treatment and disengagement was associated with higher drug use and less depression and dysfunction. At intake, symptom severity and functional impairment were clinically significant. *Outcomes* Depression, anxiety, functional impairment, and self-rated quality of health all significantly improved at follow-up with depression and functional impairment showing clinically meaningful change. Symptom and functional improvements were significantly higher than wait list control. 99% of patients provided a positive overall rating on the patient satisfaction questionnaire.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
Anderson et al., 2019	Retrospective cohort with control.	490 matched FEMAP users. 967 propensity-score matched non-user controls.	Age: FEMAP user - *M* = 19.3 years (*SD* = 2.4); Non-users - *M* = 19.2 years (*SD* = 2.4). Gender: FEMAP users - 68% female/other, 32% male; Non-users - 67% female/other, 33% male. Diagnosis: FEMAP user - 43% mood disorder, 57%	Demographic, clinical, service use and process variables in 1-year following index FEMAP admission date from linked health administrative data.	*Reach/Intake* Compared to unmatched non-users (*n* = 29389), FEMAP users were significantly younger, more likely to be diagnosed by a psychiatrist, and less likely to be male, live in rural areas, be from the most deprived areas, diagnosed with an anxiety disorder, and have prior help-seeking. *Implementation/Process/Resources* FEMAP users were 3 times more likely to see a psychiatrist and to see them substantially quicker than matched non-users (*Mdn,* 16 days vs 71 days). Compared to matched non-users, FEMAP users had significantly lower primary care and emergency service use for mental health reasons but not inpatient admissions.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			anxiety disorder; Non-user - 38% mood disorder, 62% anxiety disorder.		
Saunders et al., 2021	Cross-sectional.	364 patients receiving FEMAP treatment.	Age: 50% 16-18 years old, 50% 19-25 years old. Sex: 67% female, 33% male.	Treatment initiation defined as attendance to first clinical appointment. Questionnaires at the intake appointment: socio-demographic and mental health questions, AADIS, satisfaction for previous mental	*Reach/Intake* 81% were referred through non-physician routes. *Implementation/Process/Resources* 87% initiated treatment. There was a median of 44.5 days from intake to first clinical visit. Univariate analysis revealed that females and individuals with greater anxiety sensitivity were more likely to initiate treatment. In the multivariate analysis, only anxiety sensitivity was associated with higher treatment initiation.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
				health treatment, MADRS, ASI, THQ, SDS, and ICSRLE.	No other variables acted as a barrier or facilitator for engaging in treatment: age, sex, parental education, patient-related factors including substance use, self-referral status, or satisfaction with previous treatment, and condition-related factors such as depression scores, functioning and trauma history.
headspace Early Intervention Team (hEIT)					
Nash et al., 2021	Qualitative interview study.	9 clinicians working within or closely affiliated with hEIT (3 hEIT	No data.	Semi-structured interviews explored clinician understanding of the clinical indications, functions, and roles	Four themes were identified: (1) Building bridges between services; (2) Filling a clinical gap; (3) Service collaboration and their challenges; (4) Difficulties of small team size. *Reach/Intake*

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		clinicians, 4 headspace clinicians, 2 EIP clinicians).		of hEIT, the model of care, the relationship between hEIT and other services, and recommendations for the future.	Referral source: 111 (63%) headspace, 39 (22%) specialist mental health service, and 13 (7%) GPs. Most common presenting diagnoses are depression, mixed anxiety and depression, trauma and stress-related, and psychotic disorders. *Implementation/Process/Resources* Building bridges between services: hEIT built a bridge between primary and more specialist mental health services enabling improved understanding, collaboration, sharing of expertise and upskilling, and communication between the services and improving access and transitions for young people. Filling a clinical gap: hEIT was perceived as effectively filling an important clinical gap for

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					patients who were ‘too unwell’ for primary care services but ‘not unwell enough’ for specialist services. hEIT was valued for its clinical expertise, comprehensive and intensive care, and a flexible, assertive, and community outreach approach. However, the changing remit of hEIT (psychosis only to all mental health disorders) caused some confusion and the time-limited support was perceived as a barrier. Service collaborations and their challenges: While hEIT improved understanding through collaborative discussions, joint assessments, and ongoing clarifications of expectations, tensions in the service partnerships were also identified. There was a lack of clarity on which service was being enhanced by hEIT and the referral criteria, a lack of physical space, duplication of

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					documentation and different service cultures, philosophies, and expectations. All causing tensions in the partnerships. Difficulties of small team size: hEIT's small team size and staff shortages created major disruptions to care, ability to take on referrals, and staff wellbeing. *Outcomes* Overall, interviewed clinicians valued the services provided by hEIT, but there were some tensions in the collaboration and communications and limited resources and pressures.
White et al., 2021	Retrospective cohort study.	26 young people assessed by hEIT in 6-	Age: *M* = 19.8 years (range = 14-25).	Retrospective file audit of electronic medical records for demographic, types of services	*Reach/Intake* Referral source: 54% headspace and 19% from Sydney Local Health District (e.g., emergency department, inpatient, and community team).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		month period. 54 anonymised patient satisfaction surveys.	Gender: 58% female, 31% male, 12% other. Diagnoses (at admission): 46% anxiety, depression, or mixed anxiety/depression, 23% trauma and stress-related, 15% schizophrenia or psychosis, 8% bipolar disorder, and 8%	received, and clinical outcomes. Clinical outcomes at admission and last recorded time point included K10, HoNOS/HoNOS$_{ca}$, and SOFAS. Patient satisfaction measured using a fully anonymised Your Experience of Service (YES) survey.	54% lived with family and 27% in a shared house, 46% were in part time work, 38% at university, 27% in school, 15% in employment, and 4% were aboriginal. *Implementation/Process/Resources* Mean length of care = 227 days (*SD* = 193, range = 6 to 639 days). 2 to 159 contacts per young person (varied by need, *M* = 36, *Mdn* = 23). Following referrals were made: 22 medical, 17 psychological therapy, 9 inpatient admission, 9 social support (finance, family, housing, and employment), 7 dietician/exercise, 5 acute care, 5 GP, 2 headspace, 1 family and community services, 1 forensic service, 1 rehabilitation programme, and 1 biofeedback study.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			substance-related disorder.		Pathways at end of treatment: 19% EIP, 15% headspace, 15% private psychologist, 12% GP, 4% another hEIT, 4% Orygen Youth Health, and 27% disengaged without discharge planning. Staff shortages were a barrier and resulted in a 6-week period where the service was closed to new referrals. *Outcomes* There was little or no change in living arrangements, or education/employment between admission and discharge. There was a significant improvement in social and occupational functioning (from serious to moderate difficulty), trend level improvements in anxiety/depression/stress, and significant improvement in non-accidental self-harm in

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					under 18s. The HoNOS/HoNOS$_{ca}$ total did not significantly improve. Young people rated hEIT above average on 24/26 items on the YES survey, achieving a score of 4.9/5 on 8 items covering sense of safety, respect for values and opinions of young people, staff attitudes, environment, and facilities.
Dresden Early Recognition Centre (DERC)					
Pfennig et al., 2013	Cross-sectional.	250 youth referred to DERC.	No data.	No data.	*Reach/Intake* 2/3 had a manifest mental health disorder at assessment. All 250 youth were offered diagnostics, and counselling or a transfer of care.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
Leopold et al., 2013	Cross-sectional.	192 youth referred to DERC.	Age: *M* = 25 years. Sex/gender: 45% female, 55% male/other.	Standardised intake assessment includes psychiatric and medical history, psychopathological state, and SCID-I. If suspicion of prodromal disorder, then the following were administered: SIPS, BSABS, SPI-A, BPSS, and EPIbipolar.	*Reach/Intake* Referral sources: 27% self-referral, 16% friends or family, 46% from specialist or standard psychotherapeutic care, and 11% from other medical services. Of the 192 who made contact, 7% were referred to a different service, 6% needed no further action, and 87% were offered an assessment. Of the 149 that underwent assessment, 30% of all patients had not had any contact with specialist service and 61% of individuals with self- or friend/family referrals had not had contact with specialist services. 89% completed the full assessment procedure. 52% met criteria for any psychiatric disorder, 18% fulfilled at-risk criteria for bipolar disorder, 18%

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					high risk for psychosis, and 3% met high risk criteria for both groups. 63% of patients at-risk for bipolar disorder already had another manifest psychiatric disorder at the time of assessment. Fear of stigmatization and difficulties navigating services were often given as reasons for not accessing services.
Leopold et al., 2014	Cross-sectional.	284 youth referred to DERC.	Age of bipolar at-risk group (*n* = 29): *M* = 23.6 years (*SD* = 3.9). Gender of bipolar at-risk group (*n* = 29): 62% female, 38% male/other.	Standardised intake assessment includes psychiatric and medical history, psychopathological state, and SCID-I. If suspicion of prodromal disorder, then the following	*Reach/Intake* Referral sources for assessed individuals were (*n* = 180): 48% psychiatrists/psychotherapists, 30% self-referral, 10% family/friends, 9% others (teachers, counsellors), and 3% GP. Referral sources for the at-risk group were (*n* = 29): 38% psychiatrists/psychotherapists, 45% self-referral, 7% family/friend, 3% others (teachers, counsellors), and 7% GP.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			Diagnoses of bipolar at-risk group (*n* = 29): 79% mood disorders, 34% anxiety disorders, 7% substance related disorders, 10% personality disorders, 0% psychotic disorders, 7% adjustment disorders, 2% dissociative	were administered: SIPS, SPI-A, BPSS, and EPIbipolar.	Under-recognition of the problems by themselves and/or social environment were a reason for not previously accessing care. 180 (63%) underwent complete assessment procedures. 29/180 (16%) fulfilled at-risk criteria for bipolar disorder. The at-risk group were significantly younger and had significantly more diagnoses. 93% of at-risk patients fulfilled DSM-IV criteria for a current and/or life-time mental illness. 48% of at-risk patients had received some previous pharmacological and/or psychotherapeutic treatment. *Implementation/Process/Resources* Treatment provided: psychoeducation (100%), psychotherapy (CBT and/or preventative

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			disorders, 2% ADHD.		interventions) alone (62%), pharmacotherapy (mood stabilizers and/or antidepressants) alone (17%), and psychotherapy plus pharmacotherapy (14%).
Zurich Early Recognition Program (ZInEP)					
Theodoridou et al., 2014	Cross-sectional.	273 individuals screened for ZInEP eligibility and consented to take part.	Age: *M* = 20.99 years (*SD* = 6). Sex/gender: 40% female/other, 60% male.	Of relevance to the current review: psychopathology and high-risk assessments administered at baseline included SPI-A, SIPS, PANSS, HCL-32,	*Reach/Intake* 221 (81%) completed baseline assessment. 155/221 (70%) met at-risk criteria for bipolar disorder. 133/221 (60%) had mild depression or greater (HAMD >12) and 147/221 (67%) had mild anxiety or greater (BAI >10).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
				CDS, HAMD and BAI.	
Jano					
Gómez-Ruiz et al., 2010	Prospective cohort with control.	36 first episode bipolar patients receiving treatment at Jano. 36 healthy control participants.	Age: patients with bipolar disorder - *M* = 33.69 (*SD* = 11.61); healthy controls - *M* = 28.66 (*SD* = 9.37). Groups matched on sex, education level, premorbid IQ, and clinical variables.	Neuropsychological variables collected at intake and 12-month follow-up: verbal memory, visual memory, motor co-ordination, executive function, working memory, attention, and processing speed.	*Outcomes* At baseline and 12-month follow-up first episode bipolar patients demonstrated worse cognitive functioning than controls.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
Panic Disorder Unit (PD Unit)					
Herrán et al., 2005	Pre-test -post-test.	41 patients with untreated panic disorder receiving treatment at the PD Unit.	Age: *M* = 32.4 years. Sex: 66% female, 34% males. Presenting problem: 32% panic disorder without agoraphobia, 68% panic disorder with agoraphobia.	Measures administered at intake and 8-weeks after SSRI treatment: MINI, CGI, PDSS, STAI, MCMI-II, and blood sample to evaluate acute phase proteins and cortisol.	*Reach/Intake* Duration of untreated panic disorder at intake: *M* = 18.8 months (95% CI 6.7–31.0), *Mdn* = 5 months. *Implementation/Process/Resources* 25 patients were treated with paroxetine, 12 with citalopram, 2 with sertraline, and 1 with fluoxetine, and 24 were also treated with low-dose benzodiazepines. *Outcomes* At follow-up, 30 (73%) of patients were considered to have responded to SSRI treatment. Across all patients, there was only a trend decrease in albumin from pre- to post-treatment. When considering only patients who responded

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					to SSRIs, there was a significant decrease in albumin levels, and a trend towards a decrease in cortisol and C-reactive proteins at follow-up.
Carrera et al., 2006	Pre-test – post-test.	103 patients with untreated panic disorder receiving PD Unit treatment.	Age: *M* = 32.5 years (*SD* = 9.9). Gender: 66% females, 34% males. Presenting problems: 34% panic disorder without agoraphobia, 66% panic disorder with agoraphobia, 12% mild	Measures administered at intake and/or 8-weeks after SSRI treatment: MINI, PRIME-MD, PHQ-9, NEO-FFI, CGI, PDSS, STAI, and BDI.	*Reach/Intake* Duration of an untreated panic disorder at intake: *M* = 34.9 months (*SD* = 60.2), *Mdn* = 8 months. *Implementation/Process/Resources* Prescribed treatment: 38 (37%) SSRI alone, 57 (55%) SSRI plus benzodiazepines, and 8 (8%) benzodiazepines. *Outcomes* Following 8-weeks of pharmacological treatment, 30 (29%) patients were very much improved, 37 (36%) were much improved, 21 (20%) were minimally improved, 9 (9%) had no improvement, 1 (1%) were minimally impaired,

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			comorbid major depression, 17% comorbid generalised anxiety, and 18% premenstrual dysphoric disorder.		and 0 (0%) were much impaired or very much impaired. No personality dimensions were predictive of outcome, but female gender and baseline state anxiety were associated with worse CGI outcomes.
Biddle et al., 2008	Pre-test – post-test and cross-sectional.	Limited data. 250 individuals referred to the PD Unit (cross-sectional	Age of cross-sectional sample: *M* = 33 years. Gender of cross-sectional sample: 2/3 female.	Measures administered at intake: NEO-FFI, MCMI-II, SCID-II, CGI, and PDSS. Measures administered at 8-	*Reach/Intake* 1/3 access the service through a mental health unit, 1/3 through from hospital emergency services, and 1/3 through various sources such as inter-consultations. 2/3 of 250 referrals met inclusion criteria. Duration of an untreated panic disorder at intake: *Mdn* = 8 months.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		evaluation only).		week follow-up: CGI and PDSS.	*Outcomes* At follow-up the CGI indicated "much improved". Panic disorder severity reduced from moderately/markedly ill to borderline/slightly ill. High state anxiety, female gender, and the avoidance personality dimension were associated with worse outcomes.
Navarro et al., 2013	Pre-test – post-test.	82 patients with untreated panic disorder receiving PD Unit treatment.	Age: *M* = 34.5 years (*SD* = 10.05). Gender: 71% female, 29% male.	Measures administered at intake and/or 12-month follow-up: MINI, MCMI-II and CGI.	*Outcomes* The CGI improved from 4.33 (*SD* = 0.98) to 1.65 (*SD* = 0.93) at 12-month follow-up. There was a mean percentage improvement of 60%. Personality trait scores for all dimensions of the MCMI-II were less than 75 (>75 indicates pathology) at intake and at 12-month follow-up. Schizoid, schizotypal, borderline, phobic, and dependent personality traits normalised from intake to 12-month follow-up.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					Personality traits did not impact clinical outcomes.
Postnatal Depression Intervention Programme (PNDI)					
Chen et al., 2011	Pre-test – post-test.	1367 postpartum women screened for PNDI eligibility.	Age of intervention group (*n* = 41): 10% 18-24 years, 71% 25-34 years, 17% 35-40 years, 2% >41 years. Diagnosis in the intervention group: 68%	Questionnaires administered at baseline and at 6-months or discharge: EPDS, GAF, and EQ-5D-5L. Patient satisfaction survey was administered at 6-	*Reach/Intake* 80/1367 (6%) had a borderline EPDS score (10-12) and were offered counselling and follow-up phone reviews. 126/1367 (9%) had probable postnatal depression (EPDS score >12) and were offered the intervention programme. 41/126 (33%) of high scorers accepted intervention. High scorers that declined treatment did so for various reasons including no time, cost concerns,

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			major depression, 17% minor depression postpartum onset, and 15% other (e.g., anxiety disorder, adjustment disorder).	months or discharge.	limited insight, moved area, and the stigma of receiving a psychiatric disorder. Patients that accepted clinical interventions presented significantly later in the postpartum period and had a higher EPDS score. *Outcomes* Of those receiving counselling only, 65% demonstrated improved EPDS scores. Of those receiving clinical intervention, 78% of EPDS scores reduced to below the clinical cut-off, 76% had improved GAF, and 68% had improved EQ-5D-5L. Only 3 participants had either no change or poorer scores on the EPDS, GAF, and EQ-5D-5L. Compared to those that declined clinical care, patients that accepted intervention had

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					significantly greater reductions in their EPDS score. >95% of counselling support patients were satisfied or very satisfied. 71% of clinical intervention patients were satisfied or very satisfied (the remainder were neutral).
Chen, 2011	Pre-test – post-test.	2163 postpartum women screened for PNDI eligibility.	No data.	Questionnaires administered before and after treatment: EPDS, GAF, and Euroqol Health Index scores.	*Reach/Intake* 108/2163 (5%) had borderline EPDS scores (10-12) and were offered counselling and follow-up support. 176/2163 (8%) had probable postnatal depression (EPDS score > 12) and were offered clinical intervention. 69/176 (36%) of high scorers accepted intervention. High scorers declined intervention for various reasons including no time, cost concerns, stigma

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					or because they did not believe they had postpartum depression. High scorers that accepted intervention presented later in their postpartum period (by ~4 weeks) and had significantly higher EPDS scores. *Outcomes* 87% of intervention participants experienced at least a 20% improvement in EPDS scores, with 78% dropping below the clinical cut off. 83% of intervention participants had improvements in GAF and Euroqol Health Index. Women that accepted the intervention had significantly higher reductions in EPDS than those that declined, but 3/4 of those that declined still had lower EPDS scores.

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					Many of the women who had no change or deteriorated were experiencing social problems (e.g., marital conflict). 95% of the women who received supportive counselling were satisfied and 71% of those who received the intervention were satisfied.
Lee et al., 2016	Pre-test – post-test.	5245 postpartum women screened for PNDI eligibility.	Age of women offered intervention (*n* = 307): 12% 19-24 years, 62% 25-34 years, 22% 35-40 years, and 4% >41 years. Primary diagnosis of women offered	Questionnaires: EPDS, GAF, and EQ-5D-VAS. Data collected at baseline and 6-months (or last visit, if earlier).	*Reach/Intake* Of the 5245 women, 307 (5.9%) had an EPDS score >12 (*M* = 17.93, *SD* = 5.64) and were offered intervention. *Implementation/Process/Resources* Most patients seen for at least 2 visits. However, 10% of patients with depression were only seen once and 15% of patients with anxiety received an intervention beyond 6 months. *Outcomes*

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			intervention (*n* = 307): 61% major depression, 14% minor depression, 5% postnatal anxiety, 1% OCD, 11% adjustment disorder, 3% puerperal psychosis, 6% other.		PNDI led to a median improvement of 10 points on the EPDS (above an a priori reliable change index of 4 points), 20 points on the GAF (above an a priori reliable change index of 10 points), and 25 points on the EQ-5D-VAS.
Eastern Sydney Perinatal Mental Health (ESPM)					

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
Austin et al., 1999	Pre-test – post-test and cross-sectional.	300 women receiving ESPM. 68 Early Childhood nurses and midwives. 16 GPs.	Age of patients: *M* = 31 years. Presenting problems of patients: 41% major depression, 27% adjustment disorder, 4% panic disorder, 2% affective psychosis, 2% OCD, 8% personality disorder, and 16% had relationship	A questionnaire evaluating promptness of assessment, ease of access and acceptability of service, quality of feedback to referring agent and perceived key aspects of the intervention were sent to all relevant stakeholders over 12-months. EPDS was administered to	*Reach/Intake* Referral source: 50% Early Childhood Nurses, 16% GPs, 15% from obstetric or mothercraft hospital, 9% psychiatrist, and 10% patient or family. On average referrals were made 5-months (range: 1-102 weeks) post-partum with 39% occurring within the first 3 months and 10% during pregnancy. 84% of the women had a psychiatric diagnosis. *Implementation/Process/Resources* 70% of women received an intervention and 30% declined or did not require any further contact with the service. On average, the intervention lasted for 14 weeks (~6 home visits).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			problems or acute crisis.	women seen in the pathway at baseline and post-treatment.	25% of the women were on anti-depressants at discharge. 1/3rd required a review by a psychiatrist and in 90% of cases the diagnosis made by the nurse was the same as the psychiatrist. *Outcomes* 80% of patients returned satisfaction questionnaires. All but one was positive about the ease of access, strong educational and problem-solving component, and emotional support. All nurses and midwives were positive about the service, specifically about the promptness of assessment, efficiency of liaison, sense of having a role to play as the primary health care worker, and reduction in stress levels.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					All but one GP believed a prompt assessment was received and all but two were satisfied with the feedback provided. At discharge (*n* = 84), 85% of the women had an EPDS score <10 (below threshold for probably depression) and the mean score significantly reduced from 17.9 (*SD* = 4.9) to 5.5 (*SD* = 3.9).
The Early Motherhood Service (EMS) Judd, Stafford, Gibson, & Ahrens, 2011	Mixed method evaluation including a service document review, site visits and	8 participants for semi-structured interviews. 527 women receiving EMS (pre-	Age of women who completed pre-post measures: *M* = 30.3 years (*SD* = 5.88).	Document review, semi-structured interviews, and observations to evaluate the structure, function,	*Reach/Intake* Referral source of 487 cases: 21% consumer themselves, 20% maternity services, 19% maternal child health nurses and 16% GPs. *Implementation/Process/Resources* For 375 cases, the mean wait from referral to assessment was 6.81 days (*SD* = 6.75) with 18%

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	observations, semi-structured interviews, pre-test – post-test measures, and a cross-sectional satisfaction survey.	test – post-test measures). 107 women receiving EMS (satisfaction survey).	Semi-structure interview participants: a psychiatrist, a GP, two maternal child health nurses, and four nurses.	and procedures of the service. EPDS and HoNOS administered at initial referral and discharge. 7-item satisfaction survey sent to patients at discharge.	assessed on the same day, 52% within 5 days, and 79% within 10 days. On average, there is 94.63 days (*SD* = 99.94) between assessment and discharge. 12 key characteristics were identified as facilitating the effectiveness or success of the service: (1) broad coverage of perinatal mental health problems; (2) inclusion of early intervention/prevention; (3) outreach to women's homes increases accessibility; (4) availability of support to other health workers; (5) location and name of the service minimised stigma and promoted accessibility; (6) 'no wrong door approach' – anyone can refer; (7) staffed by senior clinicians with good mental health skills; (8) support for EMS workers from mental health services promoted safe, effective and

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					comprehensive care; (9) strong partnership with the broader health sector; (10) capacity building of non-mental health workers promoted better identification and early referrals; (11) easy referral process; (12) availability of outcome data to examine value of service. *Outcomes* EPDS (*n* = 168) and HoNOS (*n* = 184) improved significantly from intake to discharge with a small to medium effect size. 60% of patients scored above the EPDS threshold (>12) before treatment and this reduced to 1% after treatment. Most women seen by the service (almost 100%) were satisfied or very satisfied with the service, treatment, communication, confidentiality, and location.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
First Episode Rapid Early Intervention for Eating Disorders (FREED)					
Brown et al., 2018	Quasi-experimental pre-test – post-test design with historical TAU.	51 young adults with EDs receiving FREED. 89 young adults with EDs seen in the service in the 2 years before FREED was	Age: FREED - *M* = 20.64 (*SD* = 2.52); TAU - *M* = 20.47 (*SD* = 1.99). Sex: FREED - 96% female, 4% male; TAU - 98% female, 2% male. Diagnosis: FREED - 39%	Outcomes at baseline: Onset interview plus life chart to assess onset and duration ED symptoms includes items from EDDS and EDE (FREED patients only); ED onset and duration in the clinical assessment	*Implementation/Process/Resources* Compared to TAU, FREED patients waited significantly less time from referral to assessment (FREED *M* = 6.44 weeks (*SD* = 5.38) vs TAU *M* = 9.94 weeks (*SD* = 5.87)) and treatment (FREED *M* = 9.59 weeks (*SD* = 5.78) vs TAU *M* = 19.87 weeks (*SD* = 15.11)). The difference was even larger for FREED patients with limited gatekeeping issues (FREED assessment wait *M* = 3.67 weeks (*SD* = 3.35); treatment wait *M* = 6.25 weeks (*SD* = 3.63)).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		introduced (historical TAU).	AN, 33% BN, 0% BED, 28% OSFED, 0% no ED; TAU - 38% AN, 28% BN, 5% BED, 28% OSFED, 0.02% no ED.	and letter; wait from referral to assessment and treatment; and percentage treatment uptake. Patient satisfaction visual analogue scale administered to FREED patients and 3-month follow-up.	FREED patients had a non-significantly shorter duration until specialist service contact (DUSC) (FREED 15.67 months (*SD* = 10.04) vs TAU 16.16 months (*SD* = 10.63)) and duration of an untreated EDs (DUED) (FREED 16.69 months (*SD* = 10.08) vs TAU 19.09 months (*SD* = 11.67)). The difference in DUED approached significance for FREED patients with minimal gatekeeping issues (DUED 13.04 months (*SD* = 9.29); DUSC 12.45 months (*SD* = 9.14)). FREED patients had significantly higher treatment uptake rates (FREED 100% vs TAU 73%). Gatekeeping procedures in the NHS were a notable barrier to FREED. *Outcomes*

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					At 3-month follow-up, FREED patients reported high satisfaction for waiting times and the process of starting treatment.
McClelland et al., 2018	Quasi-experimental pre-test – post-test design with historical TAU.	56 young adults with EDs receiving FREED 19 carers of FREED patients. 86 young adults with EDs seen in the service in the 2 years before	Age: FREED - *M* = 20.4 (*SD* = 2.4); TAU - *M* = 20.4 (*SD* = 2.0). Sex: FREED - 96% female, 4% male; TAU - 99% female, 1% male. Diagnosis: FREED - 35% AN, 32% BN, 2% BED, 27% OSFED; TAU -	Service utilization, wait for assessment and treatment, and BMI at baseline, and 3-,6-, and 12-months were gathered from clinical notes. Questionnaires administered to FREED patients and carers at baseline, and 3-, 6-, and 12-months:	*Implementation/Process/Resources* Compared to TAU, wait from referral to assessment was 19.5 days shorter (not significant) and the wait from assessment to treatment was 14 days shorter for FREED patients (significant). Significantly more FREED patients took up treatment after their assessment (FREED 100% vs TAU 74%), but there was no significant difference in the number of treatment sessions (FREED 21.5 vs TAU 16) or treatment completion (FREED 71% vs TAU 71%). 8.9% of FREED patients and 14.1% of TAU patients needed day/in-patient treatment.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		FREED was introduced (historical TAU).	40% AN, 28% BN, 5% BED, 27% OSFED.	EDE-Q, CORE-10, DASS-21, WSAS, CIA, LEE, and AESED.	*Outcomes* FREED patients experienced significant improvements in ED symptoms, BMI, general psychopathology, work/social functioning, and expressed emotions over the 12-month study period with greatest improvements occurring in the first 6-months. The proportion of FREED patient scoring below the EDE-Q clinical cut-off increased from 18% to 70%. 61% of carers had some sort of involvement in treatment and had significant improvements in general psychopathology, expressed emotions, and less accommodating of ED symptoms over the 12-months with greatest improvements in the last 6-months.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					FREED and TAU patients experienced similar rates of improvement in BMI over the 12-month. However, TAU patients lost weight between assessment and start of treatment and FREED patients gained weight. FREED therefore had a higher marginal BMI at the start of treatment that was maintained over the 12-months. At the 12-month follow-up 58.8% of FREED patients with AN were weight recovered compared to 16.7% TAU patients with AN.
Fukutomi et al., 2020	Quasi-experimental pre-test – post-test design with historical TAU.	22 young adults with AN receiving FREED. 35 young adults with	Age: *M* = 20.4 years.	Service utilization and BMI data extracted from electronic medical records for 12-24-months period after the start of	*Implementation/Process/Resources* FREED-AN patients attended a higher number of treatment sessions than TAU-AN patients (FREED *M* = 30.5 (*SD* = 17.0) vs TAU *M* = 20.5 (*SD* = 15.4)). 23% (5/22) FREED-AN and 32% (9/28) TAU-AN patients needed day- or in-patient treatment.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		AN seen in the service in the 2 years before FREED was introduced (historical TAU).		treatment for FREED and TAU patients.	*Outcomes* FREED-AN and TAU-AN had a similar rate of improvement in BMI, but FREED-AN had a higher marginal BMI. 71% (12/17) FREED-AN and 22% (2/9) TAU-AN patients were weight recovered in the 12-to-24-month period (across all time points 59% FREED-AN and 21% TAU-AN were weight recovered).
Flynn et al., 2020	Quasi-experimental pre-test – post-test design with historical TAU.	278 young adults with EDs receiving FREED. 224 young adults with EDs seen in	Age: FREED - *M* = 20.19 (*SD* = 2.39); TAU - *M* = 20.28 (*SD* = 2.43). Sex: FREED - 93% female, 7% male; TAU -	Outcomes at baseline: Onset interview plus life chart to assess onset and duration ED symptoms includes items from EDDS and EDE	*Implementation/Process/Resources* Median wait for 48-hour engagement call was 2.5 days. FREED patients waited significantly less time for assessment (FREED *M* = 3.58 weeks (*SD* = 3.79) vs TAU *M* = 6.72 weeks (*SD* = 8.70)) and treatment (FREED *M* = 8.06 weeks (*SD* = 5.73) vs TAU *M* = 20.76 (*SD* = 16.60)). FREED

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		the services in the 1.5-2 years before FREED was introduced (historical TAU).	96% female, 4% male. Diagnosis: FREED - 42% AN, 26% BN, 1% BED, 31% OSFED; TAU - 52% AN, 26% BN, 3% BED, 20% OSFED.	(FREED patients only); ED onset and duration in the clinical assessment and letter; wait from referral to assessment and treatment; wait for engagement call in days (FREED patients only); and percentage treatment uptake.	patients without external delays waited only 2.56 weeks (*SD* = 1.64) for assessment and 6.36 weeks (*SD* = 3.21) for treatment. No significant difference in duration until specialist service contact (DUSC) (FREED 16.47 months (*SD* = 10.41) vs TAU 16.82 months (*SD* = 10.31)). The duration of untreated ED (DUED) was significantly shorter for FREED relative to TAU patients (FREED *M* = 17.85 months (*SD* = 10.38) vs TAU *M* = 19.98 (*SD* = 11.13)), especially for FREED patients without external delays (15.95 months (*SD* = 9.74)). Treatment uptake was significantly higher for FREED patients (FREED 97.84% vs TAU 71.43%).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					Approximately half of all patients experienced delays in accessing FREED care due to NHS gatekeeping issues (e.g., funding), transitioning from another service, or patient related delays (e.g., travelling, holiday).
Austin et al., 2021b	Quasi-experimental pre-test – post-test design with historical TAU.	278 young adults with EDs receiving FREED. 224 young adults with EDs seen in the services in the 1.5-2 years before FREED was	Age: FREED - *M* = 20.19 (SD = 2.39); TAU - *M* = 20.28 (SD = 2.43). Sex: FREED - 93% female, 7% male; TAU - 96% female, 4% male. Diagnosis: FREED - 42%	Service utilization data gather from electronic medical records for TAU and a study specific case record for FREED. BMI: weight and height taken from clinical notes for TAU patients at assessment,	*Implementation/Process/Resources* There was no significant difference between treatment completion (FREED 70% vs TAU 65.6%) and number of sessions (FREED 18.64 vs TAU 16.67) between FREED and TAU patients. The proportion and number of days in day- and/or in-patient treatment was significantly less for FREED (6.6%, 7.03 days) relative to TAU patients (12.4%, 17.93 days).

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		introduced (historical TAU).	AN, 26% BN, 1% BED, 31% OSFED; TAU - 52% AN, 26% BN, 3% BED, 20% OSFED.	baseline, and 3-, 6-, and 12-month follow-up. Outcomes collected from a questionnaire administered to FREED patients at baseline, and 3-, 6-, and 12-month follow-up: BMI, EDE-Q, CORE-10, DASS-21, WSAS, CIA, LEE, and PSYCHLOPS.	There was trend for significantly lower costs for FREED treatment (FREED *M* = £8781, *SD* = £21976 vs TAU *M* = £13604, *SD* = £32997) *Outcomes* FREED patients experienced a significant improvement in ED symptoms, BMI, general psychopathology, functional outcomes, and expressed emotions over the 12-month study period. Rate of recovery for FREED patients with AN increased from 0.9% at baseline to 36.7% at 12-months and for FREED patients with BN/BED/OSFED increased from 8.1% to 65.2%. Despite similar BMIs at assessment, FREED patients with AN started treatment with a higher BMI than TAU patients and continued to have a higher BMI at all time points.

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					At 12-months, 53% of FREED and 17.9% of TAU patient with AN were classified as weight recovered.
Richards et al., 2021	Quasi-experimental with historical TAU.	259 young adults with EDs receiving FREED. 224 young adults with EDs seen in the services in the 1.5-2 years before FREED was introduced	Age: FREED - *M* = 20.19 (SD = 2.34); TAU - *M* = 20.28 (SD = 2.43). Sex: FREED - 93% female, 7% male; TAU - 96% female, 4% male. Diagnosis: FREED - 42% AN, 27% BN/BED, 31%	Adherence to the FREED wait time targets of ≤ 2 days for the engagement call, ≤ 14 days for assessment, and ≤ 28 days for treatment (FREED and TAU patients). Type of treatment and use of the FREED care package at assessment and	*Implementation/Process/Resources* 89% of engagement calls were initially attempted within 2 days and 50% were received within 2 days. 51% of FREED assessments were offered within 14 days and 43% received their assessment within 14 days, and this was substantially higher than TAU patients (19%). 33% of FREED treatment was offered within 28 days and 22% started within 28 days, and this was substantially higher than TAU patients (3%). Interventions provided to patients with AN: CBT for EDs (49%), Maudsley Model of Anorexia Nervosa Treatment for Adults (48%), cognitive

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		(historical TAU).	OSFED; TAU - 52% AN, 29% BN/BED, 20% OSFED.	during treatment as recorded on the study specific patient journey record (FREED patients only).	analytical therapy (6%), or family-based therapy (1%). Interventions provided to patients with BN/BED: CBT for EDs (83%) or cognitive analytical therapy (3%). Interventions provided to patients with OSFED: CBT for EDs (90%), Maudsley Model of Anorexia Nervosa Treatment for Adults (6%), family-based therapy (3%), or cognitive analytical therapy (2%). Overall, the use of the FREED care package was moderate to high (ranged from 45% to 99%) and varied by diagnosis, stage of care, and care package component. Psychoeducation and dietary change were the most well-used care package components

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					whereas attention to transitions was less well-used.
Potterton et al., 2021	Qualitative evaluation including semi-structure interviews and survey data.	106 young adults with EDs receiving FREED (100 completed questionnaires; 14 completed interviews).	Age: *M* = 20.75 (*SD* = 2.56). Gender: 92.5% female, 7.5% male/other Diagnosis: 39% AN, 31% BN, 1% BED, 29% OSFED.	Qualitative questionnaire item asking if participants had anything they would like to share with the FREED service. Semi-structured interviews focused on exploring the patients experience of receiving treatment and the	*Implementation/Process/Resources* Five beneficial characteristics of FREED were identified: (1) rapid access to treatment was perceived positively as it prevented behaviours becoming engrained, deterioration, and disengagement, but some felt that it was not early enough and guilty about others not receiving early intervention; (2) knowledgeable and concerned clinicians; (3) focusing on family/friend involvement and building support networks; (4) focusing on life beyond the ED including flexibility around life instability and future life goals (5) becoming your own therapist. *Outcomes*

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				impact of the treatment.	75% of questionnaire participants reported positive psychological and behavioural changes during treatment (e.g., reduced symptoms, increased understanding, identity development; 1/3 reported dramatic changes: "recovered", "life-changing"). 3% of participants believed that treatment was not associated with change and 2% felt that they were discharged before change had been achieved (feeling hopeless and abandoned).
Emerge-ED Radunz et al., 2021	Pre-test – post-test.	96 youth with ED symptoms of less than 3 years duration and	Age: *M* = 19.3 years (*SD* = 2.39, range = 16-26).	Short session-by-session measure of ED cognitions (ED-15). Self-reported ED (EDE-Q), clinical	*Reach/Intake* Of the 76 that completed the EDE-Q at baseline, 48% reported binge eating, 43% driven exercise, 21% self-induced vomiting, and 5% laxative misuse. 84% had an EDE-Q score above the clinical cut-off (≥ 2.77).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		a BMI >14.5.	Gender: 92% identified as female.	impairment (CIA), mood (DASS-21), and BMI at baseline, end of treatment, and 1-month, and 3-month follow-up.	*Implementation/Process/Resource* Treatment received: 20 psychoeducation, 15 CBT-T, and 48 CBT-E (data missing for 13). The mean number of treatment sessions was 13.85 (*SD* = 12.11, range = 2-75). *Outcomes* Session-by-session measures demonstrated significant decreases in ED cognitions and behaviours over time (except laxative use which was of low frequency). Cohen's *d* effect sizes were: .45 for cognitions, .26 for objective binges, .12 for vomiting, and .27 for dietary restriction. Only baseline and end of treatment were included in the analysis due to missing data. The 30 participants that completed pre- and post-treatment measures demonstrated large improvements in global eating disorder

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					psychopathology (*d* = 2.05), clinical impairment (*d* = 2.32), and negative affect (depression: *d* = 1.60; anxiety: *d* = .89; stress: *d* = 1.14). Underweight and healthy weight groups experienced significant increases in BMI (*d* = .21). 83% scored below the EDE-Q clinical cut-off (vs 16% at baseline). The improvement in global eating disorder symptoms is comparable to other ED effectiveness studies.
Stepped Collaborative Care (SCC)					
Zatzick et al., 2004	Randomised controlled trial.	59 trauma patients receiving SCC.	Age: SCC - *M* = 37.1 years (*SD* = 13.2), TAU - *M*	Detailed logs were kept on the nature and duration of	*Implementation/Process/Resources* The number of hours required from the case managers was *M* = 10.7 hours per patient over

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		61 trauma patients receiving TAU.	= 44.4 years (*SD* = 16.3). Sex/gender: SCC - 32% female, 68% male; TAU - 33% female, 67% male. 25 participants met DSM-IV criteria for PTSD. All participants were symptomatic with PTSD (PCL score, ≥45) and/or	intervention activities. PCL was administered at intake/screening, and 1-, 3-, 6-, and 12-months. CIDI alcohol abuse and dependence modules were administered at screening/intake, and 6- and 12-months. SCID-I administered at 3-months for PTSD diagnosis.	12-months (*SD* = 9.8) and for the psychiatrist *M* = 2.7 hours per patient (*SD* = 3.4). Most of the doctoral-level therapist time was spent delivering CBT (38.9 of the 40.6 total hours). 64% of SCC patients received psychiatric evaluation and/or treatment. 37% (38/59) SCC patients were evaluated immediately by the psychiatrist for high levels posttraumatic distress, pain, insomnia, or other injury-related complications. 34% (20/59) SCC patients were offered pharmacotherapy with 10 accepting and maintaining medication. 51% (30/59) SCC patients received motivational interviewing for alcohol abuse with half receiving at least one booster session.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			depression (CES-D score, ≥16).		12/50 (24%) of SCC patients received a PTSD diagnosis at 3-months and were offered pharmacotherapy and psychotherapy. 5/12 (42%) received CBT between 3 to 12-months post injury. *Outcomes* Trend level significant differences in PTSD diagnosis between SCC and TAU at 6-months (SCC had a 6% increase and TAU had a 12% increase). At 12-months, this difference was significant, SCC had a 0.07% decrease and TAU had a 6% increase the rate of PTSD. There was a statistically significant difference in the rate of change of alcohol abuse/dependence between SCC and TAU at 6 and 12 months. At 6 months, SCC had a 20% reduction and TAU had a 7% reduction. At 12 months, SCC group had a

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					24% reduction, and TAU showed a 13% increase.
Zatzick et al., 2011	Cross-sectional.	878 admitted trauma patients screened for eligibility for the service.	Age of positively screened patients (n = 207): M = 38.4 (SD = 13.1) Sex/gender of positively screened patients (n = 207): 47% female, 53% male/other. All participants had elevated PTSD symptoms (scored greater than 35 on PCL-	PCL administered to eligible trauma inpatients at study intake.	*Reach/Intake* Of 878 admitted trauma patients screened for PTSD, 345 (39%) screened positive. 71/345 (21%) could not be reached for the second screen and 19/345 (6%) were excluded for other reasons. 207/255 (81%) screened positive for elevated PTSD symptoms at the second screen. The first screen occurred M = 7.1 days (SD = 14.9) after admission and the second screen M = 20.0 days (SD =16.8) after admission. Compared to previous studies, the two-stage screening process was successful in recruiting participants with a high lifetime cumulative

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			C on two occasions a few days or weeks apart).		trauma burden (5.8 vs 3.4) and early PTSD symptoms (50.6 vs 34.6). Participants recruited using a two-stage screening procedure were significantly more likely to be female, intentionally injured and blood alcohol positive when compared to all patients admitted for injuries.
Zatzick et al., 2013	Randomised controlled trial.	104 trauma patients receiving SCC. 103 trauma patients receiving TAU.	Age: SCC - *M* = 39.4 (*SD* = 13.4); TAU - *M* = 37.7 (*SD* = 12.8). Sex/gender: SCC - 52% female, 48% male; TAU - 44% female, 56% male.	PCL-C, service and treatment utilisation items, general health and emotional health care satisfaction items, PHQ-9, AUDIT-C, and MOS SF-36 PCS were administered	*Reach/Intake* 207/878 (24%) of screened patients were randomised. Participants were diverse, largely publicly insured or uninsured with high levels of PTSD, depressive and alcohol use symptoms, and substantial histories of trauma at baseline. Compared to all other patients admitted to the trauma centre, the study participants were more likely to be female, less severely injured,

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			All participants had elevated PTSD symptoms (scored greater than 35 on the PCL-C on two screenings a few days to weeks apart).	at baseline, and 1-, 3-, 6-, 9-, and 12-months. CAPS was administered at 1-, 6-, and 12-months. Service use, insurance status, and other clinical characteristics were abstracted from electronic records.	intentionally injured, blood alcohol positive, younger, and had greater length of surgical hospitalization. *Implementation/Process/Resource* Care managers spent *Mdn* = 13.2 hours (IQR = 13.3) with each patient over 12-months. The intensity of the input decreased over time, 60% of the care manager activity occurred in the first 6-months. 75% of the nurse practitioners' hours also occurred in first 6-months. 84/104 (81%) SCC patients received a nurse practitioner medication evaluation, 78/104 (75%) were offered PTSD pharmacology, and 48/78 (62%) accepted and maintained their medication. 80/104 (77%) SCC patients received one or more motivation interviewing sessions for alcohol use and other risky behaviours.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					93/104 (89%) SCC patients were assessed for multisession CBT with 25/93 (27%) offered CBT and 9/25 (36%) receiving more than four sessions. Compared to TAU, SCC patients were significantly more likely to receive evidence-based anti-depressant and insomnia medication. *Outcomes* SCC patients demonstrated clinically and statistically significant reductions in clinician and self-reported measures of PTSD symptoms at 6-, 9-, and 12-months post-injury. The reduction was substantially higher than TAU. SCC experienced significant improvements in PTSD treatment response criteria (≥10-point reduction), and PTSD remission criteria (score < 20) compared to TAU. No significant effect on

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					PTSD diagnostic criteria was observed. The effect sizes for PTSD were temporally associated with treatment intensity (greatest at 6-months). Patients with traumatic brain injury responded equally well to SCC. SCC patients also demonstrated significant improvements in physical functioning compared to TAU at 3-, 6-, and 9-month post-injury. There were trend level improvements on depression and alcohol consumption over the 12-month. Compared to TAU, SCC were significantly more likely to report being very satisfied with their general and emotional health care services.
Zatzick et al., 2015	Randomised controlled trial.	60 trauma patients receiving	Age: SCC - *M* = 42.80 (*SD* = 14.65); TAU - *M*	PCL-C, PHQ-9 and items assessing demographics,	*Reach/Intake*

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		technology-enhanced SCC 61 trauma patients receiving TAU	= 43.52 (*SD* = 14.84). Sex/gender: SCC - 35% female, 65% male; TAU - 36% female, 64% male. All participants screened positive to electronic medical record screen items and had a PCL-C score greater than 35.	technology access and use, satisfaction with healthcare, medication, and health service utilization were administered at baseline and 1-, 3-, and 6-months.	Of 1320 admitted trauma patients, 744 (56%) were screen positive on the electronic medical record screen. Of 247 participants screened with the PCL-C, 124 (50%) screened positive for elevated PTSD symptoms. Compared to all other patients admitted to the trauma centre, the 121 study participants were significantly more likely to be intentionally injured, younger, blood alcohol positive, admitted to the ICU, and have a longer hospital stay. The 121 participants included in the study were predominantly publicly insured or uninsured patients with multiple prior traumatic life events. *Implementation/Process*

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					87/121 (72%) of randomised participants had access to a cell phone, and 48/121 (40%) owned or had access to a smartphone at baseline. However, less than 10% had a smartphone available to download the app. The intervention required *Mdn* = 2.25 hours per patient (IQR =1.57). The time intensity gradually decreased with 80% of intervention activities in the first 3 months. 37/60 (62%) of SCC patients received one or more motivational interviewing sessions for substance use and risk behaviours. 44/60 (73%) of SCC patients expressed readiness for pharmacotherapy and 27 (45%) adhered to the medication. 35/60 (45%) of SCC patients demonstrated a readiness and interest in CBT, 14 (23.3%)

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					received one or more CBT elements during routine care management, and only 2 (3%) completed 5 CBT sessions. Compared to TAU, SCC patients were more likely to use the afterdeployment.org website in hospital (62% (*M* = 24.7 mins) vs 52% (*M* = 16.05 mins)) and over the 6 months post injury (31.7% vs 11.5%). Use of the LifeArmor app was low across both group (SCC 11.7% vs TAU 4.9%). Compared to TAU, SCC patients were significantly more likely to take anti-depressants and receive an adequate dose and use PTSD insomnia medication. There was no significant difference in psychotherapy use between the two groups. *Outcomes*

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					SCC patients demonstrated modest reductions in PTSD symptoms in the 6-months post-injury. The difference between the groups was on the margin of significance in the unadjusted (p = .055) and adjusted models (p = .049). At 6-months postinjury, 45% of SCC patients and 30% of TAU patients had more than a 10-point reduction in PCL-C scores from baseline. Although SCC patients showed a pattern of improved depressive symptoms relative to TAU, this difference was not clinically or statistically significant. Over the 6-months post-injury, SCC patient demonstrated significantly greater satisfaction with care than TAU.
Paediatric Stepped					

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
Preventative Care Intervention (PSPC)					
Kassam-Adams et al., 2011	Randomised controlled trial.	46 children/adolescents received TAU plus PSPC. 39 children/adolescents received TAU.	Age: TAU plus PSPC - *M* = 11.2 years (*SD* = 2.2); TAU - *M* = 11.9 years (*SD* = 2.7). Sex: TAU plus SPC - 50% female/other, 50% male; TAU - 28% female/other, 72% male.	Measures administered at baseline, and 6-weeks, and 6-months post-injury: CPSS, CES-D, physical health subscale of the Paediatric Quality of Life Inventory. An intervention intensity score was derived from a case note review.	*Reach/Intake* 34% (290/845) potentially eligible patients were screened. 29% (85/290) of all screened patients scored above symptom thresholds and were randomised. *Implementation/Process/Resources* 89% (41/46) of TAU plus PSPC completed intervention session 1 (approximately 3 days post-injury and 29.2 mins long) and 54% (25/46) completed intervention session 2 (approximately 22.9 days after session 1 and 17.7 mins long). On average, 10 extra minutes outside of the sessions were spent with each case (range: 0-110 mins).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					Intensity of PSPC: 85% (35/41) rated as low intensity, 12% (5/41) as moderate intensity, and 2% (1/41) as high intensity, only 3 cases needed formal mental health assessment or treatment. Engaging patients during short hospital stays was noted as a barrier to implementation. *Outcomes* Both groups demonstrated comparable significant improvements in PTSD, depression, and health-related quality of life over time, except TAU had significantly higher reductions in depression.
German Trauma Outpatient Clinic (TOC) Schürmann, 2010	Pre-test – post-test.	266 individuals	Age: *M* = 30 years (*SD* = 17.32, range = 2	For patients >14 years old the following measures	*Reach/Intake* At intake, there was a higher proportion of offenses of sexual determination and less

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		presenting at the TOCs.	to 81 years old, 211 >14 years old). Sex/gender: 75% female, 24% male, 1% unknown. Diagnoses: 49% PTSD, 21% acute stress disorder, 12% another mental disorder (e.g., adjustment disorder, depression episode, anxiety	were administered before, after, and 6-months after treatment: IES-R, SCL-27, BDI-V, GAF, and CRI.	offenses against physical integrity compared to base rate crime statistics. At presentation, 57% had a positive IES-R (PTSD is likely), 61% had clinically relevant depression, and 76% had increased symptom burden as measured by the SCL-27 and this increased to 72% for depression and 93% for SCL-27 for patients who were affected by the trauma. *Implementation/Process/Resources* Time between the trauma and start of treatment ranged from 0 to 522 days with a mode of 15 days, median of 22 days and a mean of 46 days. 2/3rd received treatment within the first four weeks. Male gender was associated with delayed access to treatment (waited approximately 3-weeks longer to access treatment).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			disorders), and 2% were clinically normal.		There was no significant difference in patients that presented early (<4 weeks) vs late (>4 weeks). The mean number of sessions was 5.63 (*SD* = 4.9, range = 1 to 23) with most contacts occurring in the first 1-5 sessions (64%). Only a third (27%) used the maximum 15 sessions with 1% receiving more than 15 sessions. Most patients received psychoeducation (80%), diagnostics (80%), and stabilisation (63%). Other interventions included advice (28%), liaising with referrers (27%), consultations (3%), referral to different forms of therapy (20%), cognitive restructuring (23%), exposure work (6%), play therapy (2%), family involvement and therapy (2%), and EMDR (16%). The average cost of TOC per patient is less than € 500.00 and TOC resulted in administrative cost

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					savings (not specified) due to the lower rejection of Victims Compensation Act applications (17% vs. 7%). *Outcomes* Fewer notices of "healed without consequences" (i.e., a health disorder that was no longer medically detectable) were issued for all Victim Compensation Act patients (15%) compared to TOC patients (24%). All symptom and functioning scales demonstrated significant improvements from pre- to post-treatment which was maintained at the 6-month follow-up (n = 34 to 40 included in analysis). Effect sizes were medium to large. As measured by the IES-R, 67% of patients were clinically significantly better, 42% could be described as recovered and 4% felt worse.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					Across all instruments, 62% of patients were clinically improved, 41% could be described as recovered, and 3% felt worse after treatment.
Bollmann et al., 2012	Pre-test – post-test.	211 individuals presenting at the TOC.	Age: >14 years old. Sex/gender: 79% female, 21% male. Diagnoses: 52% suspected PTSD, 19% acute stress reaction, 13% another mental health disorder (e.g., anxiety depression), and	Measures were administered before, after, and 6-months after treatment: IES-R, SCL-27, BDI-V, GAF, and CRI.	*Reach/Intake* Types of crimes: 32% offense of sexual determination (2% in police crime statistics), 36% offenses against physical integrity (89% in police crime statistics), 18% robbery and extortion (9% in police crime statistics), and 6% observed an act of violence but not primary victim. More than 90% of patients met criteria for Crime Victims Compensation Act and were eligible for TOC. *Implementation/Process/Resources* 57% attend the TOC within one month of trauma, 31% within three months after the trauma, and

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			2% clinically normal.		12% after 3 months (range: 0-522 days; *M* = 47 days; *Mdn* = 23 days). Victim Compensation Act applications was rejected for 7% of TOC patients compared to 17% of all patients. Interventions provided at the TOC were: 95% psychoeducation, 94% diagnostic, 75% stabilization, 35% advice on suitable forms of therapy, 29% cognitive restructuring, 27% mediation to another form of therapy, 21% conversations with caregivers, 15% EMDR, 8% exposure, and 4% consulting examination. *Outcomes* There was a significant improvement in all symptomatic and functional outcomes before and after treatment which were maintained at a 6-month follow-up (*n* = 72). Effect sizes were

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					large, except for the avoidance scale of the IES-R which had a medium effect.
Rassenhofer et al., 2016	Quasi-experimental design.	25 patients receiving treatment at a TOC within 3 months of the trauma. 14 patients receiving treatment at a TOC more than 3 months after the trauma.	Age: TOC <3 months - *M* = 47 years (*SD* = 15.1); TOC >3 months - *M* = 46.9 years (*SD* = 17.4); non-TOC - *M* = 41 years (*SD* = 11.7). Gender: TOC <3 months - 72% female, 28% male; TOC - >3 months 71% female, 29%	For both TOC groups the following measures were administered at the first appointment and at the end of treatment: PDS-D, ADSL, BQoLP, GAF, and items on demographic, trauma, and clinical variables. For non-TOC patients the	*Reach/Intake* The trauma type differed across the groups. Compared to the TOC groups, the non-TOC patients were less likely to experience physical violence (30% vs 64% and 50%), and more likely to experience sexual violence (23% vs 16% and 7%) and both sexual and physical violence (44% vs 16% and 36%). Most (96%) of the patients receiving treatment from TOC in <3 months experienced a single traumatic event (vs TOC >3 months = 64% and non-TOC = 62%). *Implementation/Process/Resources* For patients receiving TOC <3 months: the mean number of sessions was 5.2 (*SD* = 3.7) provided

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		43 trauma patients not receiving TOC (in areas where TOC is unavailable).	male; non-TOC - 84% female, 16% male.	measures were administered after receipt of Victims Compensation Act application and 12-weeks later: PDS-D, ADSL, BQoLP, and items on demographic, trauma, and clinical information.	over 8.3 weeks (*SD* = 5.1) and weekly meetings were provided for 2/3rd of patients. 74% (14/19) of TOC therapists used trauma-specific methods. Interventions included psychoeducation (95%), imaginative exposure (37%), EMDR (21%), trauma-focused CBT (16%), and other interventions (37%). 32% of TOC <3 months, 64% of TOC >3 months, and 77% of non-TOC patients received additional psychotherapy and counselling. *Outcomes* For TOC <3 months, GAF scores significantly improved from pre- to post-treatment. TOC <3 months led to substantially higher decreases in PTSD symptoms with large effect sizes compared to either those who did not have access to the TOC or did but after 3 months. The

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					effect remained after controlling for age, gender, and trauma type. The two control groups experienced reduction in PTSD symptom, but this was only significant for the non-TOC patients. There was only a significant effect of time on depressive symptoms, and no group or group x time interaction effects. However, if the groups are looked at individually, the TOC <3 months experienced a significant decrease in depression over time whereas neither control group did. The effect was not significant after controlling for age, gender, and trauma type. There was no impact on overall quality of life (except for TOC <3 months for feeling secure).
Oral and Maxillofacial					

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
Trauma Psychological Service (OMTP)					
Price et al., 2015	Pre-test – post-test.	293 maxillofacial patients screened for eligibility.	Age: *M* = 35 years. Sex/gender: 26% female, 74% male. 33% met criteria for PTSD and 84% met screening criteria for any difficulty.	Questionnaires collected at baseline and at 3-months: HADS, PTSD PC-CL, CAGE, and measures of appearance distress, functioning, and risk.	*Implementation/Process/Resources* 35/293 patients received psychology contact with full sign posting and referral, 50/293 received substantial psychoeducation and self-help information, 3/293 were offered trauma-focused psychological therapy, and 35/293 were provided with follow-up calls but did not respond. *Outcomes* Follow-up evaluation demonstrated positive feedback (89% rating the service as helpful) and improved distress and functioning.
Choudhury-Peters & Dain, 2016	Mixed method evaluation including pre-	642 OMTP patients, 51 provided	Age of patients: 3% < 18 years, 40% 18-29	Questionnaires administered at intake and 3-month	*Implementation/Process/Resources* Level of psychological intervention received: 9% screened only, 63% received brief intervention in

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
	test – post-test measures and qualitative feedback interviews.	follow-up and qualitative feedback. Physicians provided qualitative feedback (no data on sample size).	years, 30% 30-39 years, 11% 40-49 years, 7% 50-59 years, 6% 60-69 years, and 3% > 70 years. Sex/gender of patients: 27% female, 73% male. Patients positively screened for 45% anxiety, 38% depression, 32% PTSD, 63% facial distress, 46% issues with	follow-up: HADS, and unspecified questionnaires measuring PTSD, alcohol and drug use, risk to self, and facial appearance distress. Qualitative feedback gathered at 3-month follow-up.	clinic, 26% received in-depth intervention in clinic and onward referral, 1% complex case requiring extensive liaison outside of clinic, and 1% specialist psychotherapy outside of clinic. Notable infrastructure-related barriers to implementation including psychology team difficulties accessing and distributing patient information due to mental health and acute trust IT systems incompatibility, limited protected, confidential, and accessible clinic space for consultations, staff changeovers were a significant challenge, and additional resources were needed for evaluation and data entry. Notable facilitators to implementation were the relationship between the service and board members, highly qualified staff members, and a lack of enforced hierarchy among those

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			daily functioning, 31% alcohol use, 11% drug use, and 14% risk to self.		delivering the service, which brought energy to the project and where changes were welcomed. *Outcomes* The proportion of patients screening positive for mental health difficulties (e.g., anxiety, depression, PTSD) decreased from 79% at baseline to 58% at 3-month follow-up. 78% of all patients said the psychology service had slightly or significantly improved their experience of the trauma clinic. Qualitative feedback indicates that the service was highly relevant and valued by patients because of the proactive approach, and receiving empathy, support, hope and problem normalisation. Staff valued the service because of the rapid, flexible, and integrated care, the benefits for families, increased awareness of the psychological impact

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					of trauma. Both patients and staff reported that it led to improved recovery.
Karolinska Project for Early Treatment of Women with Alcohol Addiction (EWA) Dahlgren & Willander, 1989	Pseudo-randomised controlled trial [women with odd dates of birth were assigned to EWA treatment].	100 women receiving EWA treatment. 100 women receiving TAU.	Age: EWA - *Mdn* = 43 years; TAU - *Mdn* = 41 years. All women were in untreated early phase alcohol dependence.	Medical, social, and psychological data collected after detoxification and at a 2-year follow-up through interviews, questionnaires, physical/medical	*Reach/Intake* 85% self-referral and 15% physician referral. 90% were gainfully employed but 20% had a reduced work capacity (*Mdn* sick days = 30). Most were living with a male partner, of which nearly half of the partners had a drinking problem, and 30% had children <16 years old. Daily alcohol consumption was approximately 120g and laboratory test results were elevated on

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
				examinations, registers for sickness benefits, healthcare use, and social welfare, mortality, and two types of drinking behaviours: relapse and social drinking.	intake, but there was no evidence of chronic alcoholism. Duration of "loss of control" in drinking was *Mdn* = 7 years. *Implementation/Process/Resources* 60% in both groups were recommended initial hospital treatment: 50% of EWA and 31% of TAU accepted. EWA treatment lasted *Mdn* = 8 months and TAU *Mdn* = 5 months. Only 36% of EWA and 21% of TAU continued treatment for 12 months or more. *Outcomes* At follow-up, 4% of EWA and 17% of TAU lost their jobs and 8% of EWA patients and 30% of TAU had reduced work capacity.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					At follow-up, there was no difference in divorce levels and for those still with their partner 40% of EWA and 26% of TAU reported improved relations and reduced partner drinking. Significantly more EWA (35%) compared to TAU (12%) had improved relations to their children and only TAU (12%) reported worsening relations. Voluntary removal of children was also significantly higher for TAU (5% vs 25%). Significantly fewer EWA (16%) needed in-patient care relative to TAU (31%) and only TAU (6%) received additional treatment for alcohol abuse over the observation period. The median number of sick days was 31 for EWA and 37 for TAU. There is a statistically significant excess mortality for TAU but not EWA patients.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					At follow-up, total abstinence or more than 300 days without relapse was significantly higher for EWA at 1 year (67%) and 2 years (59%) relative to TAU (1 year 45%; 2 year 48%). EWA women drank significantly less when relapsing (62.5g vs 125g) and more EWA managed to drink socially (42% vs 20%). EWA patients were also significantly less likely to have daily alcohol abuse at 1 year (8% vs 33%) and 2 years (8% vs 28%). There was no difference on laboratory tests at follow-up. At 2-year follow-up, fewer EWA than TAU reported black-outs (25% vs 40%) and change in mood when intoxicated (17% EWA vs 40% TAU) and definite improvement of nervous symptoms (43% EWA vs 18% TAU).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					In both groups satisfactory outcomes (abstinence and 300 days without relapse) were associated with longer treatment.
Haver & Dahlgren, 1995	Cross-sectional.	60 women receiving EWA treatment.	Age: *M* = 44 years (range: 22-66 years). All but two participants met DSM-III-R criteria for alcohol dependence. Lifetime comorbid diagnoses: 48% mood disorder, 38% anxiety	Questionnaires and interviews at intake were used to evaluate somatic and psychiatric symptoms, alcohol and drug patterns, personality styles, social environment, and experiences of assault and violence. Interviews included SCID-I and -II,	*Referral/Intake* EWA socio-demographics were similar to other women living in Stockholm: 77% gainfully employed, 48% living with partner, and 35% living with children <16 years. Median years of drinking problem were 6 years (range: 1-28). 52% received previous psychiatric treatment. Maximum consumption of alcohol on heavy drinking days was 120g. 14 women (23%) had at least one definite personality disorder. 40% did not have any comorbid psychiatric disorder, 32% fulfilled criteria for one

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			disorder, 2% somatoform disorder, and 4% eating disorders Current comorbid diagnoses: 28% mood disorder, 28% anxiety disorder, 2% somatoform disorder, and 2% eating disorder.	KAPP, and neuropsychological and projection tests.	psychiatric disorder, and 28% met criteria for more than one disorder. There was a higher degree of alcohol dependence in those with comorbid disorders.
Haver & Franck, 1997	Narrative review.	Samples size varied or were not provided.	Not data.	Varied across study or not specified.	*Reach/Intake* Referral source: 44% self-referred, 20% significant others, 12% physician, 14% employer, and 10% social services.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					Characteristics (e.g., age, drinking patterns) of EWA women were stable over studies: numerous studies indicate that EWA women were largely representative of the general population in Stockholm in terms of education, occupation, marriage, patterns of cohabitation, and number of children. Single mothers were over-represented and never married women without children were underrepresented. Over half report previous psychiatric input, and comorbid psychiatric disorders. Most women successful concealed drinking (although drinking almost daily and an average 120g of ethanol) and met DSM-III criteria for alcohol dependence. *Implementation/Process/Resources* 80% of 100 EWA patients attributed the relationship with other patients as an important

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					factor for positive change and many stated that the woman only service acted as a pre-request for involvement in EWA. Attentiveness, respectfulness, and openness of clinicians were appreciated by the EWA patients. Staff were motivated to work in the EWA programme because of the positive treatment results documented, mutually stimulating treatment contact, participation in research projects, and the proudness of being at the frontier of the clinical area. However, the continuous demands, treatment ambivalence, and complicated family and relationship situation can result in long-term stress. *Outcomes* A 2-year outcome study demonstrated that 2/3rd EWA women had a positive drinking outcome,

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					and this was associated with improved subjective wellbeing, job performance, relationships with partners and children and the number of sick days. 2% of EWA women completely abstained and 4% were drinking daily through the follow-up period. EWA was associated with improved psychological functioning following treatment across measures. Poorer outcomes were associated with previous suicide attempts. 9/10 EWA women have reported that they were partly or wholly recovered after the inpatient programme.
Centres D'Hygiene Alimentaire (CHA)					

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
Babor et al., 1983	Narrative review.	Sample size varied across studies or were not specified.	Varied across samples or not reported.	Varied across studies or were not reported.	*Reach/Intake* Referral sources across 53 CHAs: 18% motor-vehicle violations offenders, 13% social-service agencies, 12% industrial physicians, 11% family physicians, 11% hospitals, 11% voluntary admissions, 7% family, 5% license renewal offices, and 1% blood donors. Patients were predominantly married men under the age of 40 years. *Implementation/Process/Resources* Preliminary evidence suggests that with appropriate training the Le Gô grid method of staging is a reliable method for distinguishing dependent from non-dependent drinkers and correlational data demonstrate that Le Gô grid scores vary alongside other biological and clinical indicators. However, self-train examiners

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					differed from experienced Le Gô grid raters and the tool was better at determining longer term than recent drinking behaviour. *Outcomes* A report on 17 years of the Paris CHA indicated that the level of alcohol problems amongst railroad workers were diminished due the programme: 23% of individuals were classified as having “third degree” alcohol problems (the most severe Le Gô grid rating) in 1957 and this reduced to 4% in 1965. By 1966, 75% of all the patients had become abstinent or were drinking moderately. An evaluation of 3158 patients treated across five CHAs demonstrated that 6% were abstinent, 41% were drinking in moderation, 16% "improved" but were not yet drinking moderately, 6%

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					stabilized with no further deterioration, and 19% relapsed, were unable to be contacted, were deceased, or referred elsewhere. It was estimated that approximately 70% of all cases indicated significant improvement. A survey of 53 CHAs found that amongst current patients 21% were abstinent, 33% were drinking moderately, and 31% had stabilised.
Chick, 1984	Retrospective cohort without control.	311 patients referred to the Soissons CHA for drinking-driving offences. 299 patients referred to	Age of Soissons patients: 10% 20 years, 42% 20-30 years, 23% 30-40 years, and 24% >40 years. Le Gô grid classifications for Soissons	Le Gô grid, information gathered at visits, and blood tests to assess drinking problem.	*Referral/Intake* Referral sources varied substantially across CHAs. However, most came from drinking-driving offender organisations (37-50%) or general hospitals (9-52%). Other sources included medical commission for driving licences (0-15%), family and industrial doctors (1-6%), social services (1-8%), and 'other' which included self-referral (2-5%).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		the Nice-Cimiez CHA for drinking-driving offences.	patients: 27% occasional drinkers, 44% excessive drinkers (>60g a day), 23% verging on dependent, 5% dependent. Le Gô grid classifications for Nice-Cimiez patients: 26% occasional drinkers, 47% excessive drinkers (>60g a		76% of drink driver offenders were seen in the Soissons CHA. This is higher than other CHAs (e.g., 20% and 50%). This higher attendance was attributed to the initial approach being made by the CHA, carefully worded non-threatening letters, and the offer of evening and Saturday appointments. Drinking-driving offenders who did or did not attend the Soissons CHA did not substantially differ in age or blood alcohol level. *Implementation/Process/Resources* Many CHAs have moved away from their primary role as preventative centres, e.g., 72% of cases at one CHA were already dependent on alcohol, but some still concentrate on the original goal.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
			day), 15% verging on dependent, 12% dependent.		Of 311 patients, 302 patients attended 2 or more times (the remain 9 only attended once) and of 181 patients, 57 made eight or more visits. *Outcome* Of the 302 drinking-drivers recruited between 1978-1982, 241 were still being followed at the end of this period and their states were: 113 abstinent or drinking without problems, 70 improved, 9 unchanged, and 49 were beginning treatment. Of 57 discharged cases, 29 were classed as satisfactory, 15 had been referred on or left the district, 14 did not wish to continue (four of which were well), and 4 died.
Helping Young People Early (HYPE)					

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
Chanen et al., 2008	Randomised controlled trial.	41 patients with full or sub-threshold borderline personality disorder receiving cognitive analytical therapy (CAT) at HYPE. 37 patients with full or sub-threshold	Age: CAT - *M* = 16.3 (*SD* = 0.8); GCC - *M* = 16.6 (*SD* = 1.0). Sex/gender: CAT - 83% female, 17% male/other; GCC - 68% female, 32% male/other. Percentage meeting full-threshold borderline personality disorder criteria:	Diagnosis was determined using SCID-I, SCID-II, and K–SADS-PL. Outcome assessments were administered at baseline, and 6-, 12-, and 24-months and included SCID-II borderline personality disorder dimensional score, YSR or YASR (age-dependent), a parasuicidal behaviour	*Implementation/Process/Resources* Ratings of 163 CAT sessions demonstrated satisfactory adherence and ratings of 37 GCC sessions demonstrated excellent adherence and minimal contamination. Median number of therapy sessions was 13 (IQR = 8-23) for CAT and 11 (IQR = 4.5-23) for GCC and non-therapy contacts (e.g., case management and psychiatrist appointments) was 33.0 (IQR = 20.5-54.0) for CAT and 32 (IQR = 18.5-52.5) for GCC (not significantly different). The maximum number of therapy sessions allowed for both was 24. Median interval from intake to discharge was 42.9 weeks (IQR = 24.1-58.3) for CAT, and 39.4 (IQR = 20.6-52.1) for GCC and the median number of contacts per week were 1.4 (IQR =

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		borderline personality disorder receiving standardised good clinical care (GCC) at HYPE.	CAT 39%; GCC 43%.	interview, and SOFAS. Treatment integrity: adherence, competency, and differentiation, were evaluated by rating audio-recorded sessions for use of CAT tools, using the therapist intervention checklist (CAT), and an ad-hoc scale for GCC.	0.9-1.8) for CAT, and 1.3 (IQR = 0.8-1.6) for GCC. No difference between the two groups in the numbers completing treatment, negotiating early termination, or dropping out. *Outcomes* Both groups demonstrated improvements from baseline to 24-months in borderline personality disorder symptoms, internalising and externalising symptoms, functioning, and parasuicidal behaviour. GCC group had a median improvement across all four continuous variables of 0.88 *SD* and for CAT this was 1.02 *SD*. There was also a substantial reduction in odds of parasuicidal behaviour overtime (CAT = 0.32 (OR) and GCC = 0.08 (OR)).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					CAT demonstrated a slightly better rates of improvement in externalising and internalising pathology, and GCC demonstrated better rates of improvement for global functioning. However, these differences were at best slight. There were no meaningful or substantial differences in borderline personality disorder dimensional scores or frequency of parasuicidal behaviours. At 24-months CAT was slightly more advantageous in reducing externalising pathology, but there were no other meaningful differences.
Chanen et al., 2009a	Quasi-experimental pre-test – post-test	41 patients with full or sub-threshold	Age: CAT - *M* = 16.3 (*SD* = 0.8); GCC - *M* = 16.6 (*SD* = 1.0); TAU	Diagnosis was determined using SCID-I, SCID-II,	*Implementation/Process/Resources* Good adherence, competency, and clear differentiation for CAT and GCC.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
	design with a historical TAU control.	borderline personality disorder receiving cognitive analytical therapy (CAT) at HYPE. 37 patients with full or sub-threshold borderline personality disorder receiving	*M* = 16.2 (*SD* = 1.0). Sex/gender: CAT - 83% female, 17% male/other; GCC - 68% female, 32% male/other; TAU - 72% female, 28% male/other. Percentage meeting full-threshold borderline personality disorder criteria:	K–SADS-PL, and CIDI. Outcome assessments were administered at baseline, and 6-, 12-, and 24-months for CAT and GCC, and baseline and 24-months only for TAU. Measures included SCID-II borderline personality disorder dimensional score, YSR or YASR (age-dependent), a	Median number of therapy sessions was 13 (IQR = 8-23) for CAT and 11 (IQR = 4.5-23) for GCC and non-therapy contacts (e.g., case management and psychiatrist appointments) was 33.0 (IQR = 20.5-54.0) for CAT and 32 (IQR = 18.5-52.5) for GCC (not significantly different). The median number of contacts for TAU was 15 (IQR=6.8-40.3), 10 of which were either or both psychotherapy and case management. Median interval from intake to discharge was 42.9 weeks (IQR = 24.1-58.3) for CAT, 39.4 (IQR = 20.6-52.1) for GCC, and 26.5 weeks (IQR=8.5-56.3) for TAU and the median number of contacts per week were 1.4 (IQR = 0.9-1.8) for CAT, 1.3 (IQR = 0.8-1.6) for GCC, and 0.7 (IQR=0.5-1.1) for TAU. *Outcomes*

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		standardised good clinical care (GCC) at HYPE. 32 patients with full or sub-threshold borderline personality disorder seen in the generalist older adolescent service	CAT 39%; GCC 43%; TAU 34%.	parasuicidal behaviour interview, and SOFAS. Independent rating of audio-recordings for CAT and GCC adherence, competency, and differentiation.	All three groups demonstrated significant and clinically substantial improvements in borderline personality disorder symptoms, internalising and externalising symptoms, functioning, and parasuicidal behaviour. The median absolute improvement over all continuous outcomes were 1.07 *SD*s for CAT, 0.84 *SD*s for GCC, and 0.64 *SDs* for TAU, and the reduction in the odds of parasuicidal behaviour were 0.11 for CAT, 0.09 for GCC, and 0.23 for TAU. CAT was superior to TAU in rates of change in internalising and externalising symptoms and GCC was superior to TAU in the rates of change in functioning. There was no meaningful and substantial difference between the groups in borderline personality disorder symptoms, and frequency of parasuicidal behaviour.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		immediately before HYPE was introduced (historical TAU).			At the 24-month follow-up, CAT was superior to TAU in externalising and internalising symptoms and GCC was superior to TAU on internalising symptoms and parasuicidal behaviours. The differences on other measures were negligible to small-medium.
Chanen et al., 2009b	Cross-sectional.	169 referrals to HYPE.	Age: *M* = 19.0 (*SD* = 2.7). Sex: 20% male, 80% female 43% met criteria for full syndrome borderline personality disorder.	Not applicable.	*Reach/Intake* Referral sources: 25% hospital emergency or crisis service, 24% self-referral, 18% other health agencies, 17% family or friends, and 5% educational services. *Implementation/Process/Resources* 95% of referrals receive some treatment from HYPE with a mean duration of care of 27 weeks (*SD* = 19). 82% start CAT with a mean of 11 sessions (*SD* = 7.6).

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					19% are admitted to hospital (*Mdn* = 1 admissions, IQR = 1-3; *Mdn* duration = 2.4 days, IQR = 1-5).
Sio et al., 2011	Retrospective cohort without control.	60 patients with borderline personality disorder seen at HYPE.	Age: *M* = 19.07 (*SD* = 3.11). Gender: 80% female, 20%.	Borderline personality disorder module of SCID-II at intake. Data from standardised medical records were used to gather information on employment/vocation/study activities.	*Outcomes* 67% of patients were engaged in some form of work (23/60) or study (26/40) at baseline and this increased to 73% at 12-months. Only 'impulsivity that is potentially self-damaging' was negatively associated with studying/education.
Pearce et al., 2017	Pre-test – post-test.	23 carers (family or friends) of	Age: Carers - *M* = 49.95 (*SD* = 9.04); Patients -	Patient clinical and referral information collected during	*Implementation/Process/Resources*

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
		HYPE patients who attended the making sense of borderline personality disorder psychoeducation group. 19 HYPE patients who consented to data sharing.	*M* = 17.1 years (*SD* = 1.9). Gender: Carers - 70% female, 26% male, 4% did not provide gender; Patients - 84% female, 16% male/other. Carer role: 65% mothers, 17% fathers, 9% grandparents, 4% partner, and 4% foster carer.	routine clinical care. The following questionnaires were administered to carers before and after the psychoeducation group programme: BAS, K-10, and PDKASQ.	74% attended all three psychoeducation sessions and typically within the first 6 months of the young person's registration at HYPE (63%). *Outcomes* There were significant improvements in overall burden (*d* = .48), subjective burden (*d* = .52), and personality disorder knowledge (*d* = 1.33), but no change in objective burden and distress at post-intervention.
The Outpatient Clinic for					

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
Adolescent Risk-taking and Self-harm behaviours (AtR!Sk)					
Kaess et al., 2017	Cross-sectional.	No data.	No data.	No data.	*Reach/Intake* Approximately 3-5 patients attend the open consultation hour each week. 70-80% of those who attend the open consultation completed a full diagnostic appointment and 37% of those who have a comprehensive diagnostic assessment enter the therapy programme.
ICEBREAK					
Marriott et al., 2007	Mixed method evaluation including pre-test – post-test measures	No data	Borderline and avoidant personality disorders were	Data collected at intake and 12-month follow-up.	*Reach/Intake* 47% of referrals were from 'The Zone' (youth centre) and primary care liaison team.

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
	and qualitative interviews.		commonly identified. Main difficulties: 75% self-harm, 74% suicidal thoughts, 61% suicide attempts, 27% mental health issues, 16% substance abuse.		91% were appropriate for the service and those identified as appropriate had a higher number of difficulties. On entry, patients experienced poor self-esteem, internal locus of control and high levels of hopelessness. *Implementation/Process/Resources* 82% completed an assessment, 77% were willing to use the service and 18% dropped out. *Outcomes* Although limited in number, those with follow-up measures demonstrated significant improvements in hopelessness, self-esteem, and internal locus of control. The number of individuals receiving social support and satisfaction with that support was higher at follow-up. Friends and appointed key

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					workers were identified as important sources of social support, but family less so. Interview data: young people valued and trusted the case managers and felt more able to engage with a less formal service than with professionals in the past.
Farrand et al., 2009	Prospective cohort without control.	183 youth eligible for ICEBREAK	Age: 70% were 16-20 years old, and 30% were 21-25 years. Gender: 52% female, 48% male.	Data regarding patient demographic and service utilisation and drop-out were abstracted from patient notes. Self-reported emotional and behavioural difficulties were	*Reach/Intake* At intake, most patients were living alone or with their parents (144; 81%), educated up to secondary school (106; 61%), and living in areas ranked within the top 10% of the most deprived areas in England (102; 61%). Most patients reported engaging in self-harming behaviours (160; 87%), having suicidal thoughts (143; 78%), having made suicide attempts (122; 67%), and having a mental health problem (101; 55%). Substance abuse (52; 28%), behavioural

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
				collected during the first assessment.	difficulties (34; 19%), hearing voices (13; 7%), and eating disorders (8; 4%) were less common. Most patients reported experiencing difficulties in three (146; 80%), four (53; 29%), or five (32; 18%) emotional and behavioural categories. *Implementation/Process/Resources* During the 12-month follow-up period, 83 (45%) were discharged, 39 (21%) were still using the service, and 61 (33%) dropped out. Drop-out rates were similar to other personality disorder services. Drop out was highest in the first 5 months of service use, especially months 3 to 5. Patients who reported leaving school before officially completing final year, coming from the most highly deprived areas, and reported a

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					greater number of difficulties were least likely to drop out. Drop-out was greatest in those who initially reported problems from more categories than those with the least and for those reporting mental health or substance abuse problems (compared to other types of problems).
Gilbert et al., 2012	Qualitative interview.	27 youth in contact with ICEBREAK	Age: 22% were 16-18 years old, 44% were 19-21 years old, 30% were 22-24 years old, 4% 25 years old. Sex/gender: 63% female, 37% male.	Patients were invited to interview following their 12-week assessment. The semi-structured interview explored experiences prior to and since contacting ICEBREAK.	Three key themes were identified: 'A life in turmoil: responding to chaos', 'Difficult relationships: Instability, trauma, and isolation', and 'The case co-ordinators'. *Reach/Intake* 'A life in turmoil: responding to chaos': the lives of the participants before accessing ICEBREAK were fraught with difficulties, including some or all the following: abusive relationships, prostitution, substance use, homelessness, and

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					increasing debt. The chaotic lives of participants were punctuated by episodes of self-harm, and other high-risk behaviours. A specific event would precipitate the high-risk behaviours and help-seeking. 'Difficult relationships: Instability, trauma, and isolation': relationships with family and/or partners were absent, unsupportive, or traumatic/dangerous. The participants had limited social support and were experiencing isolation, powerlessness, and self-blame. *Implementation/Process/Resources* 'The case co-ordinators': the only positive adult relationships mentioned by almost all participants were ICEBREAK case co-ordinators. All but one participant appreciated the role the case co-ordinator played in helping

Service: Authors, Year	Study design	Sample size by group	Sample characteristics	Outcome(s) of interest and time points	Key findings in relation to the review
					manage problems. Key valued aspects of the care co-ordinator's role were having someone to discuss issues with and get practical help, the accessibility of the care co-ordinators, and that they took the participant seriously and were non-judgemental. Key issues were the case co-ordinator admitting participants to wards due to safety concerns but not giving them a choice, and fears for the future when the participant was unable to access care co-ordinator support (e.g., too old for the service).

Notes. AADIS = Adolescent Alcohol and Drug Involvement Scale; ADS-L = Allgemeinen Depressions-skala (General Depression Scale); AESED = Accommodation and Enabling Scale for Eating Disorders; AN = anorexia nervosa; ASI = Reiss-Epstein-Gursky Anxiety Sensitivity Index; ASRS = Adult Attention Deficit Hyperactivity Disorder Self-report Scale; AtR!Sk = The Outpatient Clinic for Adolescent Risk-taking and Self-harm behaviours; AUDIT-C = Alcohol Use Disorders Identification Test-Consumption Items; BAI = Beck Anxiety Inventory; BAS = Burden Assessment Scale; BED = binge eating disorder; BDI-II = Beck Depression Inventory; BMI = body mass index; BN = bulimia nervosa; BPSS = Bipolar Prodromal Symptoms Scale; BQoLP = Berlin Quality of Life Profile; BSABS = Bonn Scale for the Assessment of Basic

Symptoms; CAGE = Cut-down Annoyed Guilty and Eye-opener questions; CAT = cognitive analytical therapy; CBT = cognitive behavioural therapy; CBT-E = enhanced cognitive behaviour therapy; CBT-T = 10 session cognitive behaviour therapy for non-underweight eating disorders; CDS = Calgary Depression Scale; CES-D = Centre for Epidemiologic Studies Depression Scale; CGI = Clinical Global Impression; CHA = Centres D'Hygiene Alimentaire; CIA = Clinical Impairment Assessment; CIDI = Composite International Diagnostic Interview; CORE-10 = Clinical Outcome in Routine Evaluation-10; CPSS = Child PTSD Symptom Scale; CRI = Cologne Risk Index; DASS-21 = Depression, Anxiety, and Stress Scale-21; DERC = Dresden Early Recognition Centre; DERS = Difficulties in Emotion Regulation Scale; DSM = Diagnostic and Statistical Manual of Mental Disorders; DUED = Duration of an untreated eating disorder; DUSC = Duration until first specialist service contact; ED = eating disorder; ED-15 = brief eating disorder cognitions and behaviours measure; EDDS = Eating Disorder Diagnostic Scale; EDE = Eating Disorder Examination; EDE-Q = Eating Disorder Examination Questionnaire; EIP = early intervention in psychosis; EMDR = Eye Movement Desensitisation Reprogramming therapy; EMS = The Early Motherhood Service; EPDS = Edinburgh Postnatal Depression Scale; EPIbipolar = Early Phase Inventory for bipolar disorders; EQ-5D-VAS = EuroQal-5 Dimensions-Visual Analogue Scale; ERQ = Emotion Regulation Questionnaire; ESPM = Eastern Sydney Perinatal Mental Health; EWA = Karolinska Project for Early Treatment of Women with Alcohol Addiction; FEMAP = First Episode Mood and Anxiety Program; FREED = First Episode Rapid Early Intervention for Eating Disorders; GAF = Global Assessment of Functioning; GAIN-SS = Global Appraisal of Individual Needs Short Screener; GCC = Good Clinical Care; GP = General Practitioner; HADS = Hospital Anxiety and Depression Scale; HAMD = Hamilton Depression Scale; HCL-32 = Hypomania Checklist; hEIT = headspace Early Intervention Team; HoNOS = Health of the Nation Outcome Scale; HoNOSca = Health of the Nation Outcome Scale: Child and Adolescent; HYPE = Helping Young People Early; ICSRLE = Inventory of College Students' Recent Life Experiences; IES-R = Impact of Event-Scale Revised; IQR = interquartile range; K10 = Kessler Psychological Distress; K-SADS = Kiddie-Schedule for Affective Disorders and Schizophrenia; LEE = Levels of Expressed Emotions Scale; LGBTQ+ = Lesbian, gay, bisexual, transgender, queer, plus; MADRAS = Montgomery-Asberg Depression Rating Scale; MCMI = Millon Clinical Multiaxial Inventory; MINI = Mini International

Neuropsychiatric Interview; MOS SF-36 PCS = Medical Outcomes Study Short Form 36 Physical Component Summary; NEO-FFI = Neuroticism-Extraversion-Openness Five Factor Inventory of Personality; NHS = National Health Service; NIDA-ASSIST = The National Institute on Drug Abuse Alcohol, Smoking, and Substance Involvement Screening Test; OCD = obsessive compulsive disorder; OMTP = Oral and Maxillofacial Trauma Psychological Service; OPOC = Ontario Perception of Care; OR = odds ratio; OSFED = other specified feeding and eating disorder; PANSS = Positive and Negative Symptom Scale; PCL-C = PTSD Checklist Civilian Version; PD Unit = Panic Disorder Unit; PDKASQ = Personality Disorder Knowledge, Attitudes and Skills Questionnaire; PDS-D = PTSD Diagnostic Scale; PDSS = Panic Disorder Severity Scale; PHQ-9 = Patient Health Questionnaire-9; PNDI = Postnatal Depression Intervention Programme; PRIME-MD = Primary Care Evaluation of Mental Disorders; PSPC = Paediatric Stepped Preventative Care Intervention; PSQ = Patient Satisfaction Questionnaire; PSYCHLOPS = Psychological Outcome Profiles; PTSD = post-traumatic stress disorder; QLESQ = Quality of Life Enjoyment and Satisfaction Questionnaire; SCC = Stepped Collaborative Care; SCID-I = Structured Clinical Interview for Diagnostic and Statistical Manual for Disorders for DSM-IV; SCL-27 = Symptom Checklist-27; SDS = The Sheehan Disability Scale; SIPS = Structured Interview of Prodromal Syndromes; SOFAS = Social and Occupational Functioning Assessment Scale; SPC = Stepped Prevention Care Intervention; SPI-A = Schizophrenia Proneness Instrument; SSRI = selective serotonin reuptake inhibitors; STAI = Spielberger State-Trait Anxiety Inventory; TAU = treatment as usual; THQ = Trauma History Questionnaire; TOC = German Trauma Outpatient Clinic; WSAS = Work and Social Adjustment Scale; YASR = Young Adult Self-Report; YES = Your Experience of Service; YRBS = Youth Risk Behaviour Survey; YSR = Youth Self-Report; YWC = Youth Wellness Centre; ZInEP = Zurich Early Recognition Program.

10.7.1.2 Critical appraisal

Table 25. Joanna Briggs Institute Levels of Evidence ranks and RE-AIM framework ratings.

		Reach	Effectiveness	Adoption	Implementation		Maintenance
Service: Authors, Year	Level of evidence	Participant representativeness	Outcome representativeness	Setting representativeness	Fidelity/adaptation	Cost/resources	Sustainment
YWC: Wang et al., 2020	4.b: Cross-sectional study	3	3	2	2	1	3
FEMAP: Ross et al., 2012	4.b: Cross-sectional study	3	2	1	2	1	3
FEMAP: Osuch et al., 2015	3.e: Observational study without a control group	2	3	1	2	1	3
FEMAP: Osuch et al., 2016	Mixed method [Uncategorisable]	1	3	1	2	3	3
FEMAP: Arcaro et al., 2017	3. Single qualitative study	3	1	1	1	1	3
FEMAP:	6. Single economic	3	2	1	1	3	3

John-Baptiste et al., 2019	evaluation of moderate or poor quality.						
FEMAP: Arcaro et al., 2019	3. Single qualitative study	2	3	1	2	2	3
FEMAP: Osuch et al., 2019	3.c: Cohort study with control group	3	3	1	2	1	3
FEMAP: Anderson et al., 2019	3.c: Cohort study with control group	3	2	1	2	1	3
FEMAP: Saunders et al., 2021	4.b: Cross-sectional study	3	2	1	2	1	3
hEIT: Nash et al., 2021	3: Single qualitative study	2	2	2	2	2	3
hEIT: White et al. 2021	3.e: Observational study without a control group	3	3	2	2	1	3
DERC:	4.b:	1	1	1	1	1	1

Pfennig et al., 2013	Cross-sectional study						
DERC: Leopold et al., 2013	4.b: Cross-sectional study	3	2	1	2	2	3
DERC: Leopold et al., 2014	4.b: Cross-sectional study	3	2	1	2	1	3
ZInEP: Theodoridou et al., 2014	4.b: Cross-sectional study	2	1	1	1	1	3
Jano: Gómez-Ruiz et al., 2010	3.c: Cohort study with control group	2	2	1	1	1	1
PD Unit: Herrán et al., 2005	2.d: Pre-test – post-test or historic control group study	1	1	1	2	1	1
PD Unit: Carrera et al., 2006	2.d: Pre-test – post-test or	1	1	1	1	1	1

	historic control group study						
PD Unit: Biddle et al., 2008	2.d: Pre-test – post-test or historic control group study	1	2	1	2	1	3
PD Unit: Navarro et al., 2013	2.d: Pre-test – post-test or historic control group study	1	1	1	2	1	1
PNDI: Chen et al., 2011	2.d: Pre-test – post-test or historic control group study	2	3	2	2	3	3
PNDI: Chen, 2011	2.d: Pre-test – post-test or historic control group study	2	3	1	2	2	3
PNDI: Lee et al., 2016	2.d: Pre-test – post-test or	3	2	2	2	1	3

	historic control group study						
ESPM: Austin et al., 1999	2.d: Pre-test – post-test or historic control group study	3	3	1	2	2	3
EMS: Judd, Stafford, Gibson, & Ahrens, 2011	Mixed method [Uncategorisable]	2	3	1	2	1	3
FREED: Brown et al., 2018	2.d: Pre-test – post-test or historic control group study	3	2	1	2	1	3
FREED: McClelland et al., 2018	2.d: Pre-test – post-test or historic control group study	3	3	1	2	2	3
FREED:	2.d: Pre-test – post-test or	2	2	1	2	1	3

Fukutomi et al., 2020	historic control group study						
FREED: Flynn et al., 2020	2.d: Pre-test – post-test or historic control group study	2	2	2	2	1	3
FREED: Austin et al., 2021b	2.d: Pre-test – post-test or historic control group study	2	3	2	2	3	3
FREED: Richards et al., 2021	2.d: Pre-test – post-test or historic control group study	2	2	2	3	1	3
FREED: Potterton et al., 2021	3: Single qualitative study	2	3	2	2	1	3
Emerge-ED: Radunz et al., 2021	2.d: Pre-test – post-test or	3	2	2	2	1	3

	historic control group study						
SCC: Zatzick et al., 2004	1.c: Randomised controlled trial	2	2	1	3	2	3
SCC: Zatzick et al., 2011	4.b: Cross-sectional study	2	1	1	2	1	3
SCC: Zatzick et al., 2013	1.c: Randomised controlled trial	2	3	1	3	1	3
SCC: Zatzick et al., 2015	1.c: Randomised controlled trial	2	3	1	3	2	3
PSPC: Kassam-Adams et al., 2011	1.c: Randomised controlled trial	2	3	1	2	2	3
TOC: Schürmann, 2010	2.d: Pre-test – post-test or historic control group study	3	2	2	2	2	3
TOC: Bollmann et al., 2012	2.d: Pre-test – post-test or	3	2	2	1	1	3

	historic control group study						
TOC: Rassenhofer et al., 2016	2.c: Quasi-experimental prospectively controlled study	2	2	2	2	1	3
OMTP: Price et al., 2015	2.d: Pre-test – post-test or historic control group study	3	3	1	2	1	1
OMTP: Choudhury-Peters & Dain, 2016	2.d: Pre-test – post-test or historic control group study	3	3	1	2	2	3
EWA: Dahlgren & Willander, 1989	1.d: Pseudo-randomised controlled trial	3	2	1	2	1	3
EWA: Haver & Dahlgren, 1995	4.b: Cross-sectional study	2	1	1	1	1	3

EWA: Haver & Franck, 1997	Narrative review [Uncategorisable]	1	3	1	2	1	3
CHA: Babor et al., 1983	Narrative review [Uncategorisable]	1	2	2	2	1	3
CHA: Chick, 1984	3.e: Observational study without a control group	1	2	2	2	1	3
HYPE: Chanen et al., 2008	1.c: Randomised controlled trial	2	3	1	3	1	3
HYPE: Chanen et al., 2009a	2.d: Pre-test – post-test or historic control group study	2	3	1	2	2	3
HYPE: Chanen et al., 2009b	4.b: Cross-sectional study	3	3	1	3	2	3
HYPE: Sio et al., 2011	3.e: Observational study without a control group	3	2	1	2	1	1

HYPE: Pearce et al., 2017	2.d: Pre-test – post-test or historic control group study	3	2	1	2	2	3
AtR!Sk: Kaess et al., 2017	4.b: Cross-sectional study	3	1	1	2	1	3
ICEBREAK: Marriott et al., 2007	Mixed method [Uncategorisable]	1	3	1	2	2	3
ICEBREAK: Farrand et al., 2009	3.e: Observational study without a control group	3	2	1	2	1	3
ICEBREAK: Gilbert et al., 2012	3: Single qualitative study	2	2	1	2	1	1

Notes. AtR!Sk = The Outpatient Clinic for Adolescent Risk-taking and Self-harm behaviours; CHA = Centres D'Hygiene Alimentaire; DERC = Dresden Early Recognition Centre; EMS = The Early Motherhood Service; ESPM = Eastern Sydney Perinatal Mental Health Service; EWA = The Karolinska Project for Early Treatment of Women with Alcohol Addiction; FEMAP = First Episode Mood and Anxiety Program; FREED = First Episode Rapid Early Intervention for Eating Disorder; hEIT = headspace Early Intervention Team; HYPE = Helping Young People Early; OMTP = Oral and Maxillofacial Trauma Psychological Service; PD Unit = Panic Disorder Unit; PNDI = Postnatal Depression Intervention

Program; PSPC = Paediatric Stepped Preventative Care Intervention; SCC = Stepped Collaborative Care Intervention; TOC = Trauma Outpatient Clinic; YWC = Youth Wellness Centre; ZInEP = Zurich Early Recognition Program.

Table 26. Joanna Briggs Institute checklist for randomized controlled trials

JBI Criteria	Documents					
	PSPC: Kassam-Adams et al., 2011	SCC: Zatzick et al., 2004	SCC: Zatzick et al., 2013	SCC: Zatzick et al., 2015	EWA: Dahlgren & Willander, 1989	HYPE: Chanen et al., 2008
1. Was true randomization used for assignment of participants to treatment groups?	Yes	Yes	Yes	Yes	No	Yes
2. Was allocation to treatment groups concealed?	Yes	No	No	No	No	Yes
3. Were treatment groups similar at the baseline?	No	No	Yes	Yes	Yes	No
4. Were participants blind to treatment assignment?	Unclear	No	No	No	No	No
5. Were those delivering treatment blind to treatment assignment?	No	No	No	No	No	No
6. Were outcomes assessors blind to treatment assignment?	Yes	No	Yes	Yes	No	Yes

7. Were treatment groups treated identically other than the intervention of interest?	Yes	Yes	Yes	Yes	Yes	Yes
8. Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	Yes	No	No	Yes	Yes	Yes
9. Were participants analyzed in the groups to which they were randomized?	Yes	Yes	Yes	Yes	Yes	Yes
10. Were outcomes measured in the same way for treatment groups?	Yes	Yes	Yes	Yes	Yes	Yes
11. Were outcomes measured in a reliable way?	Yes	Yes	Yes	Yes	No	Unclear
12. Was appropriate statistical analysis used?	No	No	Yes	No	No	Yes
13. Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?	Yes	Yes	Yes	Yes	Yes	Yes
Percentage of criteria met	69.23	46.15	69.23	69.23	46.15	69.23
Quality	High	Medium	High	High	Medium	High

Notes. EWA = The Karolinska Project for Early Treatment of Women with Alcohol Addiction; HYPE = Helping Young People Early; PSPC = Paediatric Stepped Preventative Care Intervention; SCC = Stepped Collaborative Care Intervention.

Table 27. Joanna Briggs Institute checklist for quasi-experimental studies (non-randomized experimental studies).

	Documents										
JBI Criteria	FREED: Brown et al., 2018	FREED: McClelland et al., 2018	FREED: Fukutomi et al., 2020	FREED: Flynn et al., 2020	FREED Austin et al., 2021	FREED: Richards et al., 2021	Emerge-ED: Radunz et al., 2021	OMTP: Price et al., 2015	PNDI: Chen, 2011	PNDI: Chen et al., 2011	PNDI: Lee et al., 2016
1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e., there is no confusion about which variable comes first)?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
2. Were the participants included in any comparisons similar?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes

3. Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	Yes	Yes	Yes	Yes	Yes	Yes	NA	NA	NA	NA	NA
4. Was there a control group?	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No	No	No
5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	NA	Yes	No	NA	Yes	NA	No	No	No	No	No
6. Was follow up complete and if not, were differences between groups in terms of their follow	NA	Yes	Yes	NA	Yes	NA	No	Unclear	No	No	No

up adequately described and analyzed?											
7. Were the outcomes of participants included in any comparisons measured in the same way?	No	Yes	Yes	No	Yes	Yes	Yes	Unclear	Unclear	Unclear	Yes
8. Were outcomes measured in a reliable way?	NA	Yes	Yes	NA	Yes	NA	Yes	Unclear	Unclear	Unclear	Unclear
9. Was appropriate statistical analysis used?	No	No	No	No	No	No	No	Unclear	Unclear	No	No
Percentage of criteria met	66.67	88.89	88.88	66.67	88.89	83.33	50	25	12.5	12.5	37.5
Quality	Medium	High	High	Medium	High	High	Medium	Low	Low	Low	Medium

Notes. FREED = First Episode Rapid Early Intervention for Eating Disorder; ED = eating disorder; NA = not applicable; OMTP = Oral and Maxillofacial Trauma Psychological Service; PNDI = Postnatal Depression Intervention Program.

Table 28. Joanna Briggs Institute checklist for quasi-experimental studies (non-randomized experimental studies) [continued].

	Documents									
JBI Criteria	PD Unit: Herrán et al., 2005	PD Unit: Carrera et al., 2006	PD Unit: Biddle et al., 2008	PD Unit: Navarro et al., 2013	ESPM: Austin et al., 1999	TOC: Schürmann, 2010	TOC: Bollmann et al., 2012	TOC: Rassenhofer et al., 2016	HYPE: Chanen et al., 2009	HYPE: Pearce et al., 2017
1. Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2. Were the participants included in any comparisons similar?	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	No	No	Yes
3. Were the participants included	NA	NA	NA	NA	NA	NA	NA	No	No	NA

in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?										
4. Was there a control group?	No	No	No	No	No	No	No	Yes	Yes	No
5. Were there multiple measurements of the outcome both pre and post the intervention/exposure?	No	No	No	No	No	No	No	No	No	No
6. Was follow up complete and if not, were differences between groups in terms of their follow up adequately	No	No	Unclear	Unclear	No	No	No	No	Yes	Yes

described and analyzed?										
7. Were the outcomes of participants included in any comparisons measured in the same way?	Unclear	Unclear	Unclear	Unclear	Yes	No	Unclear	No	Unclear	Yes
8. Were outcomes measured in a reliable way?	Unclear	Unclear	Unclear	Unclear	Yes	Yes	Unclear	No	No	Yes
9. Was appropriate statistical analysis used?	No	No	Unclear	No	No	No	No	No	Yes	No
Percentage of criteria met	25.00	25.00	0.00	25.00	50.00	37.50	25.00	22.22	44.44	62.50
Quality	Low	Low	Low	Low	Medium	Medium	Low	Low	Medium	Medium

Notes. ESPM = Eastern Sydney Perinatal Mental Health Service; HYPE = Helping Young People Early; NA = not applicable; PD Unit = Panic Disorder Unit; TOC = Trauma Outpatient Clinic.

Table 29. Joanna Briggs Institute checklist for cohort studies.

	Documents							
JBI Criteria	Jano: Gómez-Ruiz et al., 2010	FEMAP: Osuch et al., 2015	FEMAP: Osuch et al., 2019	FEMAP: Anderson et al., 2019	hEIT: White et al., 2021	HYPE: Sio et al., 2011	ICEBREAK: Farrand et al., 2009	CHA: Chick et al., 1984
1. Were the two groups similar and recruited from the same population?	Yes	Yes	Unclear	Yes	NA	Yes	Yes	NA
2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?	Unclear	Yes	Yes	Yes	NA	Yes	Yes	NA
3. Was the exposure measured in a	Unclear	Yes	Yes	Yes	Yes	Yes	No	Yes

valid and reliable way?								
4. Were confounding factors identified?	Yes	Yes	No	Yes	NA	NA	NA	NA
5. Were strategies to deal with confounding factors stated?	Yes	No	No	Yes	NA	NA	NA	NA
6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?	NA	NA	NA	NA	NA	NA	NA	NA
7. Were the outcomes measured in a	Unclear	Yes	Yes	Unclear	No	Unclear	Yes	No

valid and reliable way?								
8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?	Yes	No	Yes	Yes	Unclear	Yes	Yes	Yes
9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?	Unclear	Yes	Yes	Yes	No	Yes	Yes	Yes
10. Were strategies to address incomplete follow up utilized?	Unclear	No	NA	NA	No	NA	NA	No

11. Was appropriate statistical analysis used?	Unclear	Unclear	Unclear	Yes	Yes	Yes	No	Yes
Percentage of criteria met	40.00	60.00	60.00	88.89	33.33	85.71	71.43	66.67
Quality	Medium	Medium	Medium	High	Low	High	High	High

Notes. CHA = Centres D'Hygiene Alimentaire; FEMAP = First Episode Mood and Anxiety Program; hEIT = headspace Early Intervention Team; HYPE = Helping Young People Early; NA = not applicable.

Table 30. Joanna Briggs Institute checklist for analytical cross-sectional studies.

	Documents										
JBI Criteria	YWC: Wang et al., 2020	HYPE: Chanen, et al., 2009	FEMAP: Ross et al., 2012	FEMAP: Saunders et al., 2021	AtR!Sk: Kaess et al., 2017	DERC: Pfennig et al., 2013	DERC: Leopold et al., 2013	DERC: Leopold et al., 2014	ZInEP: Theodoridou et al., 2014	SCC: Zatzick et al., 2011	EWA: Haver & Dahlgren, 1995
1. Were the criteria for inclusion in the sample clearly defined?	Yes	Yes	Yes	Yes	No	No	No	No	Yes	Yes	Yes
2. Were the study subjects and the setting described in detail?	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes

3. Was the exposure measured in a valid and reliable way?	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
4. Were objective, standard criteria used for measurement of the condition?	No	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Yes	Yes	Yes
5. Were confounding factors identified?	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA
6. Were strategies to	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA	NA

deal with confounding factors stated?											
7. Were the outcomes measured in a valid and reliable way?	Yes	Yes	Yes	Yes	NA	Unclear	Yes	Yes	Yes	NA	Yes
8. Was appropriate statistical analysis used?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Percentage of criteria met	80.00	100.00	100.00	80.00	50.00	20.00	80.00	80.00	100.00	100.00	100.00
Quality	High	High	High	High	Medium	Low	High	High	High	High	High

Notes. AtR!Sk = The Outpatient Clinic for Adolescent Risk-taking and Self-harm behaviours; DERC = Dresden Early Recognition Centre; EWA = The Karolinska Project for Early Treatment of Women with Alcohol Addiction; FEMAP = First Episode Mood and Anxiety Program; HYPE = Helping Young People Early; NA = not applicable; SCC = Stepped Collaborative Care Intervention; YWC = Youth Wellness Centre; ZInEP = Zurich Early Recognition Program.

Table 31. Joanna Briggs Institute checklist for qualitative research.

	Documents		
JBI Criteria	FREED: Potterton et al., 2021	hEIT: Radunz et al., 2021	ICEBREAK: Gilbert et al., 2012
1. Is there congruity between the stated philosophical perspective and the research methodology?	Yes	No	No
2. Is there congruity between the research methodology and the research question or objectives?	Yes	Yes	Yes
3. Is there congruity between the research methodology and the methods used to collect data?	Yes	Yes	Yes
4. Is there congruity between the research methodology and the representation and analysis of data?	Yes	Yes	Yes
5. Is there congruity between the research methodology and the interpretation of results?	Yes	Yes	Yes

6. Is there a statement locating the researcher culturally or theoretically?	Yes	No	No
7. Is the influence of the researcher on the research, and vice- versa, addressed?	Yes	No	No
8. Are participants, and their voices, adequately represented?	Yes	Yes	Yes
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Yes	Yes	Yes
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Yes	Yes	Yes
Percentage of criteria met	100	70	70
Quality	High	High	High

Notes. FREED = First Episode Rapid Early Intervention for Eating Disorder; hEIT = headspace Early Intervention Team.

Table 32. Joanna Briggs Institute checklist for economic evaluations.

	Documents
JBI Criteria	FEMAP: John-Baptiste et al., 2019
1. Is there a well-defined question?	Yes
2. Is there comprehensive description of alternatives?	Yes
3. Are all important and relevant costs and outcomes for each alternative identified?	No
4. Has clinical effectiveness been established?	NA
5. Are costs and outcomes measured accurately?	Yes
6. Are costs and outcomes valued credibly?	Yes
7. Are costs and outcomes adjusted for differential timing?	NA
8. Is there an incremental analysis of costs and consequences?	NA
9. Were sensitivity analyses conducted to investigate uncertainty in estimates of cost or consequences?	No
10. Do study results include all issues of concern to users?	No
11. Are the results generalizable to the setting of interest in the review?	No
Percentage of criteria met	62.50

Quality	Medium

Notes. FEMAP = First Episode Mood and Anxiety Program.

10.7.2 Chapter 5: Clinician perspective of FREED in England: A qualitative study

10.7.2.1 Example quotes for each theme and sub-theme.

Table 33. Quotes for each theme and sub-theme.

Themes/Subthemes	Quotes	
Patient		
Patient engagement and a first positive experience of services	P004:	"Very rarely sometimes is it, I guess it's the service user might be a barrier in that sometimes we catch them so early on in their illness that it feels too much to them, like a little bit of overkill […] so occasionally people have kind of refused to engage on that basis"
	P010:	"We work with a lot of young people who are ambivalent about change, so that early engagement call is most integral to what we do"
	P016:	"The feedback that we've had from them both directly and indirectly is for those people who maybe didn't engage at the start, that had a very good first positive experience of treatment and of assessment, of knowing what was going to be on offer, and what the options were, so even if they decided that they, at that particular time, that they weren't quite ready, some of them have come back since"
	P002:	"They know that they haven't been waiting long. They're always very keen to just start treatment, which is just great to hear and I've noticed you know maybe I have

		like fewer DNAs or fewer cancellations. You know if we can get them in quickly then they obviously the motivation is still high so they're much more engaged"
Patient complexity and comorbidities	P011:	"You can often kind of feel that it's a FREED patient, it's someone who's quite young, someone who's you know not had much experience with mental health services in the past, often in that kind of emerging adulthood time in their life"
	P003:	"Where you're like that's a FREED patient their early, you can tell they're motivated […] I think you have some of those but then you also do meet some patients who are technically within FREED but they just they feel different […] often they're people who have more complex mental health or other mental health difficulties in the run up to developing an eating disorder"
	P019:	"It's really tricky then with do you go ahead and diagnose someone of having an eating disorder and take them into treatment when it's been there literally three months for example, or actually you know do we kind of understand this more in the context of maybe stress and control and kind of what else is going on here"
	P015:	"Sometimes you know we're seeing sort of emerging early signs of emerging personality disorders, whereas there is a lot where there are some behaviours that you see mimicked and it's almost sometimes talking to some young people it's almost like they've read up on eating disorders and they're feeding back all this classic information that it almost feels like it's acquired information"

	P010:	“Our intensive FREED package didn't seem to fit for this family because it exacerbated and actually she lost more weight with us going in heavy with the eating disorder […] it became like almost a bigger beast to manage because it wasn't the right treatment pathway for this family, so I think when we talk about going in too early sometimes, we can go in too early with the treatment because it's kind of oh this is early intervention, this is what it looks like, and not I guess sitting back with our clinical training which actually says that we do a little bit more assessment of the function of the difficulties first”
Clinician		
Hope and enthusiasm: Making sense of early intervention and FREED	P021:	“Facilitators to implementing FREED, the key ones are I think people that are enthusiastic about the model I think it's the people that really make it”
	P012:	“It's a really worthwhile project that's been put in place and that the work is life changing and useful when you're catching it at that point rather than five years down the line when things could be a lot worse. It's really meaningful and catching it early and changing things around with the young people is super important, give them quality a life, see them improve and go off to uni when otherwise they would have to have paused and went into treatment”
	P017:	“You know so that it, kind of, right it kind of aligned with what I was worried about as a clinician at the time as well, so it's kind of yeah rang some bells”

	P016:	“I believe it works I do think it does make a difference to recovery rates”
	P019:	“That is quite a big facilitator, there is a big rationale, evidence base for FREED actually”
	P005:	“I suppose kind of seeing that as well that people in early intervention can make those changes quite quickly and that being full and really positive”
Conflicting feelings: Eligibility and concerns about non-FREED patients	P002:	“The cons maybe of having an early intervention would be maybe the impact that it can have on waiting times for other people, I guess I know in this service for example it's been set up in a way so that it doesn't”
	P001:	“The only downside is this idea that some people aren't getting it so the twenty-fives plus”
	P011:	“Our experience of people over 25 is that the uptake wasn't any better than what it was with FREED, if not worse […] after we reviewed the data, we decided that we're not going to continue with offering FREED for over 25s”
	P014:	“I forget who isn't FREED and who isn't- like I said I tend to just like go with the FREED approach for everybody”
	P003:	“Resources that we can take from early intervention can then be used for other people […] so that we'll get these early intervention patients through more quickly and then other patients will also be seen more quickly”

	P004:	“From a service perspective, culturally and sort of strategically it has presented challenges, which has been positive 'cause I think it's led us as a service to thinking more creatively about the way that we deliver care and being more flexible with that. I think that's been really positive”
Self-efficacy: Experience, stress, and resilience	P003:	“Well their better at using it than the older ones […] 'cause I think it was the transition between here's the old paperwork and here's the new paperwork that got a bit lost whereas the ones who've just come in you're just like oh this is how we do FREED”
	P014:	“The current team didn't think it would work, and they didn't see how they would be able to balance two different caseloads if you like, and they weren't particularly skilled up in MANTRA and I think they were worried about having to deliver that”
	P008:	“I definitely feel as the time has gone, things have gone you know become better, a lot more understanding, a lot more clarity, more positive approach”
	P001:	“Otherwise if staff are burnt out and jaded and lack hope then that's when it's really hard to get people to do FREED”

The Model

Flexibility within structure	P014:	“I think it's a really basic obvious concept that finally has a structure and a way to implement it for services [..] yeah it's an obvious thing to do that makes complete sense and that now has a good structure so we can implement it”
	P004:	“It [FREED] forced us into thinking creatively about how we were going to manage the pathway and then that thinking creatively, being open to changes, and then sort of built up a bit of a momentum of its own and has carried forward”
	P001:	“FREED has allowed me the freedom ha-ha”
	P021:	“It's great that it offers lots of scope for creativity. That's what I love about the model is that there's a chance to offer things over and above individual or group therapy which is historically what the service has offered”
	P019:	“I think maybe the, ah it is a structure, it's there, but it's not a specific structure is it, and I think when people are quite new to working with something they like a structure”
	P011:	“FREED it is a model that allows some flexibility within your working and if your perhaps someone who doesn't enjoy the flexibility within a model, when actually like something quite concrete and quite black and white then it can be a really hard model to work with”
Champion as invaluable	P021:	“I'm not sure FREED would be doing anything if it wasn't for that FREED Champion role”

	P005:	“It's just somebody who, kind of, I suppose, keeps it going because it is hard when everybody's busy to keep lots of different priorities that are in the team going”
	P002:	“In this team it’s really helpful they have for example the FREED Champion role. So someone that's kind of spends most of their time doing FREED or being involved in FREED because I think if everyone in the team shared that responsibility it would be quite difficult to kind of keep on top of this […] it's very easy 'cause people in the team know that they can come and talk to me if they have a question about FREED or when referrals comes in then”
	P011:	“When you're kind of like a one man band I think it's really hard to kind of speak up and kind of put things on the agenda and be heard”
	P003:	“The champion can't do everything, they're already busy enough, they need someone else to kind of guide”
	P019:	“I guess I feared a little bit just perhaps some of originally how busy the role was going to be and some of the expectations that I was assuming that I take on all of the engagement calls and maybe a large chunk of the assessments. […] things didn't pan out that way actually because we shared out the responsibilities with the engagement calls for example”
Meeting people where they are at: Care package, resources and going online	P010:	“We love the materials that we're able to access, I think the website is fantastic”

	P002:	“Just holding this in mind when I'm seeing people and when I'm having the sessions with them. I think it's been really helpful just thinking about maybe the changes that they're going through at that time because you know there is already a lot going on with their identity or their really kind of trying to figure out who they are”
	P003:	“It doesn't just come from like what does an eating disorder need, it comes from like what do these people at this stage of their life need”
	P009:	“Developing online resources and utilising social media and really appealing to mediums that young people and I think that helps make it feel more tailored”
	P014:	“We generally just direct people to the website because they kept on losing the hard copies ((laugh))”
Implementation Strategy		
Practical and ongoing training	P005:	“When you're working, you don't have a lot of space to think about how you can implement these things and just having that day […] lots of the training was about how you might do it within your team, what the challenges might be and it just gives you that head space and that room, which is really really good, to think about how you might adapt it for your team and what might work”

	P002:	“Having kind of someone go through it [48-hour engagement call] with someone else as an example to just see what could happen, what could you say, what your tone of voice is like, it was really helpful for me”
	P018:	“It'd be helpful to have a refresher, or I don't know. I was thinking about going back and just doing it again, the online training, just to freshen my memory”
	P008:	“Most of the training that I received or understanding that I received that was from our FREED Champion within the team […] I think we had enough understanding, so I think for me it was enough”
	P021:	“I think until you launch and start doing it, it's hard to know what questions and what the teething problems or what the difficulties would be. I think the training gave a really good overview and detailed information about the ethos and how much flexibility there is in terms of new initiatives and creativity. I think the support afterwards has been really helpful that's been the key bit”
Being part of something bigger: The FREED Network	P006:	“Just to know that our team is involved in something that's going to make a difference and that a lot of teams around the country are interested in and enthusiastic about. It feels as if gosh this is such an important- important work to change how we work”
	P011:	“Hearing from other services and seeing how they're doing and what they're doing. I know [Place 4] were a very big advocate of that. They shared a lot of creative

ideas but also spoke a lot about the challenges and you feel reassured when you hear other services having sim- I know [Place 2] was a service that was a similar size as ours, so we often had very similar teething problems within our service in FREED and outside of FREED. It's kind of reassuring to have those conversations and hear from other eating disorder services, 'cause without the connection and without discussing it together you can keep your head down and go it alone and think that everything's working well or it's not working well and you're not sure why but actually when you hear how other services are doing it's a very good learning opportunity to see how you can do things a little bit differently or just kind of anticipate that's where we are right now and that's okay"

P010: "It's been really important. Like I say you need something that legitimises what you do. It's made sure that we keep doing what we do. I think when it got difficult and even just 'cause like I said sending in the data every couple of months it keeps us on track really, keeps us looking at kind of you know are we are we still doing this? Are we getting it right? Are we still thinking early intervention? I think it's very easy for a service like ours to slip off and just focusing on the more chronic end"

P019: "It almost resets me actually. Yes, we're really on FREED, trying to pull us back into it. I think sometimes when work life gets a bit busy you know we can lose

		track of that a little bit, so I think it almost helps to bring that focus back again and that enthusiasm again”
Service		
Capacity and competing demands	P005:	“I suppose barriers, funding or staffing levels, just have the time to be able to do assessments that quickly or treatment that quickly, that would probably be the main barrier”
	P004:	“The three most challenging aspect would be just hitting the timeframes really against the backdrop of reduced capacity […] I don't think there's a point where resourcing will make us step away from FREED 'cause it's been absolutely instrumental”
	P010:	“There always will be that temptation to shut the door and not do early intervention work, and certainly from my peers, when we link up and have these conversations that have been the resistance of a lot of teams to not do FREED because they just don't have capacity, they're not staffed well enough to be able to reserve any space for the thinking about or even the implementation of an early intervention pathway”
	P003:	“The fact that there's too many patients and we can't meet the targets. I mean not really; we're implementing the engagement calls and we're implementing assessment and treatment, but we're not implementing the targets”

	P018:	“Easy, especially as we are an expanded team now, and everyone has some capacity to be able to take things on or look at things within the timescales”
	P011:	“Just trying to embed it in a service that has many many demands of many other things, and trying to keep it a priority, and keep it present within a system that just feels quite overstretched”
Compatibility and integration	P014:	“I guess also like how it fits with the way I work; I think I haven't really had to adapt how I work as clinician too much for FREED because I think it was what I was doing anyway ((laugh))”
	P010:	“I think because we're nought to twenty-five service, not difficult, the service is set up for emerging adulthood so that's not been hard”
	P019:	“There's a lot of doing things a bit differently to how we're doing them historically, so I think as a service we're not quite there”
	P004:	“That's all kind of brought into the assessment we've got a crib sheet for assessors as well just to kind of make sure that they've got an easy to glance guide about what needs to be covered in a FREED assessment”
	P019:	“It has been helpful to kind of have that dedicated, I guess, role really or that dedicated time, there is quite a part of my role that is protected in terms of kind of FREED time”

	P005:	“The FREED huddle and I suppose I lead that, so trying to get up-to-date information from the rest of the team on what's going on with FREED more widely and I suppose just keeping everyone on the FREED side, keeping on top of how we are doing in terms of reaching targets, is anything that we need to kind of adapt or change, thinking about different ways we can kind of bring the model in, different things we can do as a team and I suppose just kind of keeping the service model at the front of people's minds
An open dialogue: Sharing, participation, and involvement	P019:	“I often in my kind of general updates to the team, or sort of in supervision you know, or sending kind of new bits out you know, can anyone share any feedback as you start using it you know, it's a new model we're implementing, we need feedback on how it's going”
	P012:	“Then to try and integrate it more into the team, and involve more people in the team, and talk about it more in our wider teams, so then they feel involved and they have an understanding of what FREED is and what we do with FREED, so they make it feel like more of a team effort, everyone's doing their part, sharing the updates as well that's a big thing”
	P008:	“They thought oh we don't know anything about it, so we really don't know what you do behind the doors, but whereas now you know the sense is very different in

		the team, everybody feels part of the you know same approach and sort of same treatment, so that feels quite positive”
	P010:	“Our worry was about splitting really, that you'd have a lovely FREED team who are doing lovely bits of early intervention whilst the rest of the team were doing kind of the chronic work and we wanted to make sure we didn't have that split within the team at all”
	P003:	“That it's privileged and that maybe it's easier because the patients aren't as severe enduring obviously by the definition of it”
Wider System		
Broader system care	P009:	“For people who are not necessarily accessing services, raising the profile of FREED might just help people with that early detection of eating disorder symptoms and it might be in themselves it might be in someone that they care about. I think obviously that is an important part of early intervention isn’t it?”
	P017:	“I suppose a big part of that is helping people recognise that they have eating disorders and engaging with GPs and IAPT services to get better at recognising eating disorders and picking them up”

	P014:	"I guess rolling it out was thinking how are we gonna get GPs and people to know about this; I would say was a challenge and something that we had to think quite a lot about"
	P002:	"And then we just need to make sure that the funding gets approved and sometimes with that being delayed it becomes difficult then to stay within the FREED time frames"
	P010:	"I'm very big on getting my team out on the streets and so that's exactly what we do […] because we're out in the schools, we do workshops at the dance schools and performing arts schools, this year we ran workshops with the sports science courses, sports performance courses, that tutors there, so we run the training workshop for them to be able to do some early intervention work with young people, who they noticed might be over exercising and struggling, so again it's kind of just going out there and doing that outreach work and FREED has gave us permission to do that"
Coronavirus disease 2019 (COVID-19)	P021:	"We went into that second lockdown and the situation on our wards in the Trust again was getting difficult […] it was like we need to launch or people are gonna get redeployed again and we were like no we want to get this up and running because we're all keen and it's already been, at that point it had obviously been six

	or seven months since we were meant to launch, so we were like right let's just give it a go then let's see what we can do"
P010:	"So yeah it feels like a challenging time to do FREED, and focus on early intervention right now, 'cause certainly feels like we're, the conversations are about just supporting our most unwell patients at the moment, rather than accepting people into the service who just need a bit of support and thinking well can they go somewhere else? Um so that's been difficult, it's been difficult to keep on the agenda"
P020:	"There's probably some positives and negatives. I reckon that age range might be happier to sit on a video than they are to actually come into a base and have a sit down assessment. There's obviously the negative some people don't have that confidential space at home, don't feel comfortable doing it, don't feel comfortable seeing their face on the screen, which is not something you normally have to deal with when you're having a conversation with someone"
P012:	"There is so much scope for like more creative work which I think now is coming in because COVID, so like virtual appointments, doing stuff on Instagram and live streaming and making psychoeducational videos and sending them out doing more of that, 'cause I think this is all about being creative and interacting with young people differently, we should have been doing that prior, I'm not really sure why

	we weren't, guess because you get stuck in a rut of just doing what you do, but I think actually having virtual appointments and things with them works really well”

Notes. COVID-19 = coronavirus disease 2019; FREED = First Episode Rapid Early Intervention for Eating Disorders; GP = General Practitioner; IAPT = Improving Access to Psychological Therapies; MANTRA = Maudsley Model of Anorexia Nervosa Treatment for Adults.

10.7.2.2 Normalisation Process Theory mechanisms underlying each theme and sub-theme.

Table 34. Normalisation Process Theory mechanisms underlying each theme and sub-theme.

Themes/Subthemes	Normalisation Process Theory Mechanisms			
	Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
Patient				
Patient engagement and a first positive experience of services	- The patients' understanding of the benefits of early intervention was an important facilitator. - The outreach work and engagement call perceived as important and worthwhile by clinicians.	- Outreach, engagement call, and emphasising the importance of early intervention enrols patients in FREED work.	- Engagement calls easy to integrate but depends on relation/interaction with patient and/or referrer. - Rota system used in some teams to distribute engagement calls.	- Individual clinician appraisal regarding the impact of FREED on motivation and engagement.
Patient complexity and comorbidities			- Difficulties determining suitability for FREED.	

Themes/Subthemes	Normalisation Process Theory Mechanisms			
	Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
			- Individual and collective work (i.e., thorough evaluation and team discussions) to determine and develop confidence in suitability.	
Clinician				
Hope and enthusiasm: Making sense of early intervention and FREED	- A high degree of individual and collective understanding of FREED, and its value. - Potential benefits were a core part of how clinicians made sense of FREED.	- Key enthusiastic individuals drive FREED forward using a range of activities to create and maintain 'buy-in'.	- Management and senior staff supporting the adoption of FREED was central to implementation and the distribution of resources.	- Appraisal of the evidence-base and the observed impact on patients and the team was used to evaluate the worth of FREED

Themes/Subthemes	Normalisation Process Theory Mechanisms			
	Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
	- High degree of personal alignment and internalisation of the objectives of FREED. - Assessing evidence-base as key mechanisms in how clinicians attribute value to FREED.			
Conflicting feelings: Eligibility and concerns about non-FREED patients	- Concerns regarding the impact on non-FREED patients were a barrier. - Comparison of FREED against standard illness prioritisation procedures. Both were perceived as		- Eligibility criteria adapted to align with the service and clinician beliefs. - Difficulties determining DUED due to confidence/skills, and	- Ongoing clinician appraisal of the broader impact of the model (i.e., impact on non-FREEDs, wider service). - Re-configuring eligibility criteria and

Themes/Subthemes	Normalisation Process Theory Mechanisms			
	Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
	advantageous for different reasons. - Most clinicians perceived FREED as beneficial for all individuals in early-stage illness, regardless of age, but eligibility criteria were also understood as pragmatic and enabled tailoring. - FREED perceived as beneficial beyond FREED patients.		clarity of information from patient.	formally (data) and informally (personal experience) appraising the change.
Self-efficacy: Experience, stress, and resilience	- Greater experience in EDs increases the		- Individual skills and belief about skills and	- Ongoing appraisal regarding oneself and

Themes/Subthemes	Normalisation Process Theory Mechanisms			
	Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
	internalisation of FREED as important and needed.		capacity to implement FREED impacted the implementation. - Continued investment and engagement with FREED builds skills and confidence around the model. - Individuals with pre-existing caseloads and many years in EDs are required to do more work to integrate FREED into their existing practice. - Active support to manage stress/anxiety provides individuals	other's ability to understand and use the model.

Themes/Subthemes	Normalisation Process Theory Mechanisms			
	Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
			with the resources to engage in FREED work.	
The Model				
Flexibility within structure	- Structure enables clear understanding of the specific tasks and steps needed to implement FREED. - An understanding of how FREED compares to standard practice is needed to adapt to the local context. - The flexibility around the model is valued.		- The work of adapting FREED to 'fit' the local context (e.g., sharing the Champion responsibilities, whole team approach) – largely undertaken by senior staff and FREED Champion.	

Themes/Subthemes	Normalisation Process Theory Mechanisms			
	Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
Champion as invaluable		- Champion as designated individual that drives FREED forward, creates, and maintains engagement, and enrols others in FREED work.	- Champion distributes and manages the work and resources needed to implement FREED. - Champion supports ongoing training and skill development to enable clinicians to implement FREED. - Insufficient capacity for Champion to complete all tasks, sharing and delegating tasks is often needed.	
Meeting people where they are at: Care package, resources and going online	- Tailoring treatment perceived as beneficial and valued.	- Tailoring treatment and having resources available online	- Standard treatment modified to	

Themes/Subthemes	Normalisation Process Theory Mechanisms			
	Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
	- Some difficulties understanding how and when to integrate adaptations into standard treatment. - Some unawareness of care package components (typically at outset or due to normalisation processes).	engages clinicians and patients into FREED work.	accommodate FREED adaptations. - FREED-related materials (e.g., tracker template), prompts, reminders, and using different communication methods made FREED easier to integrate into work. - The interaction between the patient's life stage and adaptations can make the adaptations easy (e.g., relevance) and difficult (e.g., family	

Themes/Subthemes	Normalisation Process Theory Mechanisms			
	Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
			involvement for students) to use.	
Implementation Strategy				
Practical and ongoing training	- Training and its continuation as key to developing individual and collective understanding of FREED and its benefits.	- Training supports initiation and legitimisation.	- Sufficient training was undertaken to develop the skills to implement FREED, but ongoing training is needed.	
Being part of something bigger: The FREED Network	- Network enabled teams to work together to make sense of FREED and its implementation. - Wider investment and interest lead to greater	- Network and data feedback create a broad community of practice that legitimises and maintains engagement.	- Implementation supervision and ongoing evaluation contribute towards accountability and	- Formal and informal appraisal during implementation supervision and data feedback to evaluate whether FREED and

Themes/Subthemes	Normalisation Process Theory Mechanisms			
	Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
	internalisation of importance of FREED. - Conferences as key medium to share information and "take FREED off the pedestal".		confidence in using the model. - Data collection work shared with/delegated to assistant psychologists, support workers, and administrators.	its components are working and worthwhile.
Service				
Capacity and competing demands	- Concerns regarding capacity at the outset and over time. - Existing teams linking in with new/interested teams to develop understanding of FREED and its impact.	- Champion, mini team, and Network identified as important in maintaining momentum and engagement amongst competing demands.	- Insufficient resources allocated to implement FREED in some but not all teams. - Individually and collectively adapting mental and material	- Ongoing individual and communal appraisal around capacity and the re-configuration of FREED and treatment as usual as capacity fluctuates.

Themes/Subthemes	Normalisation Process Theory Mechanisms			
	Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
			resources to address capacity issues.	
Compatibility and integration	- An understanding of how FREED differs from standard practice is needed for integration work. - At the outset, FREED was sometimes perceived as "special" and very different from standard practice. This changed over time.	- Integration and protected time supported the enrolment, legitimisation, and sustainability of FREED.	- Compatibility with the existing service and clinician values and practice was a facilitator. - Relational and contextual integration through integrating into service processes and procedures, culture, and resources (e.g., protected Champion time and meetings). - Limited integration with wider team can	- Dedicated FREED huddles and discussion in general meetings to appraise FREED work. - Appraisal and re-configuring of integrational barriers.

Themes/Subthemes	Normalisation Process Theory Mechanisms			
	Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
			disrupt working relations and FREED. - Carefully balancing FREED and non-FREED work was important.	
An open dialogue: Sharing, participation, and involvement	- Involvement and an open dialogue allowed teams to work together to develop a shared understanding of the model, its benefits, and to address concerns. - Wider team did not always value all aspects of FREED (i.e., perceived as	- Active involvement and creating an open dialogue initiate and enrol clinicians in FREED work. - Mini team enables ongoing engagement and maintenance of the model.	- Interactional work people do around FREED to develop accountability and confidence in the model. - Allocated time in meetings to enable interactional work to take place.	- Communal appraisal of the functioning, and problems around FREED was important. - Re-configuring the structure of FREED, i.e., mini vs whole team approach, following appraisal.

Themes/Subthemes	Normalisation Process Theory Mechanisms			
	Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
	‘privileged’ and ‘light’ work).		- FREED work distributed amongst the entire team or mini team. - FREED can disrupt working relations/create a divide in the service.	
Wider System				

Themes/Subthemes	Normalisation Process Theory Mechanisms			
	Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
Broader system care	- A wider shared understanding (e.g., public, healthcare services) of EDs and FREED is needed for early identification. - Outreach work as a core responsibility and a valued part of FREED.	- Identification and enrolment of referrers at the outset is needed.	- Funding/resources needs to be obtained quickly from the broader system (e.g., commissioners). - Relational work with educational institutions and referrers to ensure early identification and appropriate referrals.	- Appraisal regarding the referral pathways and processes.
Coronavirus diseases 2019 (COVID-19)	- FREED still perceived as important; however, less important relative pressing COVID-19 demands.		- COVID-19 disrupted interactional and relational work. Colleagues and patients required to re-establish relations and implement FREED in	- Informal appraisal of the positive and negative features of virtual working.

Themes/Subthemes	Normalisation Process Theory Mechanisms			
	Coherence	Cognitive Participation	Collective Action	Reflexive Monitoring
			the context of COVID-19. - Clinicians worked to re-operationalise and maintain FREED in altered circumstances (e.g., virtual appointments).	

Note. COVID-19 = coronavirus diseases 2019; ED = eating disorders; FREED = First Episode Rapid Early Intervention for Eating Disorders.

10.7.2.3 The frequency of codes and intercoder reliability estimates for the qualitative clinicians' perspective study

Table 35. The type, frequency, percentage agreement, and Cohen's kappa estimates for the shared codes (in order of highest to lowest agreement)

Code	Type of code	Code frequency			Percentage agreement	Cohen's kappa	
		Coder 1	Coder 2	Total		κ	95% CI
Challenges associated with carer/family involvement (e.g., difficulties balancing family involvement and patient autonomy)	Negative	6	6	12	100.00	1.00	[1.00, 1.00]
Difficulties establishing duration of untreated eating disorder and eligibility	Negative	2	2	4	100.00	1.00	[1.00, 1.00]
Concerns about the impact of FREED on patients not eligible for the service (e.g., impact on waiting times)	Negative	9	9	18	100.00	1.00	[1.00, 1.00]
COVID: Early intervention remains or is more important now	Positive	1	1	2	100.00	1.00	[1.00, 1.00]

Concerns that FREED may accentuate ED symptoms in certain patient groups (e.g., emerging borderline personality disorder)	Negative	2	2	4	100.00	1.00	[1.00, 1.00]
The importance of patient motivation and engagement	Neutral	12	13	25	99.57	0.96	[0.88, 1.00]
Belief that FREED could work for any age group with a short illness duration/desire to expand the age range	Negative	8	7	15	99.57	0.93	[0.80, 1.00]
FREED training as helpful and valued	Positive	8	7	15	99.57	0.93	[0.80, 1.00]
FREED positively impacting work with other patients (non-FREED)	Positive	6	7	13	99.57	0.92	[0.77, 1.00]
Funding and commissioning issues acting as a barrier (e.g., out-of-area patients)	Neutral	5	4	9	99.57	0.89	[0.67, 1.00]
Communication and support from other FREED teams as facilitative (FREED Network)	Positive	14	11	25	98.72	0.87	[0.73, 1.00]
Consistently (everyday) working on FREED	Neutral	3	4	7	99.57	0.86	[0.57, 1.00]
48-hour engagement call valued and facilitative	Positive	10	11	21	98.72	0.85	[0.68, 1.00]

FREED acting as a bridge/supporting transition between child/adolescent and adult services	Positive	3	2	5	99.57	0.80	[0.41, 1.00]
Concerns about capacity and waiting times	Negative	3	2	5	99.57	0.80	[0.41, 1.00]
Involvement of the wider team in FREED as facilitative	Neutral	11	14	25	97.86	0.79	[0.61, 0.97]
The flexibility/creativity enabled by FREED was valued	Positive	10	8	18	98.29	0.77	[0.55, 0.99]
Wider team like/buy-in	Positive	18	13	31	97.01	0.76	[0.59, 0.93]
COVID (and virtual working) disrupting services and FREED	Neutral	23	16	39	96.15	0.75	[0.59, 0.93]
Waiting time targets are being hit and are liked	Positive	3	5	8	99.15	0.75	[0.41, 1.00]
Understanding of early intervention and/or FREED	Neutral	17	12	29	97.01	0.74	[0.56, 1.00]
COVID: increased number of referrals, risk, and/or pressure on services	Neutral	10	6	16	98.29	0.74	[0.50, 0.98]
Differences between FREED and standard ED service practice can cause difficulties in implementation	Negative	6	11	17	97.86	0.70	[0.44, 0.95]
Ease of implementing FREED	Positive	11	12	23	97.01	0.68	[0.46, 0.95]

Patient complexity can be challenging	Neutral	1	2	3	99.57	0.66	[0.05, 1.00]
FREED Champion facilitates the implementation of FREED	Positive	23	12	35	95.30	0.66	[0.48, 0.85]
FREED results in better engagement	Positive	4	2	6	99.15	0.66	[0.22, 1.00]
Additional funding desired	Neutral	4	2	6	99.15	0.66	[0.22, 1.00]
Difficulties changing way of working/mode of working and resistance to change	Negative	6	6	12	98.29	0.66	[0.34, 0.97]
Early intervention and FREED are seen positively, as important, and liked	Positive	39	24	63	91.03	0.62	[0.47, 0.76]
Carer/family involvement important and valued (part of FREED care package)	Positive	6	4	10	98.29	0.59	[0.23, 0.96]
Desire for more outreach work with other services (e.g., primary care)	Neutral	4	6	10	98.29	0.59	[0.23, 0.96]
Mixture of experiences and skills in the FREED team as facilitative	Neutral	5	2	7	98.72	0.57	[0.13, 1.00]
FREED reduces pressure on services/“free-up” resources	Positive	4	3	7	98.72	0.57	[0.12, 1.00]

Integrating and embedding FREED in the service as facilitative (e.g., into service processes)	Neutral	30	15	45	91.88	0.54	[0.36, 0.72]
It takes time to get used to and understand and implement FREED	Neutral	16	9	25	95.30	0.54	[0.30, 0.78]
FREED evidence-base and research valued and facilitative	Positive	17	6	23	95.30	0.50	[0.25, 0.75]
Early intervention and FREED viewed as increasing early/quick access to care and quick access is valued	Positive	17	6	23	95.30	0.50	[0.25, 0.75]
FREED resources/materials valued	Positive	3	1	4	99.15	0.50	[-0.10, 1.00]
Difficulties with engaging patients	Negative	1	3	4	99.15	0.50	[-0.10, 1.00]
The FREED mini team as a facilitator	Positive	2	2	4	99.15	0.50	[-0.11, 1.00]
COVID: mixed impact on patients (positive and negative)	Neutral	9	3	12	97.44	0.49	[0.14, 0.84]
‘Window of opportunity’: FREED improves outcomes and reduces the impact of EDs	Positive	30	12	42	91.45	0.49	[0.30, 0.67]

Compatibility between FREED and the service as facilitative	Neutral	15	6	21	95.30	0.46	[0.19, 0.72]
FREED care package/comprehensive care valued	Positive	18	5	23	94.44	0.42	[0.16, 0.67]
Capacity and staffing issues as a barrier to implementing FREED	Negative	27	7	34	91.45	0.38	[0.18, 0.59]
Wider team understanding of FREED	Positive	5	1	6	98.29	0.33	[-0.15, 0.81]
FREED has a different treatment focus/early intervention orientation	Positive	13	5	18	94.87	0.31	[0.03, 0.59]
Conflicting feelings and difficulties with FREED eligibility criteria	Negative	6	1	7	97.86	0.28	[-0.15, 0.71]
Patient satisfaction and buy-in	Positive	6	1	7	97.86	0.28	[-0.15, 0.71]

Note. CI = Confidence Interval; ED = eating disorder; FREED = First Episode Rapid Early Intervention for Eating Disorders.

Table 36. The type and frequency of codes missing from MP/Coder 2's coding framework

Code	Type of code	Frequency
Understanding: FREED is specifically for clinical EDs	Neutral	1
Understanding: FREED is for young people with an illness duration of less than 3 years	Neutral	1
Using FREED can be easier for clinicians new to the service as it does not require a change	Neutral	1
What other (non-ED) services are doing impacts views and importance of early intervention and FREED	Positive	1
Characteristic 'FREED patient'	Neutral	1
Overall FREED does not increase engagement	Negative	1
FREED seen as 'special' and privileged	Negative	1
FREED does not impact the service	Neutral	2
Challenges with using the care package	Negative	2
FREED age criteria may be too high	Negative	2
Duration prioritisation can be advantageous	Positive	2

Mixed feelings towards prioritising based on duration	Neutral	2
Stress and resilience can impact implementation	Neutral	2
Reflecting on being a young person as helpful	Neutral	2
Implementation supervision as facilitative	Positive	2
It can be difficult for clinicians when they are not delivering the model as intended	Negative	2
Data and tracker can be challenging and additional support is required	Negative	2
Data and tracker valued	Positive	2
COVID: getting used to it	Neutral	2
Difficulties with conducting 48-hour engagement call (e.g., requires ‘chasing’)	Negative	3
Duration prioritisation does not cause tension in the team	Positive	3
Clinicians are confident in others ability to use the model	Positive	3
Concern that the mini team can cause a split in the team	Negative	3
Collaborating with other services facilitates FREED	Neutral	3
FREED increases the remit and scope of the service (includes service improvements)	Positive	3

FREED does not have detrimental impact on other patients	Positive	3
Desire for FREED to become standard practice and widely used	Positive	4
Clinicians enjoy working with FREED and young people	Positive	4
Going online and having the FREED website as facilitative	Positive	4
Eligibility criteria as pragmatic (e.g., direct resources to highest risk age groups for onset)	Neutral	4
The desire to have early intervention for everyone	Negative	4
Learning FREED can be challenging for new staff members as they are ‘finding their feet’	Negative	4
Active and ongoing promotion of FREED within the team as facilitative	Neutral	4
Finding the right FREED team members (fit between FREED and clinician)	Neutral	4
Referral pathways into FREED services as important and can hinder FREED	Neutral	4
Duration of illness criteria makes sense (e.g., it is evidence-based)	Positive	5
FREED increases knowledge, skills, and available resources	Positive	6
Physical risk will always need to be a priority in services	Negative	6
Practical training as facilitative (e.g., discussions with other teams, role playing)	Positive	6

Competing demands in the service as barrier (includes balancing FREED and non-FREED patients)	Negative	6
COVID was difficult for clinicians	Neutral	6
'Top-down' and senior staff buy-in as facilitative	Positive	7
Active outreach and engagement valued and facilitative (e.g., supporting people during 'gaps')	Positive	7
Self-efficacy and confidence impacting implementation	Neutral	7
Creating an open dialogue around the model in the team (e.g., through information sharing)	Neutral	7
Being open to change, flexible and/or creative as facilitative to FREED	Neutral	7
COVID resulted in change, using technology, and innovation	Neutral	9
Wait time targets (especially the treatment target) can be challenging to meet and reasons for delays (e.g., external-related delays)	Negative	9
Champion role as demanding and the need to share Champion responsibilities	Negative	10
Ongoing training and support as facilitative (e.g., through the Champion and post-training support)	Positive	10
The observed impact of FREED on patient impacts clinician buy-in	Positive	11
Allocated and/or protected time for FREED as facilitative (e.g., in general meetings, protected champion time)	Neutral	11

Note. ED = eating disorder; FREED = First Episode Rapid Early Intervention for Eating Disorders.

Table 37. The type and frequency of codes missing from KR/Coder 1's coding framework

Code	Type of code	Frequency
Difficulty implementing FREED alongside CAMHS	Negative	1
FREED combining mental and physical health	Positive	2
Anorexia nervosa maybe prioritised for early intervention	Neutral	3
Novelty of early intervention before FREED	Neutral	3
Young adult as a sensitive time	Positive	4

Note. CAMHS = Child and adolescent mental health services; FREED = First Episode Rapid Early Intervention for Eating Disorders

10.7.3 Chapter 7: National roll-out of early intervention for eating disorders: Process and clinical outcomes from FREED

10.7.3.1 Missing data per variable.

Table 38. Missing data per variable for all participants, participants who had an assessment, and participants who started treatment for FREED-Up and FREED-4-All cohorts.

	FREED-Up			FREED-4-All		
Outcome: time point(s)	All *n* = 278	Assessment completed *n* = 278	Treatment started *n* = 272	All *n* = 2473	Assessment completed *n* = 1803	Treatment started *n* = 1023
Age: baseline % (*n*)	0% (0)	0% (0)	0% (0)	1% (15)	1% (7)	0% (0)
Diagnosis: baseline % (*n*)	0% (0)	0% (0)	0% (0)	28% (694)	13% (248)	5% (55)
DUED: baseline % (*n*)	4% (11)	4% (11)	3% (7)	54% (1337)	39% (708)	31% (313)
Attempted engagement call % (*n*)	10% (27)	10% (27)	9% (25)	21% (520)	11% (204)	12% (123)
Completed engagement call % (*n*)	6% (18)	6% (18)	6% (17)	24% (603)	12% (223)	13% (129)
Offered assessment % (*n*)	5% (14)	5% (14)	5% (13)	20% (503)	1% (16)	3% (27)
Completed assessment % (*n*)	1% (1)	1% (1)	1% (1)	27% (674)	1% (4)	2% (21)

Offered treatment % (*n*)	8% (21)	8% (21)	7% (19)	55% (1353)	39% (707)	2% (20)
Completed treatment % (*n*)	3% (7)	3% (7)	1% (1)	59% (1452)	44% (800)	1% (2)
EDE-Q: baseline % (*n*)	0% (0)	0% (0)	0% (0)	68% (1680)	57% (1029)	39% (395)
EDE-Q: 6-month or post-treatment % (*n*)	35% (96)	35% (96)	33% (91)	95% (2338)	93% (1670)	87% (892)
EDE-Q: 12-month % (*n*)	37% (103)	37% (103)	36% (98)	NA	NA	NA
EDE-Q: pre- and post/6-month % (*n*)	35% (96)	35% (96)	33% (91)	95% (2357)	94% (1687)	89% (910)
EDE-Q: pre- and 12-month % (*n*)	37% (103)	37% (103)	36% (98)	NA	NA	NA
Binge episodes: baseline % (*n*)	0% (0)	0% (0)	0% (0)	67% (1653)	55% (1006)	36% (367)
Binge episodes: 6-month or post-treatment % (*n*)	35% (96)	35% (96)	33% (91)	94% (2322)	92% (1656)	86% (876)
Binge episodes: 12-month % (*n*)	37% (103)	37% (103)	36% (98)	NA	NA	NA
Binge episodes: pre- and post/6-month % (*n*)	35% (96)	35% (96)	33% (91)	95% (2343)	93% (1675)	87% (895)

Binge episodes: pre- and 12-month % (*n*)	37% (103)	37% (103)	36% (98)	NA	NA	NA
Vomit episodes: baseline % (*n*)	0% (0)	0% (0)	0% (0)	66% (1652)	56% (1005)	36% (369)
Vomit episodes: 6-month or post-treatment % (*n*)	35% (96)	35% (96)	33% (91)	94% (2323)	91% (1657)	86% (877)
Vomit episodes: 12-month % (*n*)	37% (103)	37% (103)	36% (98)	NA	NA	NA
Vomit episodes: pre- and post/6-month % (*n*)	35% (96)	35% (96)	33% (91)	95% (2345)	93% (1677)	88% (897)
Vomit episodes: pre- and 12-month % (*n*)	37% (103)	37% (103)	36% (98)	NA	NA	NA
Laxative episodes: baseline % (*n*)	0% (0)	0% (0)	0% (0)	67% (1650)	55% (1003)	36% (366)
Laxative episodes: 6-month or post-treatment % (*n*)	34% (96)	34% (96)	33% (91)	94% (2320)	92% (1654)	86% (875)
Laxative episodes: 12-month % (*n*)	37% (103)	37% (103)	36% (98)	NA	NA	NA

Laxative episodes: pre- and post/6-month % (*n*)	35% (96)	35% (96)	33% (91)	95% (2342)	93% (1674)	87% (895)
Laxative episodes: pre- and 12-month % (*n*)	37% (103)	37% (103)	36% (98)	NA	NA	NA
BMI (AN only): baseline % (*n*)[a]	0% (0/96)	0% (0/96)	0% (0/96)	48% (390/819)	42% (305/730)	23% (110/476)
BMI (AN only): 6-month or post-treatment % (*n*)[a]	21% (20/96)	21% (20/96)	21% (20/96)	89% (731/819)	88% (644/730)	82% (389/476)
BMI (AN only): 12-month % (*n*)[a]	31% (30/96)	31% (30/96)	31% (30/96)	NA	NA	NA
BMI (AN only): pre- and post/6-month % (*n*)[a]	21% (20/96)	21% (20/96)	21% (20/96)	89% (731/819)	88% (644/730)	82% (389/476)
BMI (AN only): pre- and 12-month % (*n*)[a]	31% (30/96)	31% (30/96)	31% (30/96)	NA	NA	NA
CORE-10/OM: baseline % (*n*)	1% (1)	1% (1)	1% (1)	77% (1896)	69% (1240)	58% (591)

CORE-10/OM: 6-month or post-treatment % (*n*)	34% (96)	34% (96)	33% (91)	96% (2385)	95% (1718)	92% (939)
CORE-10/OM: 12-month % (*n*)	37% (103)	37% (103)	36% (98)	NA	NA	NA
CORE-10/OM: pre- and post/6-month % (*n*)	35% (96)	35% (96)	33% (91)	97% (2397)	96% (1728)	93% (950)
CORE-10/OM: pre- and 12-month % (*n*)	37% (103)	37% (103)	36% (98)	NA	NA	NA

Note. AN = anorexia nervosa; BMI = body mass index; CORE-10/OM = clinical outcomes in routine evaluation-10/outcome measure; DUED = duration of untreated eating disorder; EDE-Q = eating disorder examination questionnaire; FREED = First Episode Rapid Early Intervention for Eating Disorders; NA = not applicable.

[a]The denominator (included in the parenthesis) differs for BMI as this calculation includes only patients with anorexia nervosa.

10.7.3.2 Impact of COVID-19 on missing data

Table 39. The percentage of FREED-4-All patients with data available for the engagement call, assessment, pre- and post-treatment questionnaires, and treatment start before (pre) and after (post) the onset of the COVID-19 pandemic

	Percentage completed/data available	
	Pre-COVID onset % (*n*) Sept 2018 – Feb 2020	Post-COVID onset % (*n)* Mar 2020 – Mar 2021
Engagement call date	87% (333/384)	84% (337/399)
Assessment date	97% (373/384)	90% (361/399)
Pre-treatment questionnaires	58% (221/384)	31% (123/399)
	Pre-COVID onset % (*n*) Sept 2018 – Dec 2019	Post-COVID onset % (*n)* Mar 2020 – Mar 2021
Treatment start date	83% (256/310)	48% (191/399)
	Pre-COVID onset % (*n*) Sept 2018 – Aug 2019	Post-COVID onset % (*n)* Mar 2020 – Mar 2021
Post-treatment questionnaires	29% (68/236)	5% (19/399)