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Mixed Methods Evaluation of a Novel Clinical Pathway for People with Co-occurring Eating Disorders and Autism

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Mixed Methods Evaluation of a Novel Clinical Pathway for People with Co-occurring Eating Disorders and Autism

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Doctor of Philosophy (PhD) in Psychological Medicine
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Abstract

This thesis aims to evaluate a novel clinical pathway for people with co-occurring eating disorders (ED) and autism – the Pathway for Eating disorders and Autism developed from Clinical Experience (the PEACE Pathway) – implemented at the South London and Maudsley (SLaM) NHS Foundation Trust ED service. A systematic review was first conducted to identify existing treatment adaptations for autistic people with ED, which concluded that the PEACE Pathway was the only treatment adaptation pathway for this comorbidity that has been described in publications. A second review was then conducted to investigate the impact of autism on ED clinical outcomes. While autism does not directly impact weight-related outcomes and eating pathology, it was linked with more severe comorbid symptoms such as depression and anxiety in patients with ED, and was associated with longer hospitalisations and increased use of intensive treatment. To explore these links in real clinical setting and to gain an understanding of patients' presentation at the SLaM ED service – where PEACE was developed and implemented – a cluster analysis was carried out using patients' self-reported clinical measures and found a patient group with more severe presentation than others; the same group also had higher average weight, more severe eating pathology, higher anxiety and depression, and more autistic characteristics. Clinical challenges associated with supporting autism and ED were then synthesised from PEACE case studies and clinical notes. Common challenges included autism-related communication, sensory, emotion and eating difficulties, cognitive rigidity, other comorbid complications, and issues with autism screening and maintaining treatment boundaries. In order to support patients' sensory difficulties, PEACE developed the sensory wellbeing workshop, which was evaluated next. Both in-person and online formats of the workshop produced significant improvement in patients' sensory wellbeing with no difference between the two formats. Lastly, outcomes of the PEACE pathway were evaluated clinically and economically using service audit data, and qualitatively through clinician interviews. Overall, the PEACE Pathway has increased autism awareness and met patients' needs through an individualised approach without compromising ED treatment outcomes, while reducing the length of hospitalisation for autistic patients to bring cost-savings to the service.

Abbreviations used in the dissertation

ADHD	Attention Deficit Hyperactivity Disorder
ADOS-2	Autism Diagnostic Observation Schedule – Second Edition
APA	American Psychiatric Association
AN	Anorexia Nervosa
AN-BP	Anorexia Nervosa: Binge/Purge Subtype
AN-R	Anorexia Nervosa: Restrictive Subtype
AQ-10	Autism Quotient (10 Item Version)
ARFID	Avoidant/Restrictive Food Intake Disorder
BED	Binge Eating Disorder
BMI	Body Mass Index
BN	Bulimia Nervosa
CAT-Q	Camouflaging Autistic Traits Questionnaire
CBT	Cognitive Behavioural Therapy
CBT-ED	Cognitive Behavioural Therapy for Eating Disorders
CI	Confidence Interval
CREST	Cognitive Remediation and Emotion Skills Training
CRT	Cognitive Remediation Therapy
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, fourth edition
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, fifth edition
ED	Eating Disorder
EDE-Q	Eating Disorder Examination Questionnaire
EDNOS	Eating Disorder Not Otherwise Specified
ES	Effect Size
EUPD	Emotionally Unstable Personality Disorder
F2F	Face-To-Face
GAD	General Anxiety Disorder
HADS	Hospital Anxiety and Depression Scale

ICD-10	International Statistical Classification of Diseases and Related Health Problems, tenth edition
ICD-11	International Statistical Classification of Diseases and Related Health Problems, eleventh edition
LMM	Linear Mixed Models
MANTRA	Maudsley Anorexia Nervosa Treatment for Adults
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OCD	Obsessive Compulsive Disorder
OSFED	Other Specified Feeding or Eating Disorder
PEACE	Pathway for Eating disorders and Autism developed from Clinical Experience
RAADS-R	Ritvo Autism Asperger Diagnostic Scale - Revised
RCT	Randomised Control Trial
SD	Standard Deviation
SLaM	South London and Maudsley NHS Foundation Trust
SPM-2	Sensory Processing Measure, Second Edition
SRS-2	Social Responsiveness Scale – Second Edition
SSCM	Specialist Supportive Clinical Management
TAU	Treatment As Usual
UK	United Kingdom
WSAS	Work and Social Adjustment Scale

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Kinnaird, E., Dandil, Y., **Li, Z.,** Smith, K., Pimblett, C., Agbalaya, R., Stewart, C., & Tchanturia, K. (2020). Pragmatic Sensory Screening in Anorexia Nervosa and Associations with Autistic Traits. *Journal of clinical medicine*, *9*(4), 1182.

Tchanturia, K., Baillie, C., Biggs, C., Carr, A., Harrison, A., **Li, Z.**, McFie, C., Oyeleye, O., & Toloza, C. (2021). Sensory wellbeing workshops for inpatient and day-care patients with anorexia nervosa. *Neuropsychiatrie* 1–9. Advance online publication.

Li, Z., Dandil, Y., Toloza, C., Carr, A., Oyeleye, O., Kinnaird, E., & Tchanturia, K. (2020). Measuring Clinical Efficacy Through the Lens of Audit Data in

Different Adult Eating Disorder Treatment Programmes. *Frontiers in psychiatry*, *11*, 599945.

Li, Z., Halls, D., Byford, S., & Tchanturia, K. (2022). Autistic characteristics in eating disorders: Treatment adaptations and impact on clinical outcomes. European eating disorders review: the journal of the Eating Disorders Association, 30(5), 671–690. **(Published version of Chapter 2, included in the Appendix 2.1)**

Carr, A., Toloza, C., **Li, Z.**, Nazar, B. P., & Himmerich, H. (2022). Therapy outcome of day treatment for people with anorexia nervosa before and during the COVID-19 pandemic. Brain and behavior, 12(6), e2604.

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Li, Z., (2021). Existing literature on case studies of eating disorder and autism in treatment: 1980-2018. PEACE Pathway Conference, King's College London, UK.

Li, Z., (2022). Lessons Learned from PEACE Case Studies: Practical Challenges in Meeting the Needs of Adults with Anorexia Nervosa and Autism. PEACE Pathway Conference, King's College London, UK.

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Declaration of own work

Chapter 1	All work is the candidate's own. The candidate received feedback and comments from her supervisors, Prof. Kate Tchanturia and Prof. Sarah Byford.
Chapter 2	The candidate conducted the search and screening of the articles. Shortlisted articles were reviewed independently by the candidate and Daniel Halls. The candidate was responsible for the data interpretation and write-up of the chapter and received feedback and comments from her supervisors, Prof. Kate Tchanturia and Prof. Sarah Byford.
Chapter 3	The candidate collected the data and prepared the manuscript with input from Jenni Leppanen. Jenni Leppanen analysed the data. The candidate received comments and feedback from co-authors and supervisors Prof. Kate Tchanturia and Prof. Sarah Byford.
Chapter 4	The candidate collected and analysed the data and prepared the manuscript. The thematic map was reviewed by Chloe Hutchings-Hay. The candidate received comments and feedback from co-authors and supervisors Prof. Kate Tchanturia and Prof. Sarah Byford.
Chapter 5	The candidate collected the data with Victoria Holetic and Jessica Webb. The candidate analysed the data and prepared the manuscript with input from Victoria Holetic. The candidate received comments and feedback from co-authors and supervisors Prof. Kate Tchanturia and Prof. Sarah Byford.
Chapter 6	All work is the candidate's own. The candidate received feedback and comments from her supervisors, Prof. Kate Tchanturia and Prof. Sarah Byford.

Chapter 7	All work is the candidate’s own. The candidate received feedback and comments from her supervisors, Prof. Kate Tchanturia and Prof. Sarah Byford.
Chapter 8	The candidate collected and analysed the data and wrote up the chapter. The thematic map was reviewed by Chloe Hutchings-Hay. The candidate received feedback and comments from her supervisors, Prof. Kate Tchanturia and Prof. Sarah Byford.
Chapter 9	All work is the candidate’s own. The candidate received feedback and comments from her supervisors, Prof. Kate Tchanturia and Prof. Sarah Byford.

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Chapter 1 Introduction

1.1 Aims and objectives

The aim of this dissertation is to evaluate a novel clinical pathway for people with co-occurring eating disorders (ED) and autism – the Pathway for Eating disorders and Autism developed from Clinical Experience (the PEACE Pathway) – which was developed and implemented in the South London and Maudsley NHS Foundation Trust (SLaM) ED service. Specific objectives include the following:

- To systematically review the literature to identify service-level or treatment-level interventions or adaptations to support patients with ED and autism and any associated evidence of effectiveness, cost or cost-effectiveness.
- To systematically review the impact of autism comorbidity on clinical outcomes in patients with ED.
- To explore patterns in a range of ED symptoms and severity indicators in patients at the SLaM inpatient ED service.
- To synthesise the clinical challenges associated with both autism and ED and outline the approach of the PEACE Pathway in adapting treatment.
- To evaluate the outcomes of the PEACE sensory wellbeing workshop in supporting patients with sensory difficulties.
- To examine the impact of the PEACE Pathway on clinical outcomes in patients at the SLaM inpatient ED service.
- To explore the cost-savings associated with the PEACE Pathway, with a focus on its impact on service use for autistic patients admitted to the SLaM ED service.
- To qualitatively evaluate clinicians' experience of the PEACE Pathway.

1.2 Background

1.2.1 Eating disorders

EDs are complex mental health conditions characterised by "a persistent disturbance of eating or eating-related behaviour" that significantly impairs one's physical and mental health, according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association & Association, 2013). Subtypes of ED include anorexia nervosa (AN; restricted energy intake leading to significantly low weight, distorted body image and intense fear of weight gain), bulimia nervosa (BN; recurrent binge eating followed by compensatory behaviours such as vomiting, excessive exercise, fasting or laxative use to prevent weight gain), binge-eating disorder (BED; regular and uncontrolled ingestion of large quantities of food in a short time), avoidant restrictive food intake disorder (ARFID; highly selective and limited food choices based on sensory aversions, fear of negative consequences, or a lack of interest in eating not motivated by weight or shape concerns), pica (eating non-food items), rumination disorder (unintentional regurgitation of undigested or partly digested food), and other specified feeding or eating disorders (OSFED; a subclinical category for difficulties that do not fit into the other ED diagnoses). ARFID, pica and rumination disorder are not commonly treated at the SLaM ED service where the PEACE Pathway is embedded, and therefore are not discussed in detail in this thesis.

Prevalence

The lifetime prevalence of AN was estimated to be 0.1% to 3.6% in females and 0% to 0.3% in males (Galmiche et al., 2019; van Eeden et al., 2021). BN has a higher reported prevalence, ranging from 0.3% to 4.6% in females and from 0.1% to 1.3% in males (Galmiche et al., 2019). Emerging studies estimate the prevalence of BED to be 0.6–1.8% in women and 0.3–0.7% in men (Keski-Rahkonen, 2021), however more population-based studies are warranted given that BED is a new diagnosis added to the DSM-5. Of all the ED subcategories, AN is associated with the highest mortality rate (Arcelus et al., 2011; Hoang et al., 2014) and often requires higher levels of specialist care for medical and nutritional stabilisation. The cost of treating AN is consistently among the highest of any psychiatric disorder (Stuhldreher et al., 2012; Stuhldreher et al., 2015), primarily due to the high cost of hospitalisation for weight restoration and the long duration of illness due to patients' great difficulty in adhering to treatment. While healthcare utilisation and costs for BN and BED are not as high as AN (Ágh et al., 2016), their marked negative impact on quality of life and long-term impact in terms of healthcare use should not be underestimated.

Treatment

In the UK, evidence-based treatment of ED is informed by the National Institute for Health and Care Excellence (NICE) guidelines. For adults with AN, NICE highlights the importance of multidisciplinary and coordinated support with a key focus on weight gain. Three options of psychological treatment are suggested for adults with AN:

- *Individual eating-disorder-focused cognitive behavioural therapy (CBT-ED)*

CBT-ED encompasses all forms of CBT developed for eating disorders, which share a common core of encouraging behavioural change and nutritional improvement in order to address the cognitions that underlie eating pathology and body image (Mulkens & Waller, 2021). Enhanced Cognitive Behavioural Therapy (CBT-E) (Fairburn, 2008) is well implemented in the outpatient setting of the SLaM ED service. The treatment lasts for approximately 6 to 12 months and consists of 20 to 40 sessions, depending on the level of weight loss when the patient starts treatment. The first stage of CBT-E mainly focuses on establishing regular healthy eating patterns, then moves on to address concerns about shape and weight, low self-esteem, perfectionism or interpersonal problems, before ending with a plan for relapse prevention. The middle phase can be modified to best suit patients' needs, for example by focusing on the skills they want to learn the most. Socratic questioning, cognitive restructuring, and homework, such as diaries and behavioural experiments, are incorporated throughout the intervention.

- *Maudsley Anorexia Nervosa Treatment for Adults (MANTRA)*

MANTRA is a cognitive-interpersonal treatment for adults with AN that considers the biological and psychological maintaining factors of the disorder (Schmidt et al., 2014). The MANTRA model proposes that AN typically arises in people with anxious, sensitive and/or perfectionist, obsessional traits, and is intensified by the biological effects of starvation. MANTRA therefore focuses on improving nutritional health, addressing interpersonal and emotional difficulties, and developing more helpful styles of thinking. The treatment can take 20 to 30 one-hour sessions depending on illness severity.

- *Specialist supportive clinical management (SSCM)*

SSCM treatment combines features of clinical management and supportive psychotherapy (McIntosh et al., 2006). Clinical management emphasises ongoing monitoring and review of core ED symptoms, whereas supportive psychotherapy uses techniques such as active listening, verbal and nonverbal attending, reflection and praise to build a warm and supportive therapeutic relationship. SSCM usually consists of 20 weekly sessions or more, depending on illness severity.

For adults with BN, NICE guidelines recommend bulimia-nervosa-focused guided self-help, supplemented with brief supportive sessions. Individual CBT-ED is recommended as a second line treatment when guided self-help is unacceptable or ineffective after 4 weeks of treatment. According to the CBT-E treatment protocol (Fairburn, 2008), 20 treatment sessions are recommended for individuals with a body mass index (BMI) of 17.5 kg/m^2 and above, with more sessions recommended for lower weight individuals.

For adults with BED, binge-eating-disorder-focused guided self-help supplemented with brief supportive sessions is offered as first line treatment. When guided self-help is unacceptable, contraindicated, or ineffective after 4 weeks, group CBT-ED (Fairburn, 2008) is recommended. Group CBT-ED programmes for adults with BED typically consist of 16 weekly 90-minute group sessions over 4 months, and focus on psychoeducation, self-monitoring, exposure training and coping with future risks and triggers. When group CBT-ED is declined or not available, individual CBT-ED is recommended, which typically consists of 16 to 20 sessions.

It is recommended by NICE guidelines to treat adults with OSFED using treatments for the ED it most closely resembles.

1.2.2 Autism and eating disorders

EDs are a highly comorbid illness, often associated with higher risks of comorbid depression, anxiety disorders, obsessive-compulsive disorder (OCD), substance abuse and personality disorders (Hudson et al., 2007; Keski-Rahkonen, 2021; Pearlstein, 2002; Swinbourne et al., 2012). Recent studies in the field have also found an over-representation of autism in the ED population (Dell'Osso et al., 2018; Schröder et al., 2023; Westwood & Tchanturia, 2017).

Autism is a neurodevelopmental condition associated with social communication difficulties and restricted or repetitive patterns of thought and behaviour (APA, 2013). In line with the views and preferences of UK autism community members (Kenny et al., 2016), identity-first language (i.e., ‘autistic person’ rather than ‘person with autism’) is used in this dissertation, and terms ‘autism’ and/or ‘on the autism spectrum’ are used in place of ‘autism spectrum disorder’.

The link between ED and autism was first conceptualised in the 1980s (Gillberg, 1983) and has since been substantiated by a wealth of research on the overlapping behavioural and cognitive features between ED and autism. Among all subtypes of ED, AN has the most substantial evidence base in terms of its overlap with autism: both conditions are associated with reduced cognitive flexibility (Westwood et al., 2016c), difficulties in recognising and describing emotions (Kinnaird et al., 2019c; Westwood et al., 2017a), sensory sensitivities and atypical sensory processing (Robertson & Baron-Cohen, 2017; Saure et al., 2022a), and interpersonal difficulties (Doris et al., 2014; Westwood et al., 2016b; Zucker et al., 2007). Literature on the prevalence of autism in AN varies depending on the autism screening/diagnostic tool used and sample characteristics. Among studies using the Autism Diagnostic Observation Schedule-Second Edition (ADOS-2) as a screening measure, Bentz and colleagues (2017) found that 16% of individuals in their sample with recent-onset AN and 21% of those recovered from AN scored above cut-off on the ADOS-2. In another study (Kerr-Gaffney, Harrison & Tchanturia, 2020) employing the ADOS-2 in a clinical sample, 27.5% of AN and 24% of people recovered from AN met the clinical cut-off. On the other hand, only 10% of adolescent females with AN in Postorino and colleagues (2017) sample scored above the threshold on the ADOS-2, with none reporting restricted and repetitive behaviours. Other studies using the Autism Spectrum Quotient (AQ) or its brief version (AQ-10) as assessment tools reported prevalence ranging from 7% to 40% (Kinnaird et al., 2020a; Stewart et al., 2017; Tchanturia et al., 2016; Tchanturia et al., 2013). The first study to utilise standard diagnostic assessment tools for autism was published in 2018 and found that 10% of individuals with AN met the diagnostic criteria for autism (Westwood et al., 2018). Overall, the inconsistency in the evidence suggests that there is a need for a standardised autism assessment tool suitable for the ED population.

The lack of appropriate autism assessment tool partly contributes to the underdiagnosis of autism in this population. Adult ED services primarily cater to adult women, where autism is frequently underdiagnosed. Recent research using primary care data has shown high levels of underdiagnosis in adults, particularly among older age groups in the UK (O’Nions et al., 2023). Previous studies have identified a gender disparity in autism diagnosis, highlighting that women and girls who meet the criteria for autism are at a high risk of not receiving a diagnosis (Loomes et al., 2017). This disparity may stem from differences in behavioural characteristics, with females exhibiting behaviours that may not align with conventional autism diagnostic assessments as closely as males (Hull et al., 2020). Furthermore, there is a greater propensity for camouflaging behaviours among women and girls, further complicating the diagnostic process (Lai et al., 2017). Therefore, PEACE adopted a trait-focused approach (as introduced in section 1.2.3.3) to prevent the exclusion of underdiagnosed patients whose needs might otherwise remain unrecognised. This decision was also influenced by practical considerations, including the lengthy waiting times within the NHS for formal autism diagnostic assessments. Hence, in the PEACE pathway and consistently throughout this thesis, the term 'autistic individuals' is employed to encompass both those with a confirmed diagnosis of autism and individuals scoring high on trait screening measures.

The relationship between autism and BN or BED, on the other hand, is even less studied than AN. Among the few studies available, Vagni and colleagues examined autistic traits using the Ritvo Autism Asperger Diagnostic Scale Revised (RAADS-R) in an Italian ED population and reported that 33% of participants showed autistic characteristics without significant differences between AN, BN and BED (Vagni et al., 2016). Another pilot study in 2017 reached similar conclusion using two more measures – the autism-spectrum quotient (AQ) and the adult autism subthreshold spectrum (AdAS Spectrum) – in addition to the RAADS to measure autistic traits, and reported that not only AN but also BN and BED patients show significantly greater autistic traits compared to control (Gesi et al., 2017). However, a later study highlighted significantly higher autistic traits in individuals with restrictive AN compared to those with binge-eating behaviours (Dell'Osso et al., 2018). This was contrasted by findings of Numata et al., (2021) who found that BED had the highest autistic traits among the ED subtypes in their sample, where 60% of patients with BED exceeded the cut-off value on the AQ (16.7% in patients with restrictive AN, 4.3% in BN). It should be noted that the study sample was small, with the restrictive AN group only consisting of 6 patients. Such inconsistent evidence and lack of studies suggest that the relationship between autism and EDs other than AN warrants further investigation.

Overall, the links between ED and autism have substantial implications for ED treatment. Studies have found that autism comorbidity can exacerbate the severity of ED (Saure et al., 2020) and is a negative predictor of treatment outcome (Leppanen et al., 2022; Nielsen et al., 2015), raising the need for ED treatment programmes to be modified so as to accommodate the needs of autistic people. First, studies have stressed the importance of a simple, predictable, and sensory-friendly environment for autistic individuals (Babb et al., 2021). Possible areas of improvement identified include noise reduction, adjustable lighting, adapted communication in staff and increase in routine and structure. Moreover, it has been pointed out that the structure, process and content of standard psychological treatment such as CBT require adaptation for the autistic population (Gaus, 2011). Several adaptations have been proposed (Spain et al., 2015; Spain and Happé, 2020; Ung et al., 2015) to enhance autistic people's engagement with CBT by using written and visual materials, identifying idiosyncratic descriptions of emotions, using individualised outcome measures such as visual analogue scales and examples, enhancing emotional awareness prior to CBT treatment, emphasising behavioural change and skill learning, and using more direct language. These studies, however, mainly focused on general adaptations to CBT-related factors such as process and techniques and/or treatment for anxiety disorders in autistic individuals. No protocol-specific recommendation has been proposed for adapting CBT-ED, SSCM, or MANTRA for autistic people with ED.

NICE guidelines (NICE, 2012) recommend that clinicians delivering interventions for coexisting mental disorders to autistic adults should have an understanding of the core features of autism and their impact on treatment and make adaptations accordingly. According to NICE, autistic adults with coexisting mental disorders should be offered psychosocial and pharmacological interventions informed by existing NICE guidance for the specific disorder (for example, autistic people with OCD should be offered treatment based on existing guidance for treating OCD), but with adaptations to the method of delivery of cognitive and behavioural interventions. Possible general adaptations recommended include:

- Utilise concrete structures and visual aids (e.g., worksheets, images, toolboxes) for enhanced clarity.
- Focus on behaviour modification as the primary intervention strategy.
- Clearly define rules and provide contextual explanations.
- Communicate in plain language, minimising metaphors and ambiguity.
- Engage a supportive individual (family member, partner, carer, or professional) if agreed by the autistic individual.
- Sustain attention through regular breaks and integrating special interests into therapy, such as using computers for information presentation.

At present, however, there is a lack of specific, empirically evaluated treatment adaptations to suit the needs of patients with ED and autism, together with an urgent need for systematic training for eating disorder clinicians on the identification and assessment of autistic characteristics (Babb et al., 2021; Kinnaird et al., 2017). To address these needs, a novel clinical pathway was introduced at SLaM NHS Foundation Trust National Eating Disorders Service: The Pathway for Eating disorders and Autism developed from Clinical Experience (PEACE Pathway). The development and components of the pathway are introduced in detail in the next section.

1.2.3 PEACE Pathway

1.2.3.1 Development

The development of the PEACE Pathway used a Plan, Do, Study, Act (PDSA) strategy to introduce change, based on the Institute for Healthcare's Model of Improvement methodology (Tchanturia et al., 2020b). This is an iterative cycle where each development is continuously assessed, and then improved on a small scale before full-scale implementation. In preparation for the pathway implementation, interviews with all major stakeholders, including patients (Kinnaird et al., 2019a; Kinnaird et al., 2019b), carers (Adamson et al., 2020) and clinicians (Kinnaird et al., 2017), were conducted to understand how to better support people with the comorbidity. These needs assessments identified gaps in clinician training and understanding of autism. There were also needs for a more flexible and individualised treatment approach, improved response to sensory and communication difficulties and better support for carers. Drawing from the needs assessment, the rollout of the PEACE Pathway at the SLaM National ED service commenced with clinician training (see Figure 1.1) focusing on autism recognition and assessment. Furthermore, a short screening tool (AQ-10) for autism was integrated into the standard intake procedure at the service. Following this initial phase, a series of training sessions were conducted, including autism and anxiety training (2018), ADOS and ADI training (2019), CBT modification training (2019), sensory adaptation training (2019), and DBT adaptations (2020). To facilitate ongoing professional development and collaboration, group supervision sessions, referred to as 'huddles' (explained further in the subsequent section), with an emphasis on autism-based formulation were established on a weekly basis from 2019 onwards.

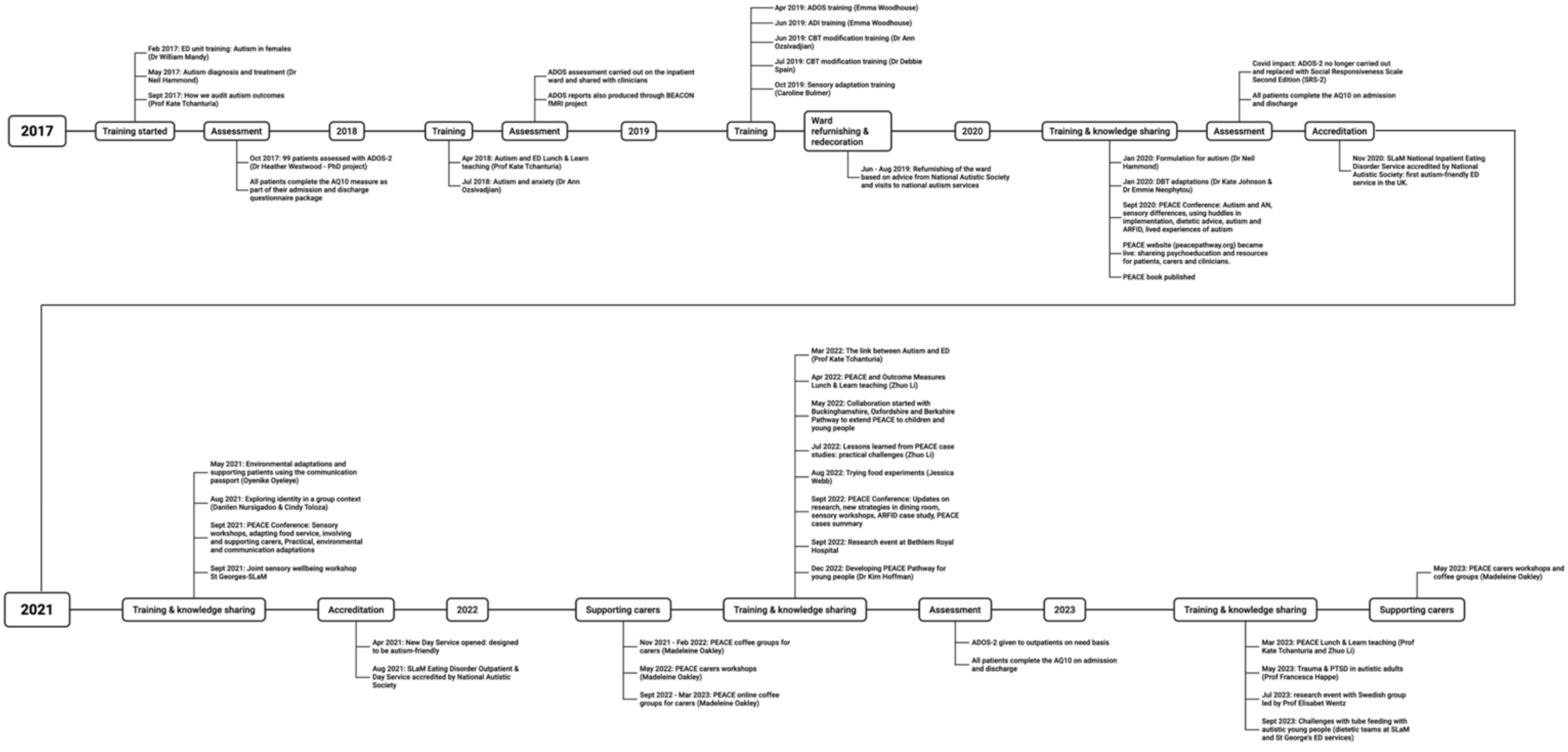
In conjunction with these training initiatives, refurbishment of the service environment began in mid-2019, guided by expert advice from the National Autistic Society and visits to national autism services. Furthermore, various resources such as the communication passport and the PEACE alternative menu were subsequently introduced. The subsequent sections provide a detailed description of each primary component of the PEACE pathway implementation.

1.2.3.2 Clinician training and PEACE huddles

Training events were introduced to the ward starting from the beginning of 2017 (Figure 1.1) to raise autism awareness among the clinical team in preparation for the rolling out of the PEACE Pathway. Training in the early phase (2017-2019) focused on recognising autism in females, common autism assessment tools and interviews, sensory adaptation, and therapy modification (e.g., CBT modification). Weekly clinical ‘huddle’ (regular, short clinical meetings attended by the multidisciplinary team) meetings (Smith & Tchanturia, 2020) were introduced in August 2019. The huddles were brief, weekly meetings used as a space for updates, training, and case discussions among clinicians in the multidisciplinary team. Initially in 2019, the inpatient service and day/outpatient service each had their own in-person huddle meetings due to the geographical distance between the two clinical sites. In April 2020, these two huddles were combined to a weekly online huddle due to COVID-19 restrictions and remained online due to the easier access for the wider team. Case studies were run monthly in PEACE huddles, focusing on challenges in supporting patients with co-occurring autism and ED and discussions on how to adapt treatment to meet their needs. A summary of past huddle case discussions has been published (Li et al., 2022) and is included in Chapter 4 in this dissertation, to illustrate the challenges in supporting the comorbidity and the development of the PEACE approach.

After the PEACE Pathway was fully implemented in 2019, more knowledge sharing events were introduced (Figure 1.1), including a PEACE conference, which has been running annually since 2020 to summarise and share learning on how to better support people with the comorbidity. Speakers included the multidisciplinary team of the clinicians, researchers and people with lived experiences who collaborated in developing PEACE. All clinicians from the SLaM ED service were encouraged to attend. In 2020, the PEACE website (peacepathway.org) was launched and the book '*Supporting Autistic People with Eating Disorders: A Guide to Adapting Treatment and Supporting Recovery*' was published summarising experiences of the multidisciplinary team in supporting the comorbidity (Tchanturia, 2021), both serving as a source of learning for clinicians and free resources for all stakeholders.

Figure 1. 1 **Timeline: PEACE Pathway implementation and development (higher definition figure is available as an electronic PDF file)**



Feb 2017: ED unit training: Autism in females (Dr William Mandy)

May 2017: Autism diagnosis and treatment (Dr Neil Hammond)

Sept 2017: How we audit autism outcomes (Prof Kate Tchanturia)

Oct 2017: 99 patients assessed with ADOS-2 (Dr Heather Westwood - PhD project)

All patients complete the AQ10 measure as part of their admission and discharge questionnaire package

Apr 2018: Autism and ED Lunch & Learn teaching (Prof Kate Tchanturia)

Jul 2018: Autism and anxiety (Dr Ann Ozsivadjian)

ADOS assessment carried out on the inpatient ward and shared with clinicians

ADOS reports also produced through BEACON fMRI project

Apr 2019: ADOS training (Emma Woodhouse)

Jun 2019: ADI training (Emma Woodhouse)

Jun 2019: CBT modification training (Dr Ann Ozsivadjian)

Jul 2019: CBT modification training (Dr Debbie Spain)

Oct 2019: Sensory adaptation training (Caroline Bulmer)

Jun - Aug 2019: Refurnishing of the ward based on advice from National Autistic Society and visits to national autism services

Jan 2020: Formulation for autism (Dr Neil Hammond)

Jan 2020: DBT adaptations (Dr Kate Johnson & Dr Emmie Neophytou)

Sept 2020: PEACE Conference: Autism and AN, sensory differences, using huddles in implementation, dietetic advice, autism and ARFID, lived experiences of autism

PEACE website (peacepathway.org) became live: shareing psychoeducation and resources for patients, carers and clinicians.

PEACE book published

Covid impact: ADOS-2 no longer carried out and replaced with Social Responsiveness Scale Second Edition (SRS-2)

All patients complete the AQ10 on admission and discharge

Nov 2020: SLaM National Inpatient Eating Disorder Service accredited by National Autistic Society: first autism-friendly ED service in the UK.

May 2021: Environmental adaptations and supporting patients using the communication passport (Oyenike Oyeleye)

Aug 2021: Exploring identity in a group context (Danilen Nursigadoo & Cindy Toloza)

Sept 2021: PEACE Conference: Sensory workshops, adapting food service, involving and supporting carers, Practical, environmental and communication adaptations

Sept 2021: Joint sensory wellbeing workshop St Georges-SLaM

Apr 2021: New Day Service opened: designed to be autism-friendly

Aug 2021: SLaM Eating Disorder Outpatient & Day Service accredited by National Autistic Society

Nov 2021 - Feb 2022: PEACE coffee groups for carers (Madeleine Oakley)

May 2022: PEACE carers workshops (Madeleine Oakley)

Sept 2022 - Mar 2023: PEACE online coffee groups for carers (Madeleine Oakley)

Mar 2022: The link between Autism and ED (Prof Kate Tchanturia)

Apr 2022: PEACE and Outcome Measures Lunch & Learn teaching (Zhuo Li)

May 2022: Collaboration started with Buckinghamshire, Oxfordshire and Berkshire Pathway to extend PEACE to children and young people

Jul 2022: Lessons learned from PEACE case studies: practical challenges (Zhuo Li)

Aug 2022: Trying food experiments (Jessica Webb)

Sept 2022: PEACE Conference: Updates on research, new strategies in dining room, sensory workshops, ARFID case study, PEACE cases summary

Sept 2022: Research event at Bethlem Royal Hospital

Dec 2022: Developing PEACE Pathway for young people (Dr Kim Hoffman)

ADOS-2 given to outpatients on need basis

All patients complete the AQ10 on admission and discharge

Mar 2023: PEACE Lunch & Learn teaching (Prof Kate Tchanturia and Zhuo Li)

May 2023: Trauma & PTSD in autistic adults (Prof Francesca Happe)

Jul 2023: research event with Swedish group led by Prof Elisabet Wentz

Sept 2023: Challenges with tube feeding with autistic young people (dietetic teams at SLaM and St George's ED services)

May 2023: PEACE carers workshops and coffee groups (Madeleine Oakley)

1.2.3.3 Autism screening

Diagnosing autism in people with ED is difficult due to diagnostic overshadowing (where autism is “overshadowed” by symptoms of comorbid conditions such as ED, depression, or anxiety) (Trubanova et al., 2014), camouflaging behaviour (where autistic women and girls mask their autistic traits more than men) (Hull et al., 2020; Lai et al., 2017), and also due to gender bias in assessment (which leads to underdiagnosed autism in women and girls) (Haney, 2016). Moreover, the primary aim of the ED service is to treat ED, rather than diagnosing autism. Therefore, it was essential to establish a pragmatic autism screening process that flags up patients with possible needs for adaptations and those who would benefit from a referral for formal assessment at a specialist autism service.

A screening process on admission was set up as part of the pathway, including an initial screening of all patient admissions using the Short (10-Item) Version Autism Spectrum Quotient (AQ-10), which assesses autistic characteristics (Allison et al., 2012). Patients who scored above clinical cut-off (6 or above) on the AQ-10 were offered advice and signposting to formal autism assessment at specialist services. They were also introduced to PEACE Pathway resources such as the PEACE website, on-going sensory workshops (which were open to all patients at the service, but may be particularly helpful for autistic patients with sensory difficulties) and the PEACE menu (sensory-adapted version of the standard menu; described further in section 1.2.3.6). Patients scoring above the cut-off on the AQ-10 or those who already had a diagnosis of autism were discussed in huddles if their presentation was challenging or complex. Where necessary, they were also followed up with the ADOS-2 (Lord et al., 2012) which provides a more in-depth assessment of autistic characteristics. When an ADOS-2 interview was not possible (e.g., due to social distancing rules during the COVID-19 pandemic), following up with the self-reported Social Responsiveness Scale – Second Edition (SRS-2) questionnaire (Constantino & Gruber, 2012) was an alternative.

1.2.3.4 Supporting sensory needs

PEACE introduced environmental changes in the service to support potential sensory difficulties in patients with autistic traits. Experts from the National Autistic Society (NAS) were invited for advice on building an autism-friendly environment, and focus groups were run with patients for needs assessment. The dining room was decluttered and redecorated to create a more calm, relaxing space. Walls were repainted with pale neutral colours, and soft furnishings were chosen to match the colour scheme. Training on sensory adaptations were carried out (Figure 1.1) with a focus on how to be attentive to patients' sensory needs during therapy sessions, for example checking if patients are comfortable with the temperature, brightness or seating at the beginning of a session. Sensory aids such as noise-cancelling ear buds and sensory toys were introduced to both inpatient and day services and were available to all patients who might need these.

A brief, pragmatic sensory screener was designed to measure sensory sensitivities in patients (Kinnaird et al., 2020a), and psychoeducation materials such as a sensory wellbeing booklet were developed to support patients' sensory wellbeing. A one-off sensory wellbeing workshop was also developed which offers both psychoeducational content and experiential activities to guide patients in creating a soothing and helpful sensory toolkit (Tchanturia et al., 2022). The sensory workshop was first designed to be in person and then adapted to a virtual workshop during the COVID-19 pandemic. An evaluation of the in-person and online sensory workshops has been published (Li et al., 2023) and is included in Chapter 4 in this dissertation.

1.2.3.5 Communication support

A communication passport was developed to enhance communication between patients and the clinical team. Similar needs-based passports have been used consistently in treatment and management programmes to enhance communication between care providers and autistic individuals (Clark et al., 2019; Javaid et al., 2020). The communication passport is a one-page personalised wellbeing record of patients' preferences in terms of communication methods (e.g., oral or written), sensory dislikes and needs, strengths and interests, and preferred ways of support. Copies of the completed passports are uploaded to electronic clinical records and shared with the clinical team involved in the patient's care. A copy of the communication passport is included in Appendix 1.1.

In addition to the communication passport, clinicians were encouraged to avoid the use of metaphors and use more direct language with patients who find this helpful (Tchanturia, 2021). It was also advised that using visual aids and/or encouraging patients to draw their thoughts down could be helpful with patients who struggle with verbal communication. With patients who need more time to process information and who find finishing a whole therapy session in one sitting challenging, it was advised to adapt the structure of the sessions accordingly (e.g., adding breaks, having shorter sessions, and allowing more time for responses; Tchanturia, 2021).

1.2.3.6 PEACE Menu

The PEACE menu is an alternative menu co-developed by dietitians and patients to address common sensory complexities in patients, whilst also ensuring all nutritional needs were met. The menu consists of meals that are "bland, soft textured and as simple and predictable as possible" (Tchanturia et al., 2020b; Williams, 2021). Furthermore, the menu was designed to minimise uncertainty by including pre-packaged items where possible and adding photographs of each meal so that they are predictable and less anxiety provoking. When piloting the menu, regular catering group meetings were held to collect patient feedback. These meetings were attended by the catering company dietitian and head chef, who were the key people in delivering this menu. Improvements and item replacements were made when necessary.

At the inpatient service, the PEACE menu is available to all patients on a need basis. Use of the PEACE menu at the day service is more limited to encourage patients to try a wider variety of food. An example of the PEACE menu used at the inpatient unit is included in the Appendix 1.2.

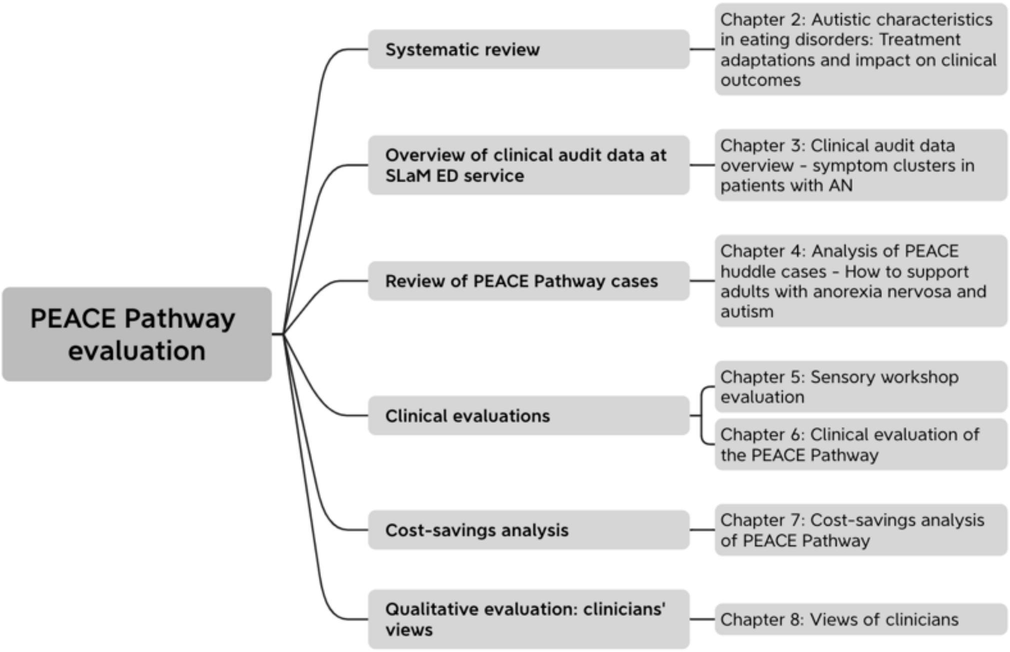
1.2.3.7 Supporting carers

During the COVID-19 pandemic, PEACE introduced online peer-led carers' groups which aimed to provide support for carers of loved ones with comorbid ED and autism (Oakley et al., 2021). The groups were led by the PEACE carers champion with lived experience and family therapy professional background. Additional groups were run after the pandemic ended to provide continuous support for carers (Figure 1.1). In 2022, a new round of carers workshops was developed for family carers with a focus on skill training and peer support. One round consists of four workshops, each with a different topic (e.g., 'when to support and when to step back', and 'de-escalating conflicts with loved ones'). Evaluation of the carers workshops is ongoing.

1.3 Thesis structure overview

The first stage of this thesis was a systematic review (Chapter 2) to explore: (1) any existing treatment adaptations or pathways for people with co-occurring ED and autism; and (2) the impact of co-occurring autistic characteristics on clinical outcomes in ED. This review highlights the need for an adapted approach and serves as background for the evaluation of the PEACE Pathway as a novel clinical pathway. Chapter 3 presents a cluster analysis of ED symptoms using clinical audit data at the SLaM ED service. This chapter provides an overview of patient characteristics at the service and highlights the association between autistic characteristics and symptom severity. It also serves as an introduction of the clinical audit database, which is also the data source for a clinical evaluation of the PEACE Pathway (Chapter 6) and an analysis of its cost-savings (Chapter 7). Chapter 4 summarises past case studies that took place in PEACE huddle meetings. It provides an overview of the practical challenges of supporting people with the comorbidity, and how these challenges were addressed by clinicians in the PEACE team. Chapter 5 and 6 are both evaluations of clinical outcomes of the PEACE Pathway. Chapter 5 evaluates a component of the PEACE Pathway – the sensory wellbeing workshop. Building on existing evidence for the sensory workshop, this chapter further compares the outcomes of in-person and online versions of the workshop. In Chapter 6, clinical outcomes of patients admitted before PEACE was implemented are compared with outcomes of admissions after PEACE implementation, to investigate the impact of the PEACE Pathway using naturalistic clinical audit data. Next, the thesis explores the potential cost-savings generated by reduced use of service in patients with co-occurring ED and autism (Chapter 7). Finally, Chapter 8 presents interviews with clinicians who were involved in the development and implementation of PEACE Pathway. Strengths, challenges, and future areas of improvement for PEACE are discussed in this chapter.

Below is a visual map of the thesis structure:



1.4 Ethical approval

Ethical approval for the qualitative interview (Chapter 7) was granted by the College Research Ethics Committee at King's College London (Reference: MRSP-21/22-28800). The qualitative summary of PEACE case studies (Chapter 3), evaluation of the sensory workshop (Chapter 4) and quantitative analyses using clinical audit data (Chapter 5, 6 and 8) received approval from the Maudsley Clinical Audit & Effectiveness Committee as a service improvement project. Copies of the consent form, information sheet and ethical clearance letter are included in the Appendices 8.1, 8.2, and 8.3, respectively.

Chapter 2 Autistic characteristics in eating disorders: Systematic Review of treatment adaptations and impact on clinical outcomes

This chapter was later modified to a manuscript and published as:
Li, Z., Halls, D., Byford, S., & Tchanturia, K. (2022). Autistic characteristics in eating disorders: Treatment adaptations and impact on clinical outcomes. European eating disorders review: the journal of the Eating Disorders Association, 30(5), 671–690.
However, the original chapter is included here for the level of details it provides. For the published manuscript, see Appendix 2.1.

2.1 Introduction

Multiple reviews have examined the overlap between AN and autism (Huke et al., 2013; Kinnaird & Tchanturia, 2021; Saure et al., 2020; Westwood et al., 2016; Westwood & Tchanturia, 2017). Huke and colleagues (Huke et al., 2013) published the first systematic review to synthesize studies on the prevalence of autism in ED populations. The mean estimated prevalence of autism from this review was 23%, although six of the eight included studies in the review were from the same Swedish longitudinal cohort (Råstam et al., 1989) which could have contributed to potential bias. Another issue that was reported in the review was the lack of consistency in autism screening measures in the included studies, which made comparison across studies difficult.

Westwood et al (2016a) conducted a systematic review of studies using the Autism Spectrum Quotient (AQ), a 50-item questionnaire investigating symptoms of autism spectrum conditions in adults (Baron-Cohen et al., 2001) or the shorter ten-item version AQ-10 (Allison et al., 2012) to assess autistic features in patients with AN. The review concluded that individuals with AN had significantly more autistic features compared to healthy controls. An updated literature review by the same group later reported consistency in literature on the over-representation of symptoms of autism in AN (Westwood & Tchanturia, 2017).

The most recent systematic review examined the association between characteristics of autism and duration of illness of AN (Saure et al., 2020), and suggested that a prolonged course of AN appears to be associated with problems in central coherence, cognitive flexibility, and emotion recognition, which are also underlying neuropsychological characteristics distinctive to autism. This finding indicates similar characteristics between autism and severe and enduring eating disorders based on self report.

A recent overview study (Kinnaird & Tchanturia, 2021) presented a framework of clinical features associated with autism in AN, including obsessional interests, emotional insight, social difficulties, attentional biases, preference for routines, and cognitive rigidity. These features, while common in autism, are more likely to be centred around food and weight in AN. For example, specific interests in autism could relate to any topic, e.g. animals, music, numbers, whereas in AN it is more likely to be centred around dieting. When these two conditions are combined, the paper pointed out, this could create an additive effect, with people with AN and autistic characteristics exhibiting worse presentation and outcomes.

These links between AN and autism could have substantial implications for current treatment strategies for ED. Indeed, studies have found that having autistic characteristics is a negative predictor of treatment outcome for EDs (Nielsen et al., 2015; Speranza et al., 2007), raising the need for treatment programmes to be modified to accommodate co-existing autism. Patients with AN and autistic characteristics may have more difficulties in expressing their needs and communicating during treatment sessions, and clinicians have also expressed their lack of confidence in treating patients with this comorbidity (Kinnaird et al., 2017). Furthermore, research has shown that over 90% of children and adults with autism have sensory difficulties in specific domains of vision and smell/taste (Leekam et al., 2007), which may contribute to active avoidance of certain foods in AN patients with autistic characteristics. These sensory difficulties may be hard to address without identifying and understanding the role of autism in the eating disorders, which again suggests the need for ED treatment options or treatment adaptations for patients with comorbid autism.

New or adapted treatment options, however, should be evidence-based to ensure they are of clinical benefit for patients with both conditions. Little is currently known about the nature of existing ED treatment options or treatment adaptations for patients with comorbid autism. In addition, any new treatment options or adaptations are likely to require additional resources to implement. In a health system with constrained resources, such additional costs must be justified through demonstration of value for money. Therefore, evidence of effectiveness and cost-effectiveness of existing options for patients with ED and autism is required to justify the required resource allocation.

2.2 Methods

2.2.1 Aims and objectives

The primary aim of this systematic review was to identify research articles describing existing interventions for patients with ED and comorbid autism, and to critically review evidence of their clinical effectiveness and cost-effectiveness (Review 1). We hypothesised that such interventions would be rare, therefore a secondary aim was included to systematically review the impact of autism comorbidity on clinical outcomes in patients with ED (Review 2), in order to provide insight into whether patients with autism have different ED outcomes or trajectory compared to patients without comorbid autism, and thus to provide evidence to support the need for new treatments or treatment adaptations.

It was hypothesized that the number of studies describing or evaluating the effectiveness or cost-effectiveness of adapted interventions for the comorbidity would be low, and that co-occurring autism would result in poorer outcomes in patients with ED, such as slower weight improvement, longer hospital admissions, and poorer ED psychopathology outcome.

This review was registered in the International Prospective Register of Systematic Reviews (PROSPERO; ID: CRD42021232322) after the search strategy was finalized.

2.2.2 Eligibility Criteria

Eligibility criteria were determined following the Population, Intervention, Comparison, Outcome and Study design (PICOS) Framework for both Review 1 (identification and evaluation of interventions for ED and autism comorbidity) and Review 2 (impact of autism comorbidity on clinical outcome in patients with ED).

2.2.2.1 Inclusion and exclusion criteria for Review 1

Population

Adults and young people over the age of 12 years, with an ED diagnosis and either high autistic characteristics or formal Autism diagnosis were included.

ED diagnoses of AN (all subtypes), bulimia nervosa, binge-eating disorder or avoidant restrictive food intake disorder from the Diagnostic and Statistical Manual of Mental Disorders IV or 5 (DSM IV/5) (Association, 1994, 2013) or the International Classification of Diseases 10 or 11 (ICD 10/11) (Organization, 1993, 2018) were included.

The targeted population should either have autistic characteristics screened using a validated screening tool or have received an autism diagnosis. autism screening is to be distinguished from a formal autism diagnosis, which requires a much more comprehensive testing and interviewing process. The purpose of autism screening is to identify and assess autistic characteristics. A positive result would then necessitate a comprehensive assessment before a formal diagnosis can be given. According to the National Institute for Health and Care Excellence (NICE) guidelines, validated screening tools for autistic characteristics include:

- Autism-Spectrum Quotient (AQ) (Baron-Cohen et al., 2001)
  The published cut-off value is ⩾32, indicating clinically significant levels of autistic characteristics.

- Autism-Spectrum Quotient 10-item version (AQ-10) (Allison et al., 2012)
  The published cut-off value is ⩾6, indicating clinically significant levels of autistic characteristics.
- Adult Asperger Assessment (AAA; includes the Autism-Spectrum Quotient [AQ] and the Empathy Quotient [EQ]) (Baron-Cohen et al., 2005)
  The cut-off is ⩾32 for the AQ component and ⩾30 for the EQ component.
- Autism Diagnostic Interview – Revised (ADI-R) (Lord et al., 1997)
  The interview covers three behavioural domains with different cut-off scores. The cut-off is ⩾10 for the social interaction domain, ⩾8 for the communication and language domain and ⩾3 for the restricted and repetitive behaviours domain. Clinically significant autistic characteristics are indicated when scores in all three domains meet the cut-offs.
- Autism Diagnostic Observation Schedule-2 (ADOS-2) (Lord, 2012)
  The cut-off value is ⩾8.
- Asperger Syndrome Diagnostic Interview (ASDI) (Gillberg et al., 2001)
  The cut-off value is ⩾5.
- Ritvo Autism Asperger Diagnostic Scale – Revised (RAADS-R) (Ritvo et al., 2011)
  The cut-off value is ⩾65.

Patients who score higher than the cut-off on the screening tools are described as having high autistic characteristics. Those who score lower than the cut-off have low or no autistic characteristics. In the body of ED literature covered by the current review, screening for autistic characteristics is much more common than formal diagnosis of autism for pragmatic reasons. In this review, therefore, the term autism comorbidity primarily refers to having high autistic characteristics rather than a formal diagnosis, unless otherwise specified.

Intervention

Both service-level or treatment-level adaptations and new treatments for patients with comorbid ED and autism were included. Service-level adaptations were defined as those applied to primary and secondary care ED services with the aim of changing the treatment environment, staff training, case management and referral process to make them more acceptable to individuals with autism. Examples include clinician training in the assessment and understanding of autism spectrum conditions, and adjusting treatment environment (noise reduction, decluttered walls etc.) in acknowledgement of atypical sensory profiles.

Treatment-level adaptations were defined as those applied to individual and group treatment processes and manuals to make them more effective for individuals with autism, such as individualised strategies modifying the length, pace, and focus of sessions, enhanced interviewing techniques, or adapted psychoeducation materials for patients and carers.

In this review, the term 'intervention' will be used when referring to new treatments or adaptations to existing treatments for patients with the comorbidity, including both treatment-level and service-level adaptations.

Comparison

For studies describing interventions for patients with ED and autism, without any assessment or effectiveness or cost-effectiveness, no comparison group was necessary and thus no inclusion criteria were applied. For studies evaluating the clinical effectiveness or cost-effectiveness of interventions for patients with ED and autism, a comparison group was required. This could be a separate, concurrent control or comparison group or the cases could be acting as their own controls in a before-and-after design.

Outcomes

Any outcome related to implementation process, clinical or economic aspects was included, for studies that either described or evaluated the effectiveness or cost-effectiveness of interventions.

Study design

All study designs were included for studies that either described or evaluated the effectiveness or cost-effectiveness of interventions.

Exclusion criteria

Non-English language publications, conference abstracts, letters and articles with no full-text available were excluded. Diagnosis of pica, rumination disorder, or feeding difficulties in children were excluded as they are not commonly treated at ED services.

2.2.2.2 Inclusion and exclusion criteria for Review 2

Population

The population of interest were the same as for Review 1, as described in detail in 2.2.2.1.

Intervention

All types of interventions targeting people with EDs were included to consider outcomes in any setting, including hospital, community, school, care institution, or outpatient-based interventions, to prevent loss of data when studies are excluded.

Comparison

To investigate the impact of autism comorbidity on ED outcomes, studies comparing between individuals with and without autistic characteristics on outcomes specified in the next section (Outcomes) were included.

Outcomes

Outcomes commonly used in ED research were included in this review, measured in physical outcomes (such as BMI or weight change), psychopathological outcomes (ED symptoms or comorbid symptoms) or service use (such as premature discharge, treatment completion or augmentation).

Study design

Clinical and community studies that investigated ED outcomes were included, including randomised controlled trials, cohort studies, case-control studies, cross-sectional studies, case series and before-and-after observational studies.

Exclusion criteria

Non-English language publications, conference abstracts, letters and articles with no full-text available were excluded. In terms of study designs, reviews and case reports of individual patients were excluded due to lack of statistical validity. Diagnosis of pica, rumination disorder, or feeding difficulties in children were excluded as they are not commonly treated at ED services.

2.2.3 Search Strategy

The same search strategies were used for Review 1 (interventions for patients with ED and comorbid autism) and Review 2 (impact of autism on clinical outcomes in patients with ED). This was accomplished by conducting a single, broad search with minimal limits, but applying different inclusion and exclusion criteria for the two reviews at the abstract screening stage.

2.2.3.1 Electronic Databases

In accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) guidelines (Moher et al., 2009), the following electronic databases were searched for relevant literature from inception to the end of December 2020: Medline, Embase, PsycINFO, Web of Science, CINAHL, Scopus and Cochrane Library. Each search strategy followed a similar structure and included relevant Medical Subject Headings (MESH terms) and keywords limited to the title, abstract and keywords of publications. All seven search strategies are provided in full in Appendix 2.2 and are described in detail below. In addition, the NHS Economic Evaluation Database was searched for relevant economic evaluation studies. The search was only based on terms for ED and autism as the database does not allow for extensive search strategies.

ED terms

MeSH libraries varied between databases, but ED-related MeSH terms were generally categorized under Feeding and Eating Disorders, Anorexia Nervosa, Bulimia Nervosa, Binge-Eating Disorder, and Avoidant Restrictive Food Intake Disorder. Other diagnostic categories that were included in the DSM-IV/V and ICD 10/11 but excluded from the database MeSH library were added in separately as keywords. For example, Eating Disorder not Otherwise Specified (EDNOS) and Purging Disorder were not in the MeSH library of all databases and were both added in separately. In Scopus and Web of Science, MeSH terms are not supported and therefore only keyword searches were used.

In initial searches, a substantial number of abstracts with a focus on feeding difficulties/food selectivity in autistic children were being picked up because of the inclusion of the MeSH term ‘Feeding and Eating Disorders’, which captured studies not only on ED but on general feeding problems as well. To reduce the inclusion of these irrelevant studies, the MeSH term ‘Feeding and Eating Disorders’ was excluded, and the keyword ‘eating dis*’ (for Eating disorder and Eating disturbances, sometimes used interchangeably in ED research) was added instead to limit the search to ED studies. Various keywords for ED were also included, such as anorex* and bulim*, to ensure the search was comprehensive.

Autism terms

Autism-related terms were generally categorised under Pervasive Development Disorders, Autism Spectrum Disorder, Asperger Syndrome, and Autistic Disorder in MeSH libraries. To ensure completeness of the search, various keywords for autism were also included: autis*, asperger*, pervasive developmental disorder, PDD-NOS and PDDNOS (pervasive developmental disorder not otherwise specified).

Intervention terms

Initially, various intervention terms were included in the search strategy, including: intervention, care, pathway, treat*, therap*, service, program*, support, training, trainer, trainor, guide*, and recommend*. However, a number of these intervention terms were too broad, such as ‘care’ and ‘support’, which resulted in too many irrelevant abstracts being identified. Furthermore, the impact of adding all of these intervention terms on the number of search results was minimal. For example, in Medline, 465 studies were located when using ED and autism terms only, and this number only dropped to 332 studies when the intervention terms were combined with the ED and autism terms using the ‘*and*’ function. To ensure comprehensiveness of the search, and given the manageable number of abstracts identified using ED and autism terms only, intervention terms were excluded. In addition, using only ED terms and autism terms allowed the same search strategy to be used by both Review 1 and Review 2.

2.2.3.2 Testing the search strategies

Before the search strategy was finalised, key researchers and groups known to undertake research in ED and autism comorbidity were checked to ensure that their work was included in the search results (Professor Christopher Gillberg, Professor Kate Tchanturia, Professor Elisabet Wentz, Dr David Vagni). In addition, key papers known to the author and supervisors were checked for inclusion (Dobrescu et al., 2020; Karlsson et al., 2013; Kinnaird et al., 2020b; Nielsen et al., 2015; Sedgewick et al., 2019a; Westwood & Tchanturia, 2017). Finally, all located reviews were checked for relevance to the current systematic review, and the reference list checked for studies that meet the inclusion criteria. All studies checked were picked up by the search strategy.

2.2.4 Screening of abstracts

Citations of all search results were first imported into the EndNote citation management software. Duplicates were removed. All abstracts were first screened by ZL for relevance and shortlisted for the two review questions, one shortlist for each. Where there was any uncertainty, abstracts were retained. Overlap was allowed and some studies were included in both shortlists. All shortlisted articles were then read in entirety by two reviewers (ZL and Daniel Halls) independently to ascertain whether they met the corresponding inclusion criteria. Disagreements were discussed with supervisors SB and KT until a consensus was reached. References of included studies and relevant reviews identified by the search strategies were also checked by hand for additional elligible studies.

2.2.5 Data extraction

For studies describing interventions for patients with ED and autism, data extracted include:

- Author
- Year of study
- Country
- Study type
- Aim of study
- Intervention

For studies evaluating the clinical effectiveness and/or cost-effectivess of interventions for patients with ED and autism, and for studies of the impact of autism cormobidity on clinical outcomes in patients with ED, the same set of data were extracted, including:

- Author
- Year of study
- Country
- Study design
- Aim of study
- Sample characteristics (size, sex composition, age range and mean age)
- Subtype of ED diagnosis and diagnostic manual used (DSM-IV, DSM-V, ICD 10, or ICD 11)
- autism assessment tool and percentage of participants with autistic characteristics
- Outcomes measured and the measures used
- Results

Three data extraction tables were designed to retrieve the above information, one table for studies describing the interventions for ED and autism comorbidity, one for studies evaluating such interventions, and one for studies of the impact of autism on clinical outcomes in ED.

2.2.6 Analysis

For the first review of interventions for ED and autism comorbidity, it was hypothesized that the number of studies describing or evaluating such interventions would be very low, and any studies that evaluated the clinical effectiveness or cost-effectiveness of such interventions would be subject to significant heterogeneity in sample characteristics and outcome measures. Thus, a narrative synthesis of the results would be most appropriate. For the second review of the impact of autism on clinical outcomes in patients with ED, a narrative review was appropriate given the nature of the question. Overall, the main output of this systematic review was descriptive.

2.3 Results

The initial search of the seven databases yielded 3,527 publications. The search located two relevant literature reviews that included studies of the impact of autism on clinical outcomes in ED (Brown & Stokes, 2020; Westwood & Tchanturia, 2017). The reference lists for the reviews were checked and no additional studies were located. A search of the NHS Economic Evaluation Database also located no additional studies.

All 3,527 records were downloaded into Endnote and duplicates were removed, leaving 2,037 abstracts to be checked and shortlisted. At the full review stage, the two reviewers agreed on 100% of the abstracts for Review 1 and 93% of abstracts for Review 2. Disagreements in Review 2 were discussed with the supervisors until agreement was reached.

2.3.1 Screening of abstracts for Review 1

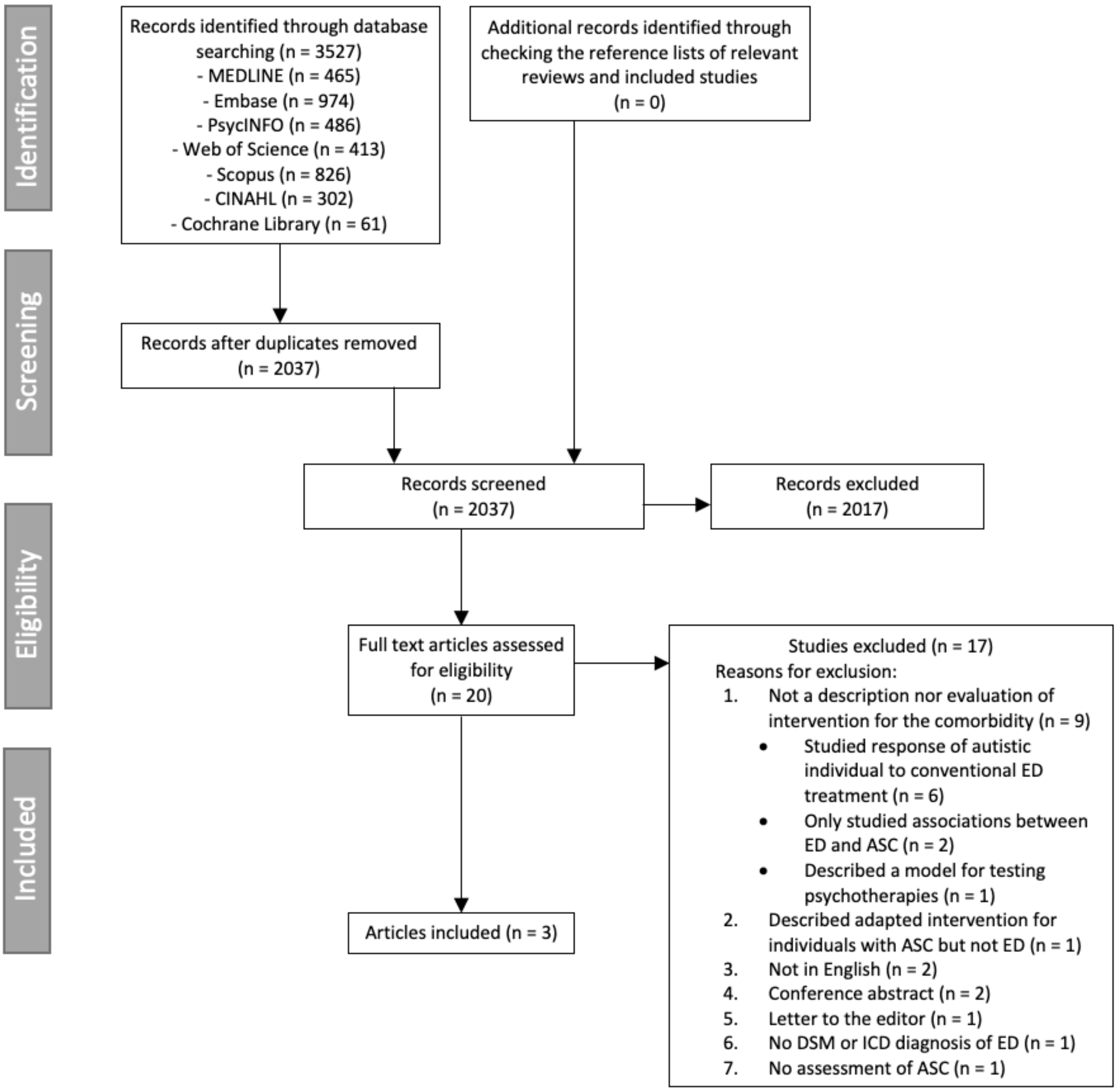
2.3.1.1 Manuscripts identified

Figure 2.1 provides the PRISMA flow diagram of the records retrieved for Review 1: description and evaluation of interventions for patients with ED and comorbid autism. Out of the 2,037 records screened, 20 articles were identified as potentially meeting inclusion criteria for Review 1 and subject to full text review. Of these, 3 articles were met inclusion criteria (Smith & Tchanturia, 2020; Tchanturia et al., 2020a; Tchanturia et al., 2020b).

The remaining 17 articles were excluded from this review for the following reasons:

- Not a description nor evaluation of interventions for ED and autism comorbidity – focused on response to conventional ED treatment of patients with autistic characteristics (n = 6)
- Not a description nor evaluation of interventions for ED and autism comorbidity – focused on associations between ED and autism (n = 2)
- Not a description nor evaluation of interventions for ED and autism comorbidity – described a model for testing psychotherapies (n = 1)
- Described interventions for autistic indivduals who do not have ED (n = 1)
- Not in English (n = 2)
- Conference abstract (n = 2)
- Letter to the editor (n = 1)
- No DSM or ICD diagnosis of ED (n = 1)
- No assessment of autistic characteristics (n = 1)

Figure 2. 1 PRISMA diagram of the records retrieved for Review 1



2.3.1.2 Characteristics of articles included

All of the three included articles were published in the UK in the same year (2020) by the supervisor KT’s research group, and either describe or evaluate the PEACE Pathway. Two articles contained a description of the intervention and the third contained an economic evaluation of cost-savings. No studies were identified which either described or evaluated any other treatment or adaptations for autism comorbidity in ED populations.

2.3.1.3 Narrative synthesis of articles included in Review 1

The two articles describing the PEACE Pathway intervention are summaried in Table 2.1. The first article (Tchanturia et al., 2020b) describes the design and implementation of the PEACE Pathway. The pathway was co-developed by the clinical team and service users following a needs assessment, and piloted at an ED service in South London and Maudsley NHS Foundation Trust, London. All patients at the ED service received a DSM-5 diagnosis of ED. The implementation involved a series of treatment adaptations, including: adaptations to various therapeutic modalities such as cognitive behavioural therapy (CBT) and formulation-based approach, introduction of workshops and psychoeducation materials on sensory wellbeing and communication, and reinforcing carers' support. Service-level adaptations were also described in this paper: the ward environment was redecorated, and clinician training on autism assessment (AQ-10, ADOS-2, ADI-R) and autism awareness was introduced.

The second article (Smith & Tchanturia, 2020) focused on one part of the implementation of the PEACE Pathway: the PEACE huddles, which are brief, weekly meetings of the clinical teams to share feedback on PEACE patients and updates on the pathway implementation. The article included a study which aimed to evaluate clinicians' opinions on the benefits of the huddles in ED treatment settings in providing a higher level of care for patients with comorbid autism. Because no patient-level measure of clinical effectiveness was evaluated and only clinician feedback was collected, the article was included in this review as a description of an intervention for ED and comorbid autism, rather than as an evaluation of the effectiveness of an intervention for ED and comorbid autism. A total of 283 responses evaluating huddles were collected from participating clinicians over a 12-months period, and the usefulness of the PEACE huddles were rated 84 out of 100 on average. Overall, the huddles were reported to be well-structured, focused, and well-received. Data extracted from this study are summarised in Table 2.1.

Table 2. 1 Data extracted from included articles describing interventions for autism co-morbidity

Author	Year	Country	Study design	Aim	Intervention
Tchanturia et al.	2020	UK	Implementation paper	To describe the design and implementation of the PEACE Pathway	Treatment-level adaptations: • Adaptations to therapeutic modalities (CBT, DBT, formulation-based approach, CRT, and CREST) • Introduction of workshops and psychoeducation materials • Reinforcing carers' support Service-level adaptations: • Redecoration of ward environment • Clinician training on autism assessment and awareness
Smith & Tchanturia	2020	UK	Survey	To evaluate the clinicians' opinions on the benefits of PEACE huddles in ED treatment settings	PEACE huddles, which are weekly meetings of the clinical team to: • Share feedback on PEACE patients who have comorbid ED and autism • Share updates and gather feedback on the pathway implementation • Improve team communication • Update on any other PEACE-related business

The third article (Tchanturia et al., 2020a), summarised in Table 2.2, was a preliminary economic evaluation exploring the cost-savings generated by the PEACE Pathway and was the only manuscript identified which contained an evaluation. Whilst not a formal assessment of cost-effectiveness, which requires the comparative analysis of both costs and effects, this was an early, hypothesis generating study to explore potential for cost-effectiveness and can be described as a partial economic evaluation, which are not themselves sufficient to inform decisions but often provide the key evidence required for decision-making (Drummond et al., 2015). The article was therefore included in the review.

The study was a service-level retrospective before and after evaluation comparing length of admission and cost of admission in patients with a DSM-5 diagnosis of ED with and without autistic characteristics. Data were collected from clinical records for 6 years before the PEACE Pathway was introduced and 2 years after the pathway was introduced. Autistic characteristics were screened by ADOS-2 (Lord, 2012). Before the pathway was implemented, the average length of admission for autistic patients was longer (mean 19 weeks) than non-autistic patients (mean 16 weeks). This finding was reversed after the pathway was implemented, with autistic patients spending less time in hospital (mean 13 weeks) than non-autistic patients (mean 17 weeks) on average. Cost-savings associated with the reduction in length of admission of patients with autistic characteristics were estimated to be £22,837 per patient and approximately £275,000 per year for the service as a whole.

Table 2. 2 Data extracted from included evaluations of interventions for autism comorbidity

Author	Year	Country	Study design	Aim	Sample	ED diagnosis	autism assessment	Outcome	Result
Tchanturia et al	2020	UK	Cohort study	To explore the impact of the development of the PEACE Pathway on the length and cost of hospital admissions.	Not reported in the text but known to the author who was a co-author on the paper: N = 333 Female = 331 (99%) Age range = 18 – 65 (mean = 28.3)	AN (DSM-V)	ADOS-2	Length of admission; cost of admission	Implementation of the pathway is associated with a reduction in length of admission of patients with autistic characteristics, leading to estimated cost-savings of £22,837 per patient and approximately £275,000 per year for the service.

2.3.2 Screening of records for Review 2

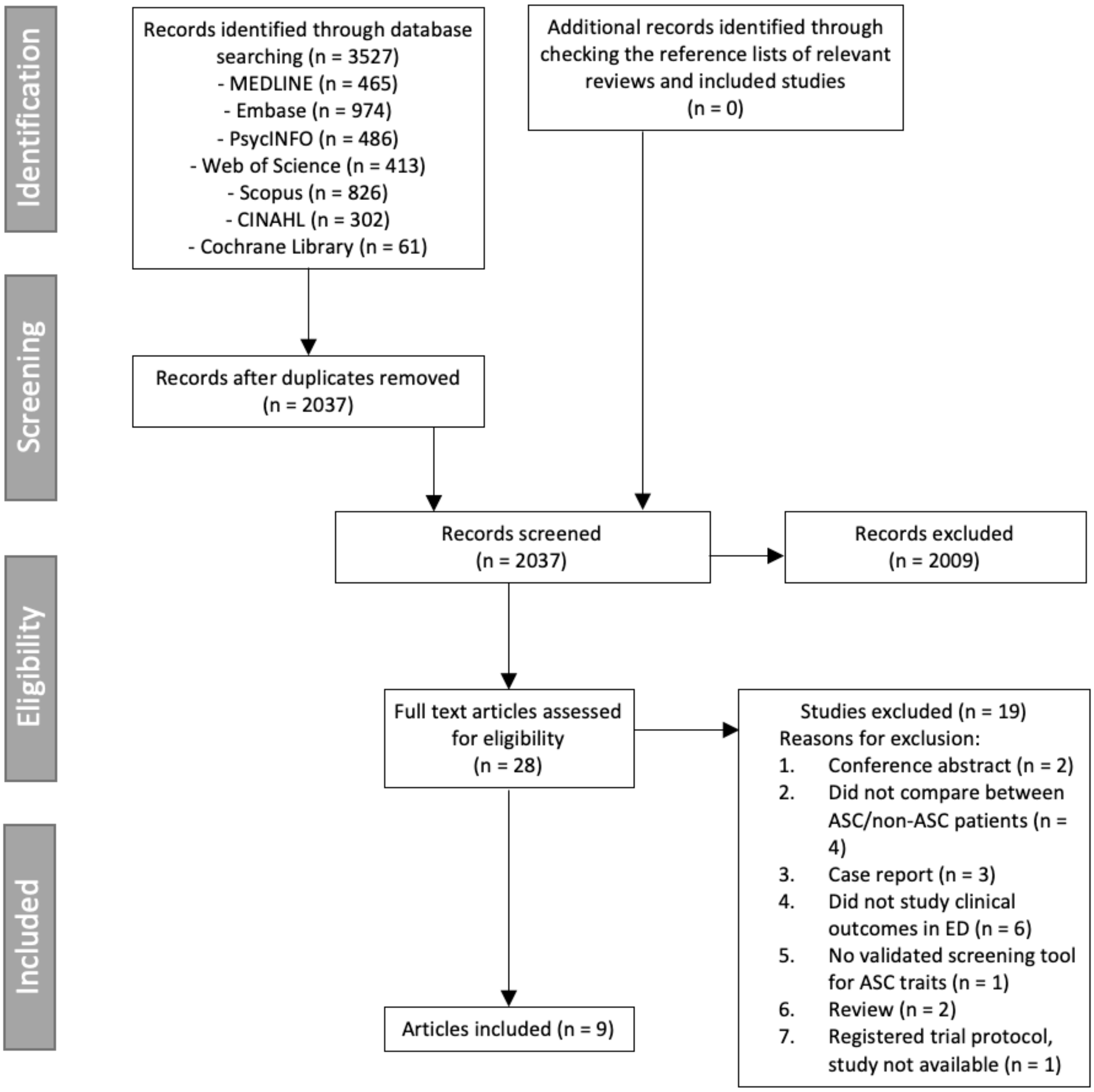
2.3.2.1 Manuscripts identified

Figure 2.2 shows the PRISMA diagram for review 2: impact of autism comorbidity on clinical outcome in patients with ED. Out of the 2,037 records, 28 articles were initially identified as potentially meeting inclusion criteria for review 2 and were subject to full text review. Of these 28 articles, 9 met the inclusion criteria.

The remaining 19 studies were excluded from this review for the following reasons:

- Conference abstract (n = 2)
- Did not compare between autism and non-autism patients (n = 4)
- Case report (n = 3)
- Did not report clinical outcomes in ED (n = 6)
- No validated screening tool for autism was used (n = 1)
- Review (n = 2)
- Registered trial protocol with no available study (n = 1)

Figure 2. 2 PRISMA diagram of the records retrieved for Review 2



2.3.2.2 Characteristics of articles included

The economic evaluation (Tchanturia et al., 2020a) included in Review 1 (described in 2.4.1.2) was also eligible for inclusion in Review 2, since it explored the impact of autism comorbidity on the length of hospital admission, which is a treatment outcome. Of the eight remaining studies eligible for this research question, the majority (n = 6) were carried out in the UK, of which three were authored by the supervisor KT's research team. The remaining two studies were carried out in Sweden. All studies included patients with AN, with two studies further including patients with EDNOS and Atypical AN (Stewart et al., 2017; Nazar et al., 2018). All were published between 2012 and 2020. Characteristics of the included articles are summarised in Table 2.3.

Table 2. 3 Data extracted from studies included in Review 2

Author (Year)	Country	Study Type	Aim	Sample	ED diagnosis	autism assessment	Outcomes measured	Results
Anckarsäter et al (2012)	Sweden	Cross-sectional, with control	To compare clinical outcomes and cognitive test results between patients with AN with and without an autism diagnosis.	N = 51 Female = 48 (94%) Age range not reported (mean = 32)	AN (DSM-IV)	ASDI[1]; DSM-IV diagnosis	Overall clinical outcome based on five scales (Morgan–Russell outcome assessment schedule; MROAS): • food intake and weight concern • menstrual pattern • disturbance of mental state • psychosexual state • social relationships and employment activity	• Individuals with AN and comorbid autism had worse overall outcome (body weight, diet restriction, menstruation, attitude to sex and menstruation, social relationships, relationship with family, and mental state) compared to individuals with AN without autism and healthy controls.

Huke et al (2014)	UK	Cross-sectional	To examine Autistic features in relation to treatment completion and ED psychopathology in patients with AN.	N = 32 Female = 32 (100%) Age range not reported (mean = 28.7)	AN (DSM-IV)	AQ[2]	ED symptoms (EDE-Q[3]); Treatment completion	• There was no significant relationship between ED symptoms and autistic characteristics. • Patients with autism were more likely to complete ED treatment as planned compared to patients without autism, although this result was not statistically significant.
Nielsen et al (2015)	Sweden	Cohort study	To analyse the influence of diagnostic stability of autism on clinical outcome in patients with teenage onset AN.	N = 51 Female = 48 (94%) Mean age = 32	AN (DSM-IV)	ASDI; AQ	Overall clinical outcome based on five scales (Morgan–Russell outcome assessment schedule; MROAS): • food intake and weight concern • menstrual pattern	• Presence of autism in individuals with AN was negatively associated with mental state, psychosexual state and social relationships and employment activities.

							• mental state • psychosexual state • social relationships and employment activity	
Tchanturia et al (2016)	UK	Case series	To investigate the effects of group cognitive remediation therapy (group CRT) for AN patients with and without autistic characteristics	N = 35 Female = 35 (100%) Age range not reported (mean age = 26.2)	AN (DSM-V)	AQ-10[4]; ADOS[5]	Cognitive flexibility (DFlex[6]); Self-reported ability to change (Motivational ruler)	• Patients with low autistic characteristics showed significantly more increase in self-reported ability to change and improvement in cognitive flexibility after the intervention, compared to the autistic group. • Current brief group cognitive remediation therapy (group CRT) had no influence on cognitive flexibility or motivation to change

								in patients with autism.
Stewart et al (2017)	UK	Cross-sectional	To report the impact of autistic characteristics on treatment outcomes of girls with AN, EDNOS-restrictive subtype, or atypical anorexia.	N = 409 Female = 409 (100%) Age range = 9 to 18 (mean = 14.6)	AN (DSM-IV and V), EDNOS-Restrictive (DSM-IV), Atypical Anorexia (DSM-V)	AQ; SAS[7]	Composite outcome on BMI, bulimic symptoms and menstrual pattern (Morgan Russell Criteria); ED symptoms (EDE-Q); Depression symptoms (Moods and Feelings Questionnaire); Anxiety symptoms (Screen for Child Anxiety Related Disorders); Obsessive and compulsive disorder symptoms (Child Obsessional Compulsive Inventory); Treatment augmentation (through admission to inpatient or intensive day patient programme)	• There was no significant difference in BMI, bulimic symptoms or menstrual pattern between patients with high and low autistic characteristics. • Autistic characteristics were not correlated with ED symptoms. • Autistic characteristics were significantly correlated with depression, anxiety, and obsessive compulsive symptoms. • Patients with autistic characteristics showed

								a greater need for treatment augmentation compared to patients without autism.
Nazar et al. (2018)	UK	Cross-sectional study	To examine the clinical outcomes of adolescents and young adults with anorexia nervosa (AN) comorbid with broad autism spectrum disorder (autism) or autistic characteristics.	N = 149 Female = 137 (92%) Age range = 13 to 21 (mean = 16.9)	AN, EDNOS, Atypical AN (DSM-IV)	autism diagnosis (DSM-IV and ICD 10); SAS	BMI increase; ED symptoms (SEED[8]); Socioemotional difficulties (SDQ[9]) ; Treatment augmentation (through admission to inaptient or intensive day patient programme)	• There was no significant difference in change in BMI or ED symptoms between patients with or without autism. • The autism group appeared to have more socioemotional difficulties compared to those without autism. • The autism group showed a greater need for treatment augmentation

								compared to patients without autism.
Tchanturia et al (2020)	UK	Cohort study	To explore the impact of the development of the PEACE Pathway on the length and cost of hospital admissions.	Not reported in the text but known to the author who was a co-author on the paper: N = 333 Female = 331 (99%) Age range = 18 – 65 (mean = 28.3)	AN (DSM-V)	ADOS	Length of admission; cost of admission	• Prior to implementation of adapted interventions, patients with autism had longer admissions compared to patients without autism • Implementation of the pathway is associated with a reduction in length and therefore costs of admission of patients with autistic characteristics
Dandil et al (2020)	UK	Case series	Examine the effects of individual cognitive remediation therapy (individual CRT) treatment for adult	N = 99 Female = 99 (100%) Age range not reported	AN (DSM-V)	AQ-10	Bigger picture thinking (ROCF[10]); Set shifting (Brixton Spatial Anticipation Test)	• High autistic characteristics did not impact the effects of individual cognitive remediation therapy (CRT); both groups

			women with AN with or without autistic characteristics.	(mean = 23.9)				with or without autistic characteristics showed improvement in set shifting after individual CRT treatment.
Li et al (2020)	UK	Cross-sectional	To examine the outcomes in patients with AN with and without autistic characteristics in three different treatment settings: inpatient, day treatment, and step-up treatment	N = 476 Female = 466 (98%) Age range = 18 to 65 (mean = 26.9)	AN (DSM-V)	AQ-10	BMI; ED symptoms (EDE-Q); Anxiety and depression symptoms (HADS[11]); Work and social functioning (WSAS[12])	• There was no difference in discharge BMI and ED symptoms between patients with and without autistic characteristics. • Patients with autistic characteristics showed more severe depression and anxiety symptoms as well as more severe social impairment compared to patients without autistic characteristics.

[1]ASDI=Asperger Syndrome Diagnostic Interview; [2]AQ=Autism-Spectrum Quotient; [3]EDE-Q=eating disorders evaluation questionnaire; [4]AQ-10=Autism-Spectrum Quotient 10-item version; [5]ADOS=Autism Diagnositc Observation Schedule; [6]DFlex=Detail and Flexibility questionnaire; [7]SAS=Social Aptitude Scale; [8]SEED=Short Evaluation of Eating Disorders; [9]SDQ=Strengths and Difficulties Questionnaire; [10]ROCF=Rey-Osterrieth Complex Figure test; [11]HADS=hospital anxiety and d epression scale; [12]WSAS=Work and Social Adjustment Scale

2.3.2.3 Narrative synthesis of articles included in Review 2

Swedish studies

Two of the included studies (Anckarsäter et al., 2012; S. Nielsen et al., 2015) were based on a Swedish longitudinal cohort initiated in the mid 1980s (Råstam et al., 1989). The longitudinal cohort sample contained 51 participants with AN and 51 gender-matched controls in Gothenburg, Sweden who were examined with assessments of psychiatric disorders, health-related quality of life and general outcomes on different occasions: at the ages of 16 (baseline, Study 1), 21 (Study 2), 24 (Study 3), 32 (Study 4). All AN cases fulfilled DSM-III-R (APA, 1987) and subsequently DSM-IV (APA, 1994) criteria for AN within a year of the assessment of Study 1 (Råstam, 1992; Råstam et al., 1989). At all four occasions, an investigator blinded to group status assigned autism diagnoses using instruments that were most up-to-date and comprehensive at each time point: a structured interview with the mother was used at baseline; the Dewey social awareness test (Dewey, 1991), DSM-III-R and a checklist for Asperger's syndrome outlined by Gillberg and Gillberg (1989) were used at Study 2; the ASDI (Gillberg et al., 2001), DSM-IV and the checklist for Asperger's syndrome were used at Study 3; and the ASDI, DSM-IV, the checklist for Asperger's syndrome and the Autism-Spectrum Quotient (AQ) (Baron-Cohen et al., 2001) were used at Study 4.

Anckarsäter et al, published in 2012, used cross-sectional data from Study 4 (at mean age 32 years) of the Swedish longitudinal cohort to investigate the autism symptoms, personality profiles, neurocognition and outcomes in the sample (Anckarsäter et al., 2012). A lifetime prevalence of autism of 33.3% was noted in the AN sample at this time point, compared with 2% prevalence in the matched controls (Anckarsäter et al., 2012). Outcomes were measured with the Morgan-Russell outcome assessment schedule (MROAS) (Morgan & Hayward, 1988), a clinical assessment of AN which summarises outcome data on five dimensions: food intake and weight concern; menstrual pattern; mental state; psychosexual state; and social relationships and employment activity. The results indicate that participants with AN and comorbid autism had higher prevalence of personality disorders (20%) and poorer overall outcomes as measured by the MROAS ($p < 0.01$) compared to participants without autism.

Nielsen et al, published in 2015, used data from Study 1 to Study 4 of the Swedish longitudinal cohort to investigate the impact of autism diagnostic stability on outcomes in AN (Nielsen et al., 2015). Outcomes were measured with the MROAS (Morgan & Hayward, 1988) at each follow-up. Additionally, the Morgan-Russell criteria of good/intermediate/poor, based on the combined status of BMI, bulimic symptoms and menstrual pattern, were reported. The results indicated that positive development in body weight, dietary restriction, menstrual pattern, sexual behaviour and social relationship was limited to those individuals who had never been assigned an autism diagnosis. Additionally, the diagnostic stability of autism, particularly when autism was present at all examinations, contributed to poorer outcomes in mental state, psychosexual state, social relationships and employment activity compared with individuals with no autism diagnosis.

UK Studies

The remainder of the included studies were from the UK. Huke and colleagues (Huke et al., 2014) investigated the relationship between Autistic features and treatment completion and ED psychopathology in patients with AN. Thirty-two participants with AN were recruited from the Yorkshire Centre for Eating Disorders (YCED, Leeds, UK), all were female and the mean age was 28.7 years. Healthy controls ($n = 32$) were matched for age and gender. Supervisor KT was familiar with the YCED and was able to confirm that all patients received a DSM diagnosis of ED in the service. Autistic characteristics were measured with the AQ (Baron-Cohen et al., 2001). Outcomes measures included ED symptoms assessed with the Eating Disorders Evaluation Questionnaire (EDE-Q) (Fairburn et al., 1993) and treatment completion (‘premature termination of treatment’ vs ‘treatment completed as planned’). Obsessive-compulsive characteristics and anxiety and depression symptoms were also assessed, although not compared between those with and without autism. The results indicate that there was no significant relationship between autistic characteristics and ED symptoms, nor between autistic characteristics and premature termination of treatment. One non-significant but interesting finding was that 87.5% (n = 7/8) of participants with autism completed treatment as planned compared with 50% (n = 12/24) of those without autism. This may suggest enhanced treatment adherence in autism patients, who may respond well to the rules and routines in an inpatient ward since these may ease anxieties in a novel environment.

Tchanturia et al, published in 2016, examined the treatment response of group format Cognitive Remediation Therapy (CRT) for AN patients with and without autistic characteristics (Tchanturia et al., 2016). The study recruited 35 participants from an inpatient ED unit in London. All were female with a mean age of 26.2 years. All had a DSM-5 (Association, 2013) diagnosis of AN. Autistic characteristics were assessed with either the AQ-10 (Allison et al., 2012) or the Autism Diagnostic Observation Schedule (ADOS) (Gotham et al., 2007). Motivation and cognitive styles (rigidity and attention to detail) were assessed with motivational ruler (Miller & Rollnick, 2012) and DFlex (Roberts et al., 2011) before and after the groups received the CRT intervention, and compared between patients with and without autistic characteristics. The results indicate that patients without autism showed significant improvement in cognitive rigidity (p = 0.007) and self-reported ability to change (p = 0.004), whereas patients with autistic characteristics showed no significant improvement in any outcome measure.

Dandil et al, published by the same research group in 2020, carried out an evaluation in the same London ED unit which aimed to examine the treatment response to individual format (rather than group format) CRT for AN patients with and without autistic characteristics (Dandil et al., 2020). A total of 99 inpatients were recruited. All were female with a mean age of 23.9 years, and all had a DSM-5 diagnosis of AN. Autistic characteristics were screened using the AQ-10. Treatment outcome was measured in change in cognitive styles (bigger picture thinking assessed with Rey-Osterrieth Complex Figure (ROCF) test (Rey, 1941) and set shifting assessed with Brixton Spatial Anticipation Test (Burgess & Shallice, 1996)) and compared between patients with and without autistic characteristics. The results showed that although neither group saw improvement in central coherence after CRT, there was positive improvement in set shifting in both groups with and without autistic characteristics ($p < 0.001$ for both groups), and high autistic characteristics did not impact the effects of individual CRT.

Stewart et al, published in 2017, investigated through clinical audit the impact of autistic characteristics on treatment outcomes of patients at a specialist outpatient child and adolescent ED service in London (Stewart et al., 2017). A total of 409 female patients were recruited, with a mean age of 14.6 years. All patients had a DSM-IV or DSM-V diagnosis of AN, restrictive subtype Eating Disorder Not Otherwise Specified or Atypical Anorexia. Autistic characteristics were measured using the Social Aptitude Scale (Liddle et al., 2009) and the AQ (Baron-Cohen et al., 2001). Morgan-Russell criteria of good/intermediate/poor (based on the combined status of BMI, bulimic symptoms and menstrual pattern) were used to classify physical treatment outcomes. ED psychopathology was also measured using the EDE-Q. The results showed no differences in physical outcomes and ED psychopathology between patients with and without autistic characteristics. However, autistic characteristics were associated with symptoms of depression ($p < 0.001$), anxiety ($p < 0.001$), OCD ($p < 0.001$) and treatment augmentation reflected by greater use of the intensive day patient or inpatient treatment ($p < 0.01$).

Nazar et al, published in 2018, also examined the impact of autistic characteristics on clinical outcomes of patients with AN (Nazar et al., 2018). This study was a secondary data analysis from a multi-centre randomized controlled trial in the UK. A total of 149 patients were recruited, 137 were female and the mean age was 16.9 years. All patients received a DSM-IV or ICD-10 diagnosis of AN or atypical AN. Formal diagnosis of autism was based on DSM-IV and ICD 10, and autistic characteristics were additionally assessed with the Social Aptitude Scale (SAS) (Liddle et al., 2009). Patients with and without autism showed similar reductions in ED symptoms and BMI change at 12-month follow-up. However, social difficulties and global dysfunctioning remained higher in the autism group at follow-up compared to those without autism ($p = 0.002$). In addition, the autism group showed treatment augmentation marked by a greater use of intensive inpatient or day-patient treatment ($p = 0.015$) and medication use prior to admission to hospital ($p < 0.001$).

Lastly, Li et al, published in 2020 and authored by the PhD student and supervisor KT, investigated the treatment outcomes in inpatient and day-patient treatment settings through clinical audit data (Li et al., 2020). Impact of autistic characteristics on the clinical outcomes was evaluated as part of the study objectives. Data from 476 patients were collected, 466 of whom were female, and the mean age was 26.9 years. All patients had a DSM-V diagnosis of AN. Autistic characteristics were assessed with the AQ-10. Outcomes were measured by BMI, ED symptoms represented by the EDE-Q, comorbid depression and anxiety symptoms and social impairment, and all outcomes were compared between patients with and without autistic characteristics. The results indicate no difference in discharge BMI and ED symptoms between patients with and without autistic characteristics. However, patients with autistic characteristics exhibited more severe depression symptoms ($p = 0.009$), anxiety symptoms ($p = 0.013$) and social impairment ($p = 0.008$) compared to patients with no autistic characteristics.

2.4 Discussion

2.4.1 Summary of findings

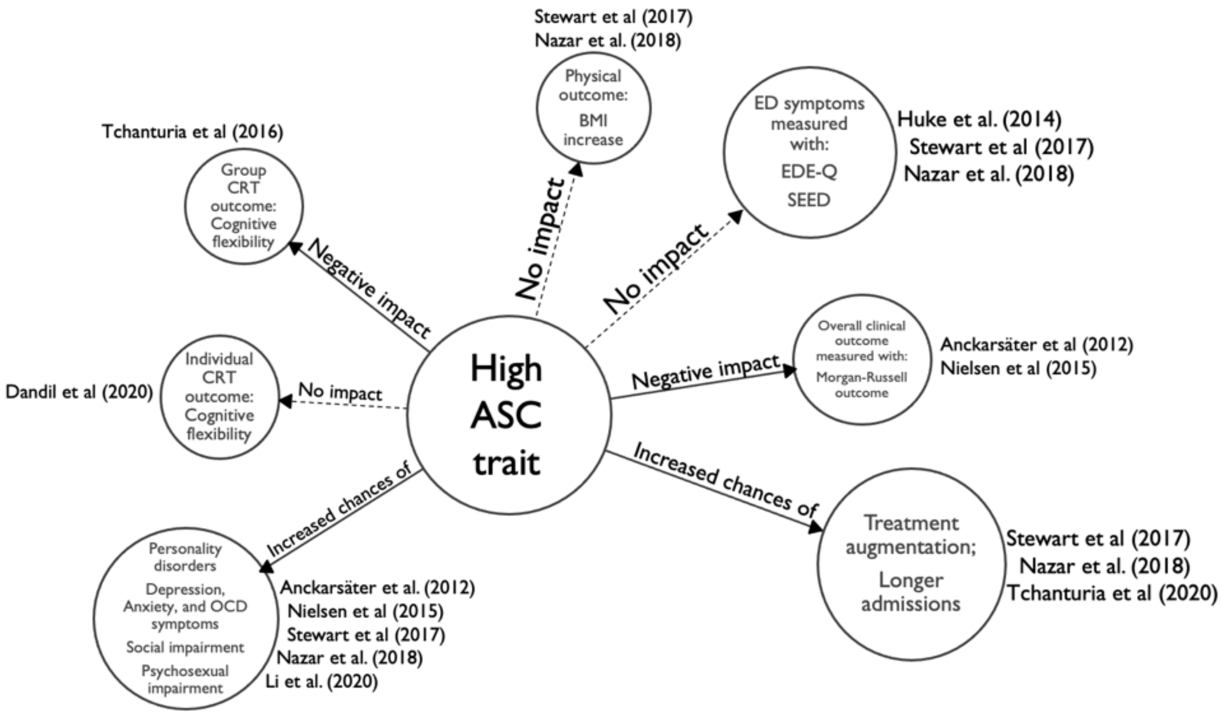
Overall, the number of studies identified in Review 1 (description or evaluation of treatments or adaptations for comorbid autism) was low and all related to the same intervention – the PEACE Pathway. The PEACE Pathway was the only intervention for patients with ED and autism that has been described and evaluated in published manuscripts (Smith & Tchanturia, 2020; Tchanturia et al., 2020a; Tchanturia et al., 2020b), despite the broad search strategy, indicating that few such treatments have been developed and few adaptations have been carried out for autistic people with ED. No RCTs of treatments or adaptations were identified, and the partial economic evaluation of the PEACE Pathway (Tchanturia et al., 2020a) explored cost-savings only and so does not provide any evidence of either effectiveness or cost-effectiveness. This means there is currently no evidence base to support the development of interventions to improve the effectiveness of ED services for patients with comorbid autism and no evidence of cost-effectiveness. This contrasts with current evidence base for adapting services for other mental health conditions for autistic people. For example, a number of RCTs have been undertaken to evaluate modified Cognitive Behavioural Therapy (CBT) manuals for treating autistic young people with anxiety disorders such as OCD and showed that adapted versions had additional advantages (Wood et al., 2020; Jassi et al., 2021). However, there remains a dearth of evidence supporting service-wide implementation of adapted treatments for autistic adults. Moreover, strategies effective for addressing other mental health conditions may lack the specificity for treating eating disorders in the autistic population.

Nine studies were identified for Review 2 (impact of autism on treatment outcomes in AN), including the partial economic evaluation identified in Review 1. These studies were predominantly cross-sectional or case series and all were published in the past decade. The main findings from the studies included in review 2 are clustered and visualised in a diagram (Figure 2.3). Autistic characteristics were shown to have no impact on physical outcomes or ED symptoms in studies using the EDE-Q, SEED or BMI change to assess ED symptomatology (Huke et al., 2014; Nazar et al., 2018; Stewart et al., 2017). However, when an overall clinical outcome was measured with the Morgan-Russell assessment schedule (Anckarsäter et al., 2012; Nielsen et al., 2015), autistic characteristics came to have a negative impact on the outcomes. It is worth noting that the Morgan-Russell outcome is a composite score summarizing an individual’s food intake, weight concern, mental state, psychosexual state and social relationships, whereas the EDE-Q and the SEED target food intake and weight concerns only. Subsequently, social-emotional processing difficulties and cognitive rigidity which are common features of an autistic individual (Davies et al., 2016; South et al., 2007) might be reflected negatively on the Morgan-Russell assessment, but would not have an impact on the EDE-Q or SEED outcome. Hence, when evaluating treatment outcomes in patients with Autistic features, the outcome measure should be chosen and interpreted with caution. The majority of the included studies also found a positive association between autistic characteristics and other comorbidities such as personality disorders (Anckarsäter et al., 2012), depression and anxiety symptoms (Li et al., 2020;

Stewart et al., 2017), obsessive compulsive symptoms (Stewart et al., 2017), and social and psychosexual impairment (Li et al., 2020; Nazar et al., 2018; Nielsen et al., 2015).

High autistic characteristics were also shown by a number of studies to lead to treatment augmentation either through greater use of intensive day-patient or inpatient treatment (Nazar et al., 2018; Stewart et al., 2017) or longer hospital admissions (Tchanturia et al., 2020a) compared to patients without autistic characteristics (Figure 2.3). Since patients with autistic characteristics showed no difference in ED symptoms or rate of BMI change compared to others without autism, this treatment augmentation could potentially be explained by the high rate of other comorbidities that could have an impact on treatment effectiveness. Indeed, in one of the included studies, autistic characteristics did not predict treatment augmentation once levels of depression had been accounted for (Stewart et al., 2017). Thus, the need for treatment augmentation in autistic patients may be a result of untreated comorbidities or unfulfilled emotional needs.

Figure 2. 3 Visual synthesis of the findings of the included studies



Items in bigger circles appeared in the findings of more studies; their related studies are listed next to the circles.

2.4.2 Clinical implications of autism comorbidity in ED treatment

Patients with autistic traits showed a need for treatment augmentation and prolonged hospitalization in ED units (Nazar et al., 2018; Stewart et al., 2017; Tchanturia et al., 2020a), indicating that they were not responding well to conventional treatment which primarily targets ED cognitive symptoms. Moreover, the high rate of comorbidities associated with autistic characteristics might be a risk factor for future relapse. Therefore, these patients with autistic characteristics may be in need of adapted treatment strategies in order to recover fully and prevent relapse.

Two case series included in this review examined treatment response to group and individual format of CRT (Dandil et al., 2020; Tchanturia et al., 2016). Patients with autistic did not respond to group CRT, whereas the individual CRT study reported favourable outcomes in autistic patients. This indicates that the group environment may have presented difficulties for patients on the autism spectrum. Future treatment adaptations could take into account similar social difficulties and focus on individual, rather than group, sessions.

It was also suggested in a study that common autistic features, such as preference for routines and difficulties in set shifting, may enhance treatment completion and adherence (Huke et al., 2014). Thus, modifying psychological therapies for autistic processing styles could in turn enhance treatment effectiveness. Indeed, as was demonstrated in the partial economic evaluation of a novel pathway for patients with the comorbidity (Tchanturia et al., 2020a), once appropriate adaptations had been made in treatment settings, patients with autistic characteristics showed reduced lengths of hospital admission compared to autistic patients prior to the introduction of the pathway and compared to non-autistic patients, which may suggest the pathway generated comparatively more favourable treatment outcomes, although further research is needed to confirm this .

2.4.3 Screening tools

One main issue arising from this review is the lack of a consistent screening system for autism in ED, similar to previous reviews on the autism and ED population (Huke et al., 2013). A variety of screening measures were used in the included studies, such as the AQ, AQ-10, ADOS, ASDI, SAS, Dewey social awareness test and more. This lack of consistency in screening measures makes comparison across studies difficult. Some of the earlier studies also used screening tools that had not been specifically tested for reliability or validity (Nielsen et al., 2015). More recently, there has been an increase in studies using the AQ or the shorter version AQ-10 to examine autistic characteristics in clinical groups (Allison et al., 2012; Baron-Cohen et al., 2001; Kinnaird et al., 2020b; Li et al., 2020; Mealey et al., 2014; Mito et al., 2014). Although self-report measures such as the AQ or AQ-10 have the benefit of being brief and low cost, it is worth noting that they only focus on the present time frame and the information provided by the patients themselves, missing early developmental history and input from carers which are two crucial elements in a formal autism assessment. Specific to assessing autism in patients with AN, there is the possibility that social withdrawal and social anhedonia exacerbated by ongoing starvation (Keys et al., 1950) could also confound the results of autism screening, if only current presentation is considered and developmental aspects are not screened. Moreover, it has been suggested that the common tools for screening autism do not adequately identify difficulties in girls who may have a qualitatively different presentation than boys (Halladay et al., 2015). Indeed, females often show fewer repetitive and restricted behaviors than males and are more prone to “camouflage” their social difficulties (Hull et al., 2020; Westwood et al., 2017) leading to increased obstacle to assessing autism using the available tools. Hence, there is an urgent need for a pragmatic and universal screening tool for autism in a predominantly female population with ED.

2.4.4 Eating Disorders Diagnoses

Although we used a broad search strategy that covered all ED subtypes, almost all identified studies focused on AN. A possible explanation could be that compared to other subtypes, AN is associated with more intensive service use given the need for medical stabilization, and therefore generates more data available for publication. Patients with bulimia nervosa (BN), on the other hand, are less likely to be hospitalised despite the often serious physical complications brought by purging, because they tend to be at a healthier weight, more active sexually, and more likely to menstruate regularly in contrast with patients with AN (Russell, 1979). Binge-eating disorder (BED), despite being the most prevalent ED (Kornstein et al., 2016), is often underdiagnosed and undertreated (with < 40% of individuals with BED having ever been treated for an ED), partly because BED was only widely recognised as a diagnostic entity in the early 1990s (Stice, 1999), and partly because individuals with BED may be reluctant to seek treatment because of shame and lack of awareness of the disorder (Kornstein et al., 2016).

There has been a wealth of work showing that children, young people and adults on the spectrum are more likely to be overweight or obese than their non-autistic peers (Broder-Fingert et al., 2014; Hill et al., 2015; Sedgewick, Leppanen, & Tchanturia, 2019). This finding has implications for association between autistic characteristics and BED, a disorder frequently observed among overweight or obese individuals. Indeed, recent pilot data showed that not only AN but also BN and BED patients exhibited greater autistic characteristics compared to controls (Gesi et al., 2017). In this study, patients with BN also scored higher than patients with AN on sensory difficulties, and the BED group showed the most mentalizing deficits. In a more recent study investigating autistic characteristics in patients with binge-purge AN, restrictive AN, BN and BED, an association was found between high autistic characteristics and non-vomiting behaviour (Numata et al., 2021). Of the four ED subtypes, the BED group had the highest autistic characteristics.

Given that the consequences of other subtypes could be just as debilitating as AN, and ‘crossovers’ between ED subtypes are not uncommon, it is worth expanding the scope of research on autism comorbidity to BN and BED as well. Further research on how treatments can be adapted for autistic individuals with BN or BED is warranted.

2.4.5 Strengths and Limitations of the Reviews

To our knowledge, this is the first review of new or adapted treatments for ED and comorbid autism, and of the impact of autism comorbidity on clinical outcomes in patients with ED, that has used a broad range of databases and a systematic search strategy. An earlier literature review which focused on autism in AN briefly explored the potential impact of autism symptoms on treatment outcome in ED groups as a sub-topic (Westwood & Tchanturia, 2017) and included three publications (Nielsen et al., 2015; Stewart et al., 2017; Tchanturia et al., 2016), all of which were included in the current review.

This review has some limitations. Including manuscripts in English language only could potentially lead to loss of data when studies are excluded. Search strategies were therefore carefully tested and bibliographies of included studies and relevant reviews hand checked to minimise data loss. A number of the included studies suffered from small sample sizes, with five (55%) having fewer than 100 and two (22%) having fewer than 50 participants, which may have led to a lack of power to identify true differences between patients with and without autism. Missing data was another pervasive problem in the clinical studies included in this review, with one case series reporting only 41% complete data for patients with high autistic features (Dandil et al., 2020), and another cross-sectional study using audit data also reporting high attrition rates at follow-up (Li et al., 2020). Nevertheless, the results synthesised from these early studies are hypothesis generating and warrant future research on autism and EDs with more robust study designs.

2.4.6 Conclusion and Future directions

There has been only one identifiable clinical pathway of treatment adaptations for patients with AN and comorbid autism – the PEACE Pathway. Early studies, one focusing on the value of a single component of the pathway (PEACE huddles), as perceived by clinicians, and one focusing on the impact of the pathway on length of hospital stay and associated costs, have produced positive indications to hypothesise that the PEACE Pathway may generate benefits for autism comorbid patients. Results from the cost-savings analysis, in particular, may suggest that the PEACE Pathway is better able to support patients with comorbid autism, leading to reduced lengths of hospital stay, however further research is needed to confirm this. Evidence of clinical and cost-effectiveness is therefore needed to determine whether similar adaptations should be implemented in more ED services.

Studies exploring the impact of autism comorbidity on treatment outcomes in patients with ED suggest that autistic characteristics have no impact on ED symptoms and physical outcomes of treatment, but could be associated with higher rates of comorbidities and greater use of, and thus perhaps need for, intensive treatment. This may suggest that any new treatments or adaptations to existing treatments may not directly impact on ED symptoms, but may be better able to support the complex needs of the autistic population, thus reducing subsequent need for intensive support. Initial evidence from the PEACE Pathway supports this hypothesis that treatment and service level adaptations may help to reduce this greater use of intensive treatment. Nevertheless, controlled studies utilising a robust longitudinal design and following stringent diagnostic criteria are clearly needed to further elucidate the relationship between autistic characteristics and treatment outcomes in ED. A universal screening tool for autism in ED is also needed to establish consistency across studies.

Chapter 3 Patients' presentation at SLaM Eating Disorder service

This chapter includes the publication:
Li, Z., Leppanen, J., Webb, J., Croft, P., Byford, S., & Tchanturia, K. (2023). Analysis of symptom clusters among adults with anorexia nervosa: Key severity indicators. Psychiatry Research, 115272.
The candidate ZL contributed to the data collection, data analysis, drafting and revising of the manuscript, in collaboration with co-first author JL (data analysis, drafting and revising of the manuscript), co-authors JW (data collection, review of the manuscript), PC (data collection, review of the manuscript), and supervisors Prof Sarah Byford (review of the manuscript) and Prof Kate Tchanturia (review of the manuscript). The manuscript has been modified and expanded to incorporate into this thesis. A PDF version of the original publication is provided in the Appendix 3.1.

3.1 Preface

This chapter uses cluster analysis, an exploratory, data-driven method to explore patterns in a range of ED symptoms and severity indicators in patients with AN at the SLaM inpatient ED service. The results help to shed light on the complexities in patients' presentation at the service and also provides an introduction to the audit database, which is the data source for the clinical evaluation (Chapter 6) and cost-savings analysis (Chapter 7) of the PEACE Pathway. The analysis in this chapter included patients with AN only, because the clustering measures included body mass index (BMI) which is a severity indicator for AN but not for other ED diagnoses (such as BN and BED), and also the majority of inpatients have AN.

As outlined in Chapter 2 results (see 2.4.1: Summary of findings), review of past literature found that co-occurring autism leads to worse Morgan Russell outcomes in ED and also more anxiety and depression symptoms, obsessive-compulsive symptoms, and longer admissions. This chapter further identified two severity groups with varying symptom severity in the patients at the service:

one group that is higher weight, more autistic, has higher symptoms with more severe eating pathology, anxiety and depression; and one group that is lower weight, less or non-autistic, and has lower symptoms overall. Echoing the findings from Chapter 2, the more severe, autistic group also had more comorbidities, hospitalisations, and purging. The findings enable us to better understand patients' presentation at the SLaM ED service and discuss treatment optimisation considering a broader range of symptom severity indicators, not just based on weight alone.

3.2 Background

Clinical decisions on the severity of AN are often guided by the patient's weight and weight change trajectory, as significantly low body weight for the individual's height, age and developmental stage is a part of the diagnostic criteria for the illness. The 11th Edition of the International Classification of Diseases (ICD-11) (World Health Organization, 2019) has provided guidance on weight cut-offs and BMI-based severity indicators for AN, and the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013) also outlines weight criteria for AN. On this basis, both DSM-5 and ICD-11 also acknowledge the individual variation in the importance of low weight alone, highlighting that the trajectory of weight change is often of greater significance. The Morgan-Russell outcome assessment schedule (Morgan and Hayward, 1988), which is often used in the clinical assessment of AN, defines patient outcomes based on body weight and menstrual function. Additionally, it has been reported that those with severe or extremely severe AN defined by BMI < 16.0 scored higher on measures of perfectionism and clinical impairment, suggesting that BMI is a crucial severity indicator in AN (Dakanalis et al., 2018).

However, some studies have raised questions about the clinical validity of weight-based severity specifiers (Machado et al., 2017; Engelhardt et al., 2021; Toppino et al., 2022). One study reported that individuals who have lost a significant amount of weight but are not as emaciated as other patients with AN can still experience similar levels of life-threatening medical complications

(Whitelaw et al., 2014). Other studies have found no significant evidence in favour of grouping AN patients into the BMI-based severity categories in terms of ED psychopathology or treatment outcomes (Machado et al., 2017; Toppino et al., 2022). Although low BMI remains a significant factor in AN, exploration of illness severity may benefit from including a wider range of psychological features, such as ED psychopathology.

AN has been reported to be a highly comorbid illness with some estimates suggesting that up to 97% of adult patients have at least one comorbid psychiatric diagnosis (Blinder et al., 2006; Marucci et al., 2018). The most common comorbid psychiatric diagnoses include depression and anxiety (Guinhut et al., 2021), which have been reported to be key factors in the development and maintenance of the AN (Lulé et al., 2014). Indeed, a recent network analysis by Monteleone and colleagues (2019) reported that depression and anxiety symptoms were central to the psychopathology of adolescent inpatients with AN. Another network analysis further documented that depression and anxiety symptoms, specifically feelings of worthlessness and avoidance of social eating, were not only strongly linked to core ED symptoms amongst adult AN patients, but also predicted recovery status at post-treatment follow-up (Elliott et al., 2020). Although most recent work has reported that severe depressive symptoms are associated with more severe AN pathology (Sternheim et al., 2015), worse treatment outcomes (Vall and Wade, 2015), and elevated risk of suicide (Kostro et al., 2014), there is some suggestion that moderate depression may have a positive association with weight gain and recovery in AN (Eskild-Jensen et al., 2020 for review). A large-scale study found that inpatients with AN who showed clinically significant improvements upon discharge were more likely to report moderate depression at admission when compared to deteriorated/unchanged patients (Schlegl et al., 2014). A similar effect of depression was found by Zeeck and colleagues, where inpatients with depression stayed longer in psychotherapy and may have a higher chance for clinically significant changes (Zeeck et al., 2005). These findings suggest that comorbid depression and anxiety are likely key factors contributing to illness severity in AN, but individual differences may also be present.

In addition to psychiatric comorbidities, recent evidence suggests that there is an over-representation of autism (Westwood and Tchanturia, 2017) and autistic features in AN (Kinnaird and Tchanturia, 2021). The estimated prevalence of autism or autistic characteristics in ED populations varies across studies from 22.9% to 36.2% (Wentz et al., 2005; Huke et al., 2013; Anckarsäter et al., 2012; Kinnaird et al., 2020; Vagni et al., 2016). Autistic patients often struggle with sensitivities to the sensory aspects of food, for example its smell, temperature, colour or texture (Leekam et al., 2007; Kinnaird et al., 2020) which may contribute to avoidance of certain food types in AN. Furthermore, both AN and autism are associated with high levels of alexithymia (Kinnaird and Tchanturia, 2021), interpersonal problems and social anxiety (Kerr-Gaffney et al., 2020), and neurocognitive aspects such as weak central coherence (Lang et al., 2014) and difficulties in set-shifting (Westwood et al., 2016). These findings warrant attention, as being autistic is often associated with greater use of intensive day-patient and inpatient treatment (Stewart et al., 2017; Nazar et al., 2018) and worse clinical outcomes in AN (Nielsen et al., 2015; Tchanturia et al., 2016).

Using exploratory, data-driven methods, such as cluster analysis, to explore patterns in a broad range of AN symptoms and severity indicators could help to shed light on the complexities in patients' presentation and guide clinical decision making in treatment of AN. Cluster analysis explores patterns by grouping datapoints based on distance and thus can be used to identify subgroups in data without prior assumptions of the internal structure of the subgroups. Several previous studies have explored clustering of neuro- and social-cognitive measures, personality measures, and autistic features in adults with AN (Renwick et al., 2015; Rose et al., 2016; Bentz et al., 2020; Holliday et al., 2006). These studies have identified a variety of different clusters within the data used, but the clusters have not differed in ED symptoms, severity markers, or comorbidities, limiting the clinical implications of these findings. One study (Damiano et al., 2015) has examined clustering of behaviour and general psychopathology in adolescents with AN and identified two subgroups: one group that was underweight and scored lower on general and ED-specific psychopathology measures, and one group with higher general and ED psychopathology and higher BMI. This seems to be in contrast with previous finding that lower BMI predicts higher AN symptom severity (Löwe et al., 2001), but it is important to note that the sample size (N = 39) was small for cluster analysis. Interestingly, another study conducted a cluster analysis of a broad range of ED risk factors within a large community sample (Miles et al., 2022). Similar to the findings by Damiano and colleagues (2015), the authors identified low-, medium-, and high-risk groups, with the high-risk group reporting higher BMI and more depression and general ED symptoms than the medium- and low-risk groups. To our knowledge, no studies have yet used cluster analysis to explore subgroups in a broad range of illness severity indicators in a large sample of people with AN.

Based on the work outlined above, we explored patterns in a broad range of data, including information regarding BMI, ED psychopathology, common comorbid symptoms, and autistic features, which were collected from inpatients with AN upon admission. Given the exploratory nature of this approach, we first pose the research question in place of hypotheses:

Can the analysis yield independent subgroups of patients that are not specific to the diagnostic criteria for AN, each with a different level of severity on the clustering variables?

Should clusters of different levels of severity arise from the analysis, we then compare the clusters in other aspects of illness, such as duration of illness, bingeing and purging behaviour, number of hospital admissions, and number of comorbidities, with the null hypothesis that there is no difference between the groups.

3.3 Methods

3.3.1 Clinical service audit

This analysis utilised clinical service audit data collected at the SLaM NHS inpatient ED service. The audit is a dataset containing self-reported demographic information and clinical measures from over 900 admissions dating back to year

2004. As part of the admission and discharge procedure at the service, patients are asked to complete a set of self-report questionnaires consisting of:

- Demographic questionnaire (including age, gender, living condition, employment status, years of education, marital status, family history of autism, previous hospitalisation due to ED, leave from work or study due to ED, and illness duration of ED).

- Eating Disorder Examination Questionnaire (EDE-Q; Fairburn & Beglin, 1994), which is a well-established assessment that measures ED symptoms including restraint, purging, and shape and weight concern. It is the self-reported version of the Eating Disorder Examination (EDE; Fairburn et al., 1993) interview. The questionnaire is scored using a 7-point rating scale (0-6) and generates four subscale scores (Restraint, Eating concern, Shape concern, and Weight concern) and one global score that summarises overall symptom severity by averaging the results on the four subscales. Scores of 4 or higher are indicative of clinical range. Only the global score was used in this dissertation as it represents the overall ED symptom severity.

- Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), which measures the severity of anxiety and depression symptoms in a hospital setting. The HADS comprises seven questions for anxiety and seven questions for depression. Scores on both anxiety and depression subscales were included in the analysis. For both subscales, scores of 8 or higher are indicative of clinical severity.

- Work and Social Adjustment Scale (WSAS; Mundt et al., 2002), which is a simple 5-item measure of functional impairment in work, home management, leisure activities and relationship with others. It is scored using a 9-point rating scale (0-8) and final scores above 20 suggest severe impairment in day-to-day tasks.

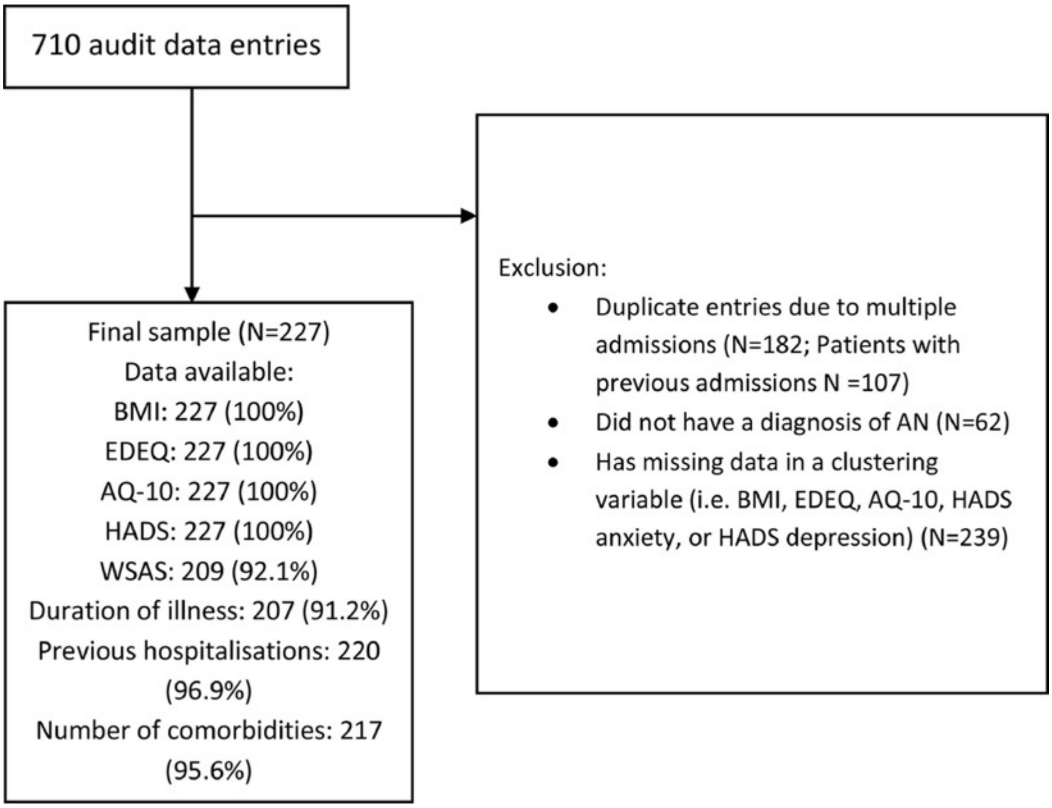
- Autism Spectrum Quotient, short version (AQ10; Allison et al., 2012) which is a short 10-item version of the Autism Quotient (AQ; Baron-Cohen et al., 2001) questionnaire and is recommended by the National Institute for Health and Care Excellence (NICE) guidelines for identifying possible autism in adults. The assessment measures traits of autism such as auditory sensitivity and interpersonal difficulties. A score of 6 or higher indicates possible autism and need for formal assessment.

A sample copy of the audit questionnaires is included in the Appendix 3.2. Patients' height, weight, BMI, diagnoses and medication use are also recorded on the audit database by a member of staff. The use of audit data for service evaluation and improvement was reviewed and approved by the Clinical Governance Committee Research and Development Office in SLaM NHS Trust in 2004.

3.3.2 Participants

Data from patients with a diagnosis of AN were included in the present study. Patients who did not complete the clinical measure questionnaires that were used in the cluster analysis (EDE-Q, AQ10, HADS; see 3.3.3 for details) or for whom admission BMI was not available were excluded. If a given patient had multiple previous admissions, the admission with the most complete data was included to minimise missing data and other repeated admissions for the same person were excluded. A total of 107 patients had one or more readmissions, and 182 duplicate entries of admissions for these patients were therefore excluded. Out of the original 710 entries in the clinical service audit database, we ended up with a sample of 227 patients (Figure 3.1).

Figure 3. 1 Data processing flowchart



3.3.3 Measures

Measures used in the cluster analysis

The cluster analysis used five clustering variables: BMI, EDE-Q global score (Cronbach's α = 0.96), HADS anxiety and depression subscale scores (Cronbach's α = 0.9), AQ-10 (Cronbach's α = 0.78). These variables were used to separate all patient data points into distinct groups on the basis of how closely associated they are in these variables. On all of the self-reported measures, higher scores indicate more severe symptoms. All measures had acceptable to excellent internal consistency.

Measures used to investigate differences between clusters

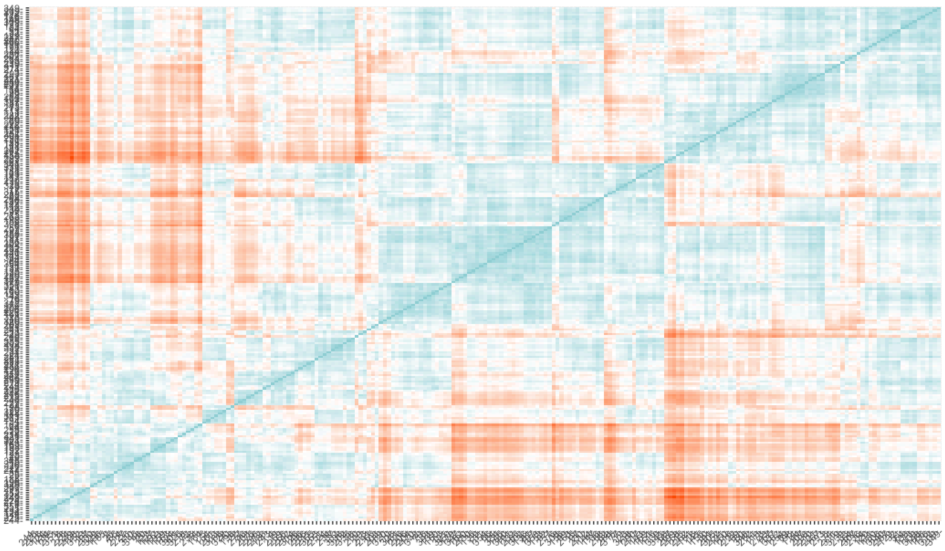
The following measures were used to investigate differences between clusters. These included measures of general functioning, such as the Work and Social Adjustment Scale (WSAS; Mundt et al., 2002), which measures degree of everyday functional impairment with good internal consistency (Cronbach's α = 0.82). Items on the WSAS scale encompass different domains, including ability to work, home management, leisure activities, and ability to maintain close relationships. We also included data regarding participants' age, their living situation (alone or with others), and the number of years they had faced unemployment due to their illness.

We also examined other indicators of illness severity and complexity including duration of AN, number of previous hospital admissions due to AN, number of comorbid diagnoses, and self-reported importance and ability to change ED behaviour on the Motivational Ruler (Miller and Rollnick, 2012). In addition to information regarding AN subtype, the open-ended questions in the EDE-Q regarding binge eating and purging behaviour were also included as additional markers of severity and complexity.

3.3.4 Data analysis

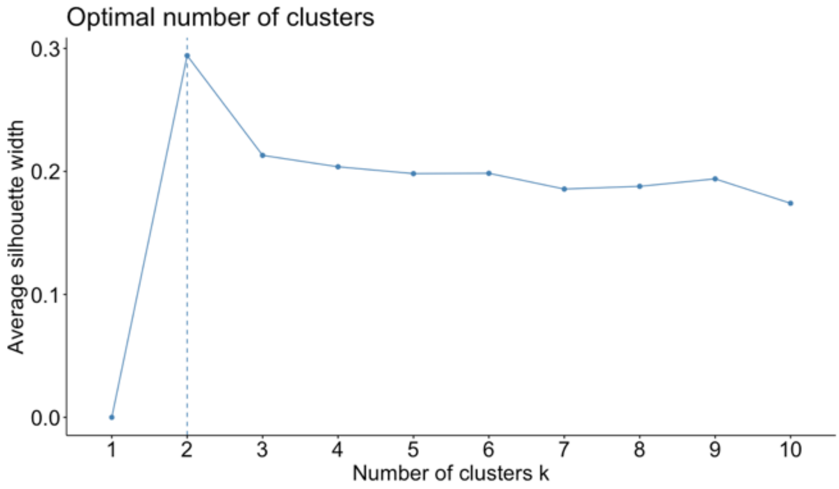
All data were analysed with R 4.1.0 (R Core Team, 2013). Admission BMI, EDE-Q total, AQ-10, HADS anxiety and depression scores were centred and scaled, and then entered into robust sparse k-means cluster analysis conducted using the RSKC package (Kondo et al., 2016). The distance matrix plot was below (Figure 3.2):

Figure 3. 2 Distance matrix plot



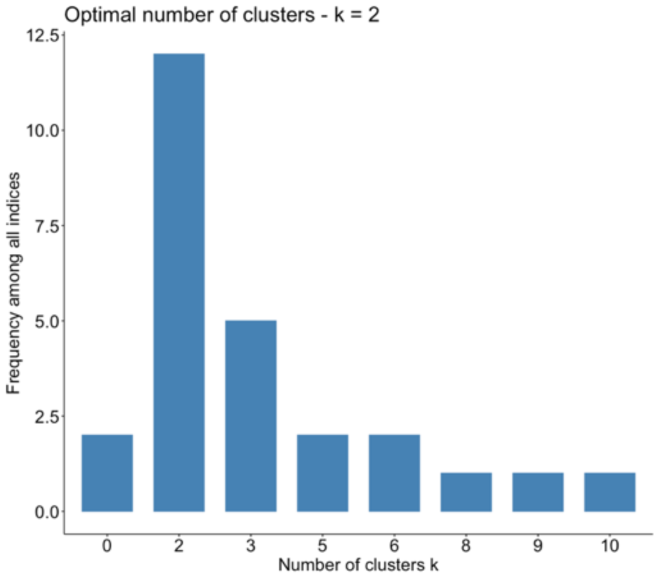
Robust sparse clustering was used to handle any potential outliers and reduce the impact of noise arising from any variables that didn't make strong contributions to cluster formation (Kondo et al., 2016). The silhouette method, as implemented in the factoextra package, was used to first determine the number of clusters before conducting the final RSKC analysis (Kassambara and Mundt, 2020). The silhouette plot generated was as below (Figure 3.3):

Figure 3. 3 Silhouette plot for the number of clusters



The number of clusters was then confirmed using another package, NbClust, which utilises multiple indices (Charrad et al., 2014). The frequency graph generated was below (Figure 3.4), which confirmed that the optimal number of clusters is two:

Figure 3. 4 Confirmation of the optimal number of clusters using NbClust



The clusters were then compared using the clustering measures (BMI, EDE-Q total, HADS anxiety, HADS depression, AQ-10) to evaluate which variables made strong contributions. The resulting clusters were then also compared using measures that were not included in the cluster analysis to determine if the clusters differed in other meaningful ways. These measures included the demographic and general functioning measures, as well as the illness severity and complexity measures. The cluster comparisons were conducted within the Bayesian framework using the rstanarm package, and probability of direction (PD) and the region of practical equivalence (ROPE) was estimated (Goodrich et al., 2022). Using Bayesian approach instead of frequentist statistics allowed for quantification of evidence strength, which increases the interpretability of observational clinical data. Additionally, Bayesian approach enabled us to evaluate whether the evidence was in favour of the alternative or the null hypotheses, which is not possible using frequentist approaches as even very large p-values cannot be taken as evidence in favour of the null hypothesis (Quintana and Williams, 2018). Differences in continuous variables, including WSAS score and illness duration, were analysed by conducting a Bayesian generalised linear regression, while count variables, such as number of previous hospital admissions and number of comorbid diagnoses, were subject to Bayesian generalised Poisson regression. Due to the heavily skewed nature of the data, binge eating and purging variables in the EDE-Q (‘How many such episodes have you had over the past four weeks’) were turned into binary variables (i.e. one or more episodes vs. no episodes). These and other binary variables were entered into Bayesian logistic regressions. Information regarding AN subtype was analysed by conducting a Bayesian analysis of contingency tables. Weakly informative priors were used in all analyses because information about the clusters was not known prior to analysis. Variable weights were calculated to inspect the importance of each variable in cluster formation, where the higher the variable weight, the more important the variable was in the partition of data. Bayes factors (BF) were calculated comparing the alternative (clusters are different) and null hypothesis (clusters are not different) using the bayestestR package (Makowski et al., 2019) to estimate the strength of the evidence. The Bayes factors were interpreted in accordance with Jeffreys’ (1961) proposed classification system (Table 3.1 summarises this system to aid interpretation).

Table 3. 1 Bayes factor interpretation table: classification of strength of evidence

BF	Interpretation
> 100	Decisive evidence for the alternative hypothesis
30 – 100	Very strong evidence for the alternative hypothesis
10 – 30	Strong evidence for the alternative hypothesis
3 – 10	Moderate evidence for the alternative hypothesis
1 – 3	Anecdotal evidence for the alternative hypothesis
1	no evidence
$1 - \frac{1}{3}$	Anecdotal evidence for the null hypothesis
$\frac{1}{3} - \frac{1}{10}$	Moderate evidence for the null hypothesis
$\frac{1}{10} - \frac{1}{30}$	Strong evidence for the null hypothesis
$\frac{1}{30} - \frac{1}{100}$	Very strong evidence for the null hypothesis
$< \frac{1}{100}$	Decisive evidence for the null hypothesis

BF = Bayes factor

3.4 Results

3.4.1 Cluster characteristics

The silhouette method indicated that there were two clusters present in the data (Figure 3.3). The clinical and demographic characteristics of the clusters are presented in Table 3.2 and Figure 3.5. The clusters were of almost equal sizes with 115 (51%) patients forming cluster 1, and 112 (49%) forming cluster 2. There was decisive evidence to indicate that the patients in cluster 2 reported more ED symptoms (BF = 4.39e+07), anxiety (BF = 3.63e+14), depression (BF = 3.77e+09), and autistic features (BF = 2.50e+13) than those in cluster 1. Cluster 2 is subsequently labelled “higher symptoms cluster”, and cluster 1 “lower symptoms cluster”.

Table 3. 2 Differences between clusters

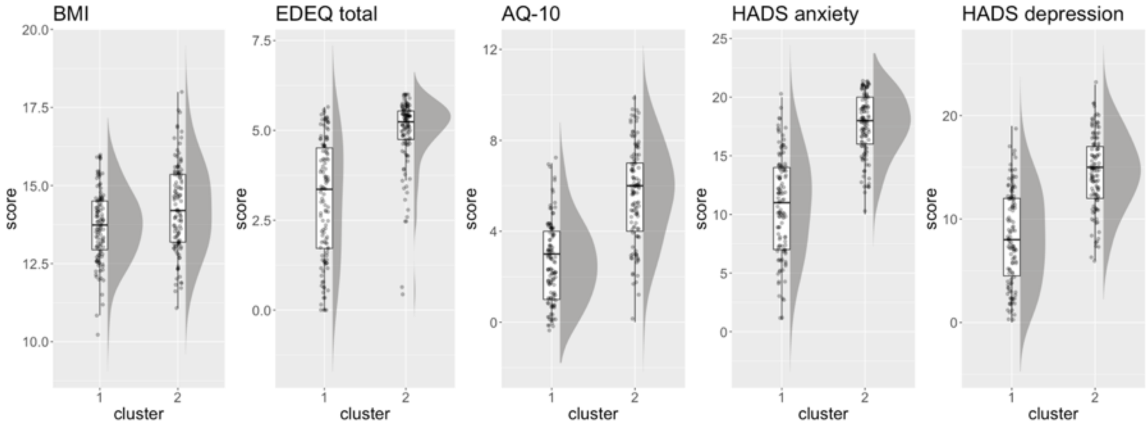
	Measure	Cluster 1 (N=115)	Cluster 2 (N=112)	Bayesian regression results			
				Median	% in ROPE	PD	BF

				[95% CrI]			
Clustering variables	Admission BMI Mean (SD)	13.70 (1.13)	14.29 (1.41)	0.59 [0.26, 0.92]	0%	99.98%	4.35
	EDEQ total score Mean (SD)	3.07 (1.64)	4.95 (0.99)	1.88 [1.52, 2.23]	0%	>99.99%	4.39e+07
	AQ-10 score Mean (SD)	2.63 (1.71)	5.69 (2.07)	3.06 [2.56, 3.56]	0%	>99.99%	2.50e+13
	HADS anxiety score Mean (SD)	10.89 (4.21)	17.58 (2.61)	6.69 [5.77, 760]	0%	>99.99%	3.63e+14
	HADS depression score Mean (SD)	8.24 (4.54)	14.56 (3.59)	6.32 [5.24, 7.38]	0%	>99.99%	3.77e+09
General functioning and demographic variables	Age Mean (SD)	28.00 (12.01)	26.93 (9.01)	-1.08 [-3.84, 1.69]	45.26%	77.72%	1/46.07
	WSAS total Mean (SD)	24.89 (10.27)	26.88 (8.99)	1.99 [-0.65, 4.64]	21.37%	93.12%	1/16.79
	Years of unemployment due to AN Mean (SD)	12.21 (27.35)	10.46 (20.63)	-1.74 [-12.32, 8.80]	34.63%	62.89%	1/24.19
Illness severity and complexity variables	Duration of AN (years) Mean (SD)	8.98 (9.80)	10.20 (8.03)	1.23 [-1.25, 3.67]	36.67%	83.58%	1/33.08
	Medication use N (%)	54 (48.65%)	69 (64.49%)	0.65 [0.11, 1.21]	2.03%	99.05%	1/1.52
	Number of hospital admissions Mean (SD)	1.39 (2.39)	2.39 (3.86)	0.54 [0.34, 0.74]	0%	>99.99%	698.82
	Number of comorbidities Mean (SD)	0.66 (0.95)	1.25 (1.39)	0.64 [0.36, 0.93]	0%	>99.99%	113.18
	Binge eating N (%)	56 (48.70%)	82 (73.21%)	1.06 [0.51, 1.63]	0%	>99.99%	39.34
	Purging N (%)	35 (30.43%)	64 (57.14%)	1.12 [0.58, 1.67]	0%	>99.99%	69.92
	Motivational ruler: importance to change Mean (SD)	8.36 (2.34)	7.37 (2.47)	-0.98 [-1.64, -0.37]	0%	99.88%	1.45

	Motivational ruler: ability to change Mean (SD)	6.31 (2.99)	3.85 (2.69)	-2.46 [-3.19, -1.70]	0%	>99.99 %	1.48e+04

BMI = body mass index; EDEQ = eating disorder examination questionnaire; AQ-10 = autism spectrum quotient, short version; HADS = hospital anxiety and depressions scale; WSAS = work and social adjustment scale; SD = standard deviation; CrI = credible interval; ROPE = region of practical equivalence; PD = probability of direction; BF = Bayes factor.

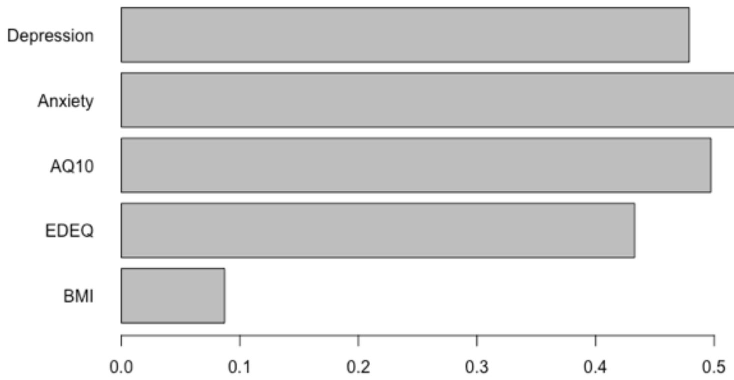
Figure 3. 5 Differences between clusters in clustering variables



BMI = body mass index; EDE-Q = eating disorder examination questionnaire; AQ-10 = autism spectrum quotient, short version; HADS = hospital anxiety and depressions scale.

The two clusters did also significantly differ on BMI, such that patients in cluster 2 had higher admission BMI than those in cluster 1. However, the evidence was only moderate (BF = 4.35) suggesting that compared to the other measures admission BMI did not make substantial contributions to the cluster formation. This is further supported by observing the relative contributing weights of each cluster analysis variable (Figure 3.6). As can be shown on Fig 3.6, BMI as a variable had the lowest contributing weight (0.09) in clustering, therefore the least important variable in the grouping of the data.

Figure 3. 6 Relative contributing weights of clustering variables



3.4.2 General functioning and demographic characteristics

The clusters did not differ significantly in WSAS scores, the number of years the patients had been unemployed due to their illness, or in age. In fact, there was strong to very strong evidence in favour of the null hypothesis. The clusters also did not differ in the distribution of AN diagnostic subtypes (Table 3.3), with strong evidence in favour of the null hypothesis (BF = 1/22.26).

Table 3. 3 Distribution of AN diagnostic subtypes between the clusters

	Cluster 1 (N=115)	Cluster 2 (N=112)
AN Restrictive, N (%)	84 (73.04%)	80 (71.43%)
AN Binge-purge, N (%)	26 (22.61%)	29 (25.89%)
AN Atypical, N (%)	5 (4.35%)	3 (2.68%)

3.4.3 Illness severity and complexity

There was no significant difference between the clusters in duration of illness but there was decisive evidence that patients in cluster 2 had experienced significantly more previous hospitalisations due to AN than those in cluster 1. Additionally, patients in cluster 2 also reported lower self-efficacy in their ability to change, and more complex presentation including more comorbid diagnoses and a greater tendency to binge and purge than those in cluster 1 with very strong to decisive evidence. There was also a significant difference between the clusters in the self-reported use of psychotropic medication on admission, such that a higher proportion of patients in cluster 2 were taking medication on admission. However, there was only anecdotal evidence for this difference (BF = 1/1.52), suggesting no firm conclusions about medication use can be drawn based on the present data. Similarly, there was a significant difference between the clusters in motivation to change, but the evidence for this difference was only anecdotal (BF = 1.45), suggesting no firm conclusion about this variable can be drawn based on the observed data.

3.5 Discussion

This study aimed to derive clinically distinct subgroups of adult patients with AN through a data-driven clustering approach. Patients were clustered based on their BMI, self-report eating pathology and general psychopathology. Amongst the two resulting clusters of similar sizes, cluster 2 ("higher symptoms cluster") reported higher scores on eating pathology, anxiety, depression, and autism screening than cluster 1 ("lower symptoms cluster"). The higher symptoms cluster also reported lower self-efficacy to change, more previous hospitalisations, comorbid diagnoses, binge eating and purging behaviours and use of psychotropic medication than the lower symptoms cluster. It should be highlighted that although the higher symptoms cluster also had slightly higher admission BMI, our inpatient sample overall had very low weight and BMI did not make major contributions to cluster formation.

3.5.1 The higher symptoms cluster

We found that the higher symptoms cluster scored high on all clustering variables, as well as on several illness severity and complexity indicators, such as binge and purge behaviours and number of comorbidities. Furthermore, the elevated autistic characteristics in this cluster are consistent with previous research suggesting an over-representation of autism in EDs (Westwood and Tchanturia, 2017). In particular, our results are in line with the literature highlighting emotional difficulties in autistic women with AN (Brede et al., 2020), which often relate to exacerbated anxiety and depression (Tchanturia et al., 2019). The maladaptive presentation and increased hospitalisations in this cluster also confirm previous research where individuals with co-occurring autism and EDs often present with worse treatment outcomes (Nielsen et al., 2015) and increased service use (Nazar et al., 2018). Similarly, a previous study clustering individuals with AN based on neuropsychological features (i.e. executive function, central coherence, and theory of mind) also identified an autism-like subset with difficulties in executive function and central coherence (Renwick et al., 2015). This link between autistic characteristics and illness severity warrants clinical attention, as autistic individuals' sensory and cognitive profile may make it more difficult for them to benefit from standard ED treatment designed for neurotypical patients, which calls for treatment adaptations and innovations for autistic patients.

Previous empirical work has also highlighted that purging behaviour is associated with negative outcomes, comorbidities, and life-threatening physical complications such as electrolyte disturbances (Keel et al., 2004; Solmi et al., 2015; Royal College of Psychiatrists, 2022). Indeed, the higher symptoms cluster in the current study presented with more binge and purge behaviours in combination with more negative affect. Notably, patients in this cluster also had more previous hospital admissions, despite having similar duration of illness as the lower symptoms cluster. This finding is in direct contrast with previous work which has argued that duration of illness is a key severity indicator (Maguire et al., 2012). On the other hand, this is in line with previous findings linking binge-purge behaviours and low affect with treatment resistance in severe AN (Smith and Woodside, 2021; Di Lodovico et al., 2021). Interestingly, despite one cluster reporting more binge-purge behaviours than the other, the two clusters did not differ in the proportion of individuals with AN binge-purge diagnosis. It is possible that for some patients, their frequency of binge and purge behaviours simply did not meet the clinical cut-off for receiving a diagnosis. Our results show that regardless of the level of engagement, binge-purge behaviour is linked to more complex and severe presentation and therefore needs clinical attention. Another possible explanation is that individuals reported binge-purge behaviours on the questionnaire but denied these behaviours when questioned in a diagnostic interview and therefore did not receive a binge-purge subtype diagnosis. This is in line with previous finding that approximately 40% of participants who reported purging behaviour on self-report measures subsequently denied this in a face-to-face interview (Mond et al., 2007), possibly due to a greater shame in disclosing purging behaviours when faced directly with an interviewer. This inconsistency between self-report and clinical assessment should be addressed with caution to prevent problematic behaviours like purging from being missed by the clinical team.

We also found that the higher symptoms cluster had significantly higher, not lower, admission BMI (Mean=14.29, SD=1.41) than those in the lower symptoms cluster (Mean=13.70, SD=1.13, *p*<.001). This is in line with previous clustering studies using larger (Miles et al., 2022) and smaller (Damiano et al., 2015) samples of patients with ED which identified high symptom groups reporting higher BMI. However, it is important to consider that this statistically significant difference may not be clinically meaningful. Indeed, the associated Bayes factor (BF=4.35) and cluster weight (0.09) of the BMI variable suggest that admission BMI did not make substantial contributions to the cluster formation. Together, the findings suggest that weight alone may not be a significant symptom severity indicator amongst inpatients with AN, most of whom have very low BMI. This is consistent with previous work showing that improvement in psychopathology in AN does not correlate with BMI improvement (Mattar et al., 2012), suggesting for a better indicator for illness severity such as purging behaviour and comorbid symptoms, rather than BMI alone. Furthermore, this finding brings attention to individuals who have lost a significant amount of weight but may still be at a higher weight than other patients. These patients are commonly diagnosed with atypical AN (Moskowitz and Weiselberg, 2017). Despite not being as emaciated as patients who are more underweight, these patients can experience a similar profile of life-threatening complications (Whitelaw et al., 2014) and deserve just as much clinical attention.

3.5.2 The lower symptoms cluster

With lower scores on the self-report measures, individuals in the lower symptoms cluster appear to have better functioning and fewer difficulties with eating and general psychopathology. This is in line with previous findings that individuals reporting less fear of weight gain and ED symptoms also appeared to have less severe psychopathology (Ramacciotti et al., 2002). However, it is also possible that patients in this cluster are simply more used to suppressing their emotions, a problem that is most pronounced in the acute phase of the illness

(Oldershaw et al., 2015), thereby leading to lower self-reported symptoms. It has been suggested that starvation may at least partly serve as a strategy to regulate unwanted emotions and feelings (Haynos and Fruzzetti, 2011). Starvation numbs both physiological and emotional responses thus provides escape or a safe place, but it also potentially makes it more difficult to describe or identify own internal states (Malova and Dunleavy, 2022; Lavis, 2018; Oldershaw et al., 2015; Rowsell et al., 2016). Therefore, the lower symptoms reported in this cluster might in fact be a warning sign of emotional avoidance. On the other hand, it is also possible that the lower scores on self-report measures were due to denial of symptoms, particularly on the EDE-Q where some patients reported next to no ED symptoms. Deliberate denial and distortion of symptoms are common in AN due to body image disturbance and resistance to change (Vitousek et al., 1991). This also reflects reduced insight and low self-awareness in this cluster, which may dangerously lead to a more difficult recovery path (Errichiello et al., 2016). Longitudinal research would be of interest to shed light on the underlying mechanisms and outcomes for under-reported symptoms amongst inpatients with AN.

3.5.3 Limitations

One limitation of this study is the use of self-report questionnaires alone. As previously discussed, it is possible for individuals to deny or minimise symptoms in self-report measures such as the EDE-Q. Moreover, the accuracy of self-report autism screening tools such as the AQ-10 in the ED population has been controversial. The internal consistency for AQ-10 in this study (Cronbach's $\alpha = 0.78$) was acceptable but not excellent. Future studies should consider combining assessment interviews with self-report measures of ED symptoms, as well as more rigorous measures of autistic characteristics. Another limitation of the study was the number of patient entries excluded due to missing data; although patients who were included in the end had complete data in all of the clustering variables, there was missing data in other clinical and demographic variables not used in clustering. This was inevitable, given that the study used observational clinical audit data. However, this does not affect the robustness of the clustering, and Bayesian inference was used for its enhanced interpretability in observational data. Lastly, due to demographic constraint of the inpatient setting, the current study only examines inpatients mostly with severe AN. Any conclusions on the significance of weight, purging, autistic characteristics, or negative affect would need to be validated within a larger cohort of people with a broader range of ED severity and subtypes.

3.6 Conclusions

This study suggests that distinct groups of illness severity exist in adults with AN. More complex and severe presentation in AN is associated with more comorbidities (including autism, anxiety and depression), previous hospitalisations, binge eating and purging behaviours and use of psychotropic medication. BMI did not make major contributions to the clustering, suggesting that weight alone may not be a significant severity indicator. Our findings warrant future studies that investigate aetiological categorisation including other ED populations (e.g., bulimia nervosa) and promote the use of a broader range of validators to guide treatment tailoring in ED.

Chapter 4 Analysis of PEACE huddle cases: How to support adults with anorexia nervosa and autism

This chapter includes the publication:
Li, Z., Hutchings-Hay, C., Byford, S., & Tchanturia, K. (2022). How to support adults with anorexia nervosa and autism: Qualitative study of clinical pathway case series. Frontiers in Psychiatry, 13, 1016287.
The candidate (ZL) contributed to the data collection, data analysis, drafting and revising of the manuscript, together with the assistance of co-author CHH (data analysis, review of the manuscript) and supervisors Prof Sarah Byford (review of the manuscript) and Prof Kate Tchanturia (review of the manuscript).). The manuscript has been modified and expanded to incorporate into this thesis. A PDF version of the original publication is provided in the Appendix 4.1.

4.1 Preface

The PEACE huddle (short, regular clinical meetings) was a crucial element in the development and implementation of the PEACE Pathway (see section 1.2.3.2). As part of the Pathway from 2019, the huddles have been held regularly to discuss cases with co-occurring ED and autism, associated practical challenges and possible treatment adaptations. These discussions fed into further service adaptations supporting the continuous development of the PEACE Pathway over time.

This chapter summarises the clinical challenges (in communication, boundary maintenance, autism screening, addressing other comorbidities, sensory difficulties, atypical eating behaviours, cognitive rigidity, and emotional regulation) and adaptations associated with the comorbidity based on case notes and minutes from the PEACE huddle discussions. An understanding of the PEACE approach is essential to enable the interpretation of what outcomes are meaningful in the evaluation of the pathway. This chapter also corroborates clinicians' views in Chapter 8, providing a background for their accounts of the benefits and challenges in implementing PEACE Pathway.

4.2 Background

The PEACE Pathway was developed and implemented in the South London & Maudsley (SLaM) NHS Foundation Trust Adult Eating Disorders Service with the aim of improving care for patients with co-occurring ED and autism (Tchanturia et al., 2020). It is, based on Chapter 2 systematic review, the first systemic attempt to adapt an ED service for this comorbidity. Since the pathway's instigation, adaptations have been introduced relating to clinician training, psychoeducation resources (newly developed for patients), patient screening, treatment environment (to make it more sensory-friendly) and food menus (see section 1.2.3 for details).

As part of the implementation of the PEACE Pathway, weekly team meetings (known as 'PEACE huddles'; Smith & Tchanturia, 2020) have been held to discuss cases with co-occurring autism presentation or existing autism diagnosis, associated practical challenges and possible treatment adaptations. These discussions fed into further service adaptations supporting the continuous development and team distillation of the PEACE Pathway over time. Examples of subsequent service adaptations include the introduction of an alternative bland menu (the 'PEACE menu') for individuals with sensory sensitivities and a need for predictability, environmental adjustments such as the refurnishing of the ward and the provision of sensory soothing toys to create a more calming environment for patients, modifications in session structure (e.g., shorter sessions and increased breaks) for those with difficulties with information processing, the implementation of a new sensory wellbeing workshop to provide psychoeducation on sensory sensitivities, and the introduction of a communication passport for all admissions to communicate their needs effectively with the care team.

The aim of this chapter is to present a synthesis of clinical challenges associated with both autism and ED based on a review of the case notes and minutes from the huddle discussions, and to outline the team's approach to the subsequent adaptation of treatment. As a considerable body of earlier research has already covered autistic features in ED as well as patients' experience accessing support (Babb et al., 2021; Kinnaird & Tchanturia, 2021; Westwood et al., 2016; Westwood et al., 2017a), it is hoped that this study will present the clinical reality faced by clinicians trying to individualise care for those with the comorbidity, and thereby inform decision-making and treatment adaptations for this population.

4.3 Methods

4.3.1 Study design

This study reports the results of a review of clinical case notes and team meeting minutes relating to patients with co-morbid ED and autism. The study was part of a service quality improvement project and permission to audit patient data was obtained from the Clinical Governance and Audit Committee in South London and Maudsley NHS Trust (032019) in April 2019. In accordance with the institutional requirements written consent from the participants was not required. All clinical notes were fully anonymised to protect patient privacy.

4.3.2 Setting and sample

As part of the PEACE Pathway implementation process at the SLaM Adult ED Service (including inpatient and day services) between September 2019 and March 2022, clinicians attended regular PEACE huddle meetings to discuss select patient cases with complex presentation who scored above the threshold on autism trait screening tool and/or had established autism diagnosis. The huddles, which were utilised as group supervision, provided attending clinicians with an opportunity to share thoughts and challenges about patients with autism and develop consistency in treatment implementation. Cases were discussed in huddles if they either had a previous diagnosis of autism or presented with autistic characteristics, and their treatment was considered challenging by the care team (e.g. atypical eating difficulties due to autism). All case notes were de-identified using pseudonyms before they were shared among the team to aid discussion. Minutes from the discussion, which included suggestions for adaptations and feedback on what was helpful for the cases, were also circulated among the team after the huddles.

The de-identified clinical notes contained clinician-written case management notes, progress and updates, nursing notes, summary of challenges and exploration of autistic characteristics. At SLaM ED service where the PEACE Pathway was implemented, autistic characteristics were routinely explored for all patients admitted to the ED service through audit questionnaire (see 3.3.1: Clinical service audit). Screening primarily involved application of the Autism Spectrum Quotient short version (AQ-10) (Allison et al., 2012; Westwood et al. 2016). Where deemed necessary by the care team (for example, patients scored below the short screener but clinical team observed autistic presentation), autistic characteristics were further explored using the Autism Diagnostic Observation Schedule Module 4 (ADOS; Hus & Lord, 2014) and/or the Social Responsiveness Scale, Second Edition (SRS-2; Kerr-Gaffney et al., 2020), to provide more information for the care team and to guide treatment adaptation. In the huddles as well as in this study, both patient cases with a formal diagnosis of autism and those presenting with autistic characteristics are included. They are referred to as “individuals with autism comorbidity” or “autistic individuals”.

4.3.3 Data analysis

This study collected data from clinical notes and minutes from the PEACE Pathway team meetings (already de-identified using pseudonyms when presented at team meetings), as both sources of information referred to treatment challenges, potential treatment adaptations to meet these challenges and feedback on adaptations that had been helpful. Thematic analysis (Braun & Clarke, 2006; 2018) was used to analyse clinicians’ notes and minutes of the PEACE huddles to identify clinical challenges and adaptations in supporting adults with EDs and autism.

ZL first read all case notes and minutes repeatedly to inductively generate and refine potential codes. Coded data were then analysed to identify themes and subthemes relevant to clinical challenges and treatment adaptations in supporting those with the comorbidity, and a thematic map was developed to represent the themes and subthemes in a visual format. A co-author (CHH) independently reviewed and checked the thematic map against the case notes. Disagreements were discussed between the co-authors and with supervisors until consensus was reached. The final thematic map was reviewed and finalised in consultation with supervisors SB and KT.

4.4 Results

4.4.1 Demographic characteristics

In total, 34 cases were discussed in the PEACE huddles. Thirteen cases were cross-Trust consultations by teams from other ED services and therefore excluded from analysis. One case discussion focused on scoring of the autism screening tools rather than patient presentation and was therefore excluded from the study. Table 4.1 shows the demographic characteristics of the remaining 20 cases that were included in the study.

Table 4. 1 Summary of demographic information

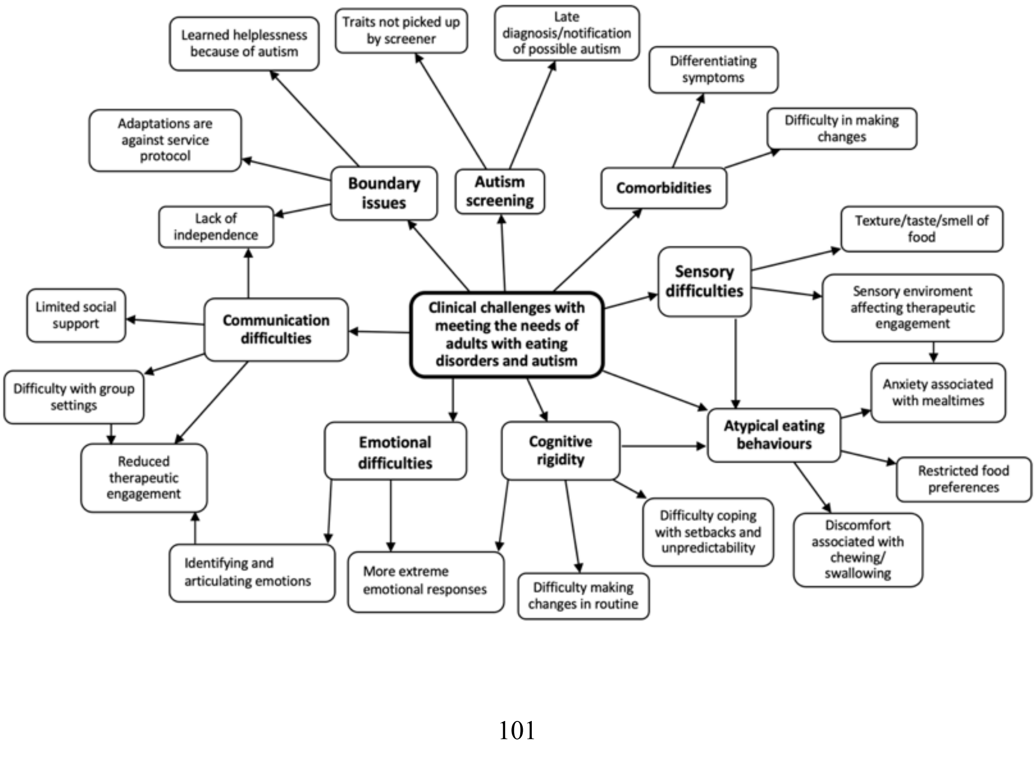
	Cases (n = 20)
Gender, n (%)	
- Female	16 (80%)
- Male	4 (20%)
Ethnicity, n(%)	
- White British	17 (85%)
- White Other	1 (5%)
- Black African	1 (5%)
- Asian	1 (5%)
Age, mean (SD)	26 (10.7)
ED diagnosis assigned, n(%)	
- AN restrictive subtype	13 (65%)
- Atypical AN	5 (25%)
- AN binge-purge subtype	2 (10%)
Number of co-morbidities (other than autism), mean (SD)	1.85 (1.2)

The majority of cases were female (n=16, 80%) and the mean age at contact with the service was 26 years (SD=10.7, range 19–68). Half of the cases had a formal diagnosis of autism prior to contact with the ED service (n=10, 50%), whilst the other half were flagged up by the AQ-10 or ADOS-2 as having high autistic characteristics and recommended to receive formal assessment at a specialist service (n=10, 50%). In addition to autism or autistic characteristics, further co-morbidities were reported, the most common of which was generalised anxiety disorder (GAD; n=10, 50%), obsessive-compulsive disorder (OCD; n=8, 40%) and depression (n=8, 40%). Other common co-morbidities included emotionally unstable personality disorder (EUPD; n=2, 10%) and attention deficit hyperactivity disorder (ADHD; n=2, 10%).

4.4.2 Clinical challenges in supporting adults with AN and autism

Figure 4.1 shows the main themes that emerged from analysis of the case notes and meeting minutes. Subthemes that are relevant and connected to each other (e.g. 'Autistic traits not being picked up by the screener' and 'Late diagnosis of autism') are categorised under a broader key theme (e.g. 'Autism screening'), which is visualised in Figure 4.1. In total, eight key themes relevant to the research question were identified: communication difficulties, boundary issues, issues related to autism screening, presence of comorbidities, sensory difficulties, atypical eating behaviours, cognitive rigidity, and emotional difficulties.

Figure 4. 1 Thematic map: clinical challenges with meeting the needs of adults with eating disorders and autism



Communication difficulties

Communication difficulties were highlighted in most cases, with severity ranging from mild difficulties in articulating thoughts to selective mutism. Patients also had issues with open questioning and found it hard to answer broad and open questions like: “how can I help?”. This affected patients’ therapeutic engagement and posed challenges for the care team.

> *“[The patient] struggles with trying to explain what [the patient] means, [and with] verbalizing ED… Difficult knowing if the patient understands, there is lots of nodding and it seems fairly superficial at times.” (Case 20)*
>
> *“Communication has been a struggle. Some meetings may have some verbal input from [the patient], but this is rare.” (Case 12)*

The clinical team tried different ways of adapting care to support patients with communication difficulties, including individual-level modification of communication style and use of conversation cards and other resources (diagrams or art) to understand patients’ preferred ways of communication. The team also asked patients to fill in the communication passport, which is a one-page self-report document including a patient’s preferred way to communicate, their sensory needs, their dislikes and their special interests and strengths. The passport was then shared with the wider care team to ensure team awareness and consistency.

> *“Multiple choice is easier than ‘what do you need/how can I help’.” (Case 14)*
>
> *“Continue using visual aids (which [the patient] found helpful so far).” (Case 4)*
>
> *“Suggest revisit the communication passport; suggest written communication (patient is very good at writing letters).” (Case 15)*

Communication difficulties also affected group participation, as some patients felt anxious about speaking in front of others and found the group therapy setting overwhelming. This affected both online groups and groups in person.

> *"[the patient] would often voice that [the patient] is quite anxious to speak in front of everyone. There are times where staff has noticed [the patient] has 'checked out' from the group and looks disengaged by staring out in front of [the patient]." (Case 4)*
>
> *"[the patient's] engagement in [online] groups was minimal and would not look at the screen as a way of avoiding eye contact." (Case 19)*

Looking for ways to encourage group participation, clinicians noticed that sometimes patients would only share information on direct questioning and therefore tried to encourage their participation by inviting them to contribute. For online groups, patients found it easier to be able to join with audio only.

> *"What worked well: inviting [the patient] to contribute and share [the patient's] views was helpful in groups" (Case 19)*
>
> *"Voice-only session with the family is working well. Past cases also mentioned that audio-only sessions allow more space for patients to process what others are saying. Can be a useful adaptation for patients with autistic characteristics." (Case 8)*

Social isolation from peers was reported in all cases, within and outside treatment settings. This was sometimes accompanied by over-dependence on family carers and clinical staff, which was identified to be a major barrier to independent living and returning to the community after treatment completion.

> *"[The patient] can find it really difficult to make decisions, [the patient] asks for mum's support with certain things e.g. which therapy [the patient] should do/what to pick from the menu." (Case 14)*

Challenges in maintaining boundaries

Boundary issues were described in the majority of cases, with patients described as becoming over-dependent on therapeutic relationships, clinical teams having to adapt treatment in a way that was sometimes against ward protocol (e.g. allowing patients to touch or smell food without eating it, or to have headphones on during dinner time instead of social eating), and patients refusing change or treatment owing to a 'learned helplessness' mindset about autism (i.e. insisting that their autism means that they are not capable of making changes essential to recovery and independent living). These boundary issues would often leave the clinical team with the difficult decision of whether to accommodate some of the autism-related difficulties or further encourage changes in the recovery journey from ED.

> *"[The patient's] sensory needs sometimes are in conflict with the ward protocol and other patients' needs…Team can struggle with when to accommodate and when to encourage for change." (Case 15)*
>
> *"Difficult to manage boundaries with [the patient]; Need to limit the number of adaptations which can be agreed." (Case 6)*

Compromises were often made to meet patients in the middle. However, when over-accommodation could risk impeding patients' recovery from their ED, clinicians would try to limit the number of adaptations that can be agreed and challenge patients' mindset with transparent, goal-oriented conversations to encourage changes.

> *"Challenge [patient's] mindset about ASD: positive mindset to manage and work on sensory sensitivities and other challenges autism brings, instead of a learned helplessness mindset (e.g. I have autism, I'm never going to be able to..). Start by exploring strengths and gifts." (Case 15)*

Screening of potential autism

Autism screening brought further challenges for clinicians within the ED service. In all cases concerned, the AQ-10 (Allison et al., 2012) was used as a pragmatic short screener for potential autism, sometimes accompanied by an ADOS-2 (Hus & Lord, 2014) interview when a qualified ADOS-trained member of the team was available, or by an SRS-2 self-report questionnaire when an ADOS-trained interviewer was not available. However, some patients scored below the threshold on the AQ-10 despite their strong presentation of autism or already having a formal diagnosis. Furthermore, the majority of patients were not aware of their potential presentation of autism prior to the screener and had limited knowledge about autism. Therefore, informing patients and their families about a positive result on the screening tools was often met with surprise, causing anxiety for the patient and their families and for the clinical team member involved.

> *"…the results of the ADOS-2 created some anxiety for [the patient] and parents – they were left with questions needing a forum in which to raise them. Psychologist anxiety about leaving patient to process the report feedback and how best to support them." (Case 7)*
>
> *In their reflection, clinicians noted the need for more autism-related psychoeducation and training, particularly on normalizing autism and feeding back autism screening results to families.*
>
> *"[R]eflections and what we learned included: how little people know about autism and the need for more psychoeducation; importance of being open with patients and families that we are trying to learn about the comorbidity; … identify patients' strengths and work with this; need for a learning training session on feeding back ADOS results to patients and carers and to normalize Autism." (Case 7)*

Comorbidities

Case notes and meeting minutes also documented the care team spending considerable time helping patients distinguish between problems caused by different comorbidities, such as between rigidity around food caused by autism and inflexible mealtime routines driven by obsessive-compulsive disorder (OCD), or between food avoidance caused by AN cognitions and sensory avoidance driven by autism. This was challenging because the cases presented with a variety of complex comorbidities and symptoms were often intertwined, sometimes fuelling one another, making changes and recovery even more difficult.

> *"Fairly clear on what is AN vs autism/OCD but it is harder to differentiate Autism and OCD due to the common factor of rigidity to routines etc." (Case 16)*
>
> *"Comorbidities predate ED and are intertwined with it. [OCD] symptoms … daily focused on fear of being ill. … restricting food because [the patient] is worried about being ill. …Autism makes routines even more rigid." (Case 18)*
>
> *Differentiating between behaviours caused by ED and other comorbidities is nevertheless important in establishing focus*

> *for treatment. Clinicians would work with patients collaboratively to differentiate between specific eating-related behaviours and identify those rooted in ED that required intervention.*
>
> *"Using napkins to wipe hands is ED/sensory related, does not like the feeling of food on fingers. ...Not completing meals based on OCD obsession. ...autism related – needing foods to be a specific 'right temperature'." (Case 6)*

Sensory difficulties

Sensory difficulties also made it more difficult for clinicians to treat patients with the comorbidity, particularly at mealtimes. These sensory difficulties included sensitivity to texture, taste, or smell of certain foods on the menu, and sensory overload due to environmental factors that affected therapeutic engagement, such as distraction by the noise or brightness of the surroundings.

> *"Very sensitive to noise and lights. Describes [themselves] as having increased interoceptive awareness and [the patient] experiences lots of physical pain associated with this." (Case 9)*
>
> *"[The patient dislikes] flashing lights, loud noises, sudden noises such as clapping." (Case 20)*
>
> *"Hypersensitive to human sounds especially chewing food." (Case 14)*

Clinicians reported that cases with sensory sensitivities found attending the PEACE sensory workshop (workshops on sensory wellbeing psychoeducation; see 1.2.3.4 for introduction and Chapter 5 for evaluation) helpful. Sensory items and low stimulus quiet areas were made available for patient use. Clinicians also adapted the environment of individual therapy sessions, checking in with patients in the beginning of the sessions to confirm if they felt comfortable with making eye contact, their seating position, temperature and lighting in the room and other environmental elements.

> *"Attended the sensory wellbeing workshop and was really engaged with the content, and was able to complete the sensory booklet." (Case 19)*

> *“[The patient] would carry sensory items, and made use of low stimulus quiet areas.” (Case 6)*
>
> *“[M]et prior to starting therapy to [help the patient] get accustomed to the therapeutic process, to the consulting room and for [the clinician] to adjust the consulting room accordingly (lights, window, fan and seating). (Case 4)*

Atypical eating behaviours

Cases presented with atypical eating behaviours, some caused by food-related sensory sensitivities and some by strict rules and routines around meals, which posed another challenge for the care team. Restricted food intake in EDs is typically connected to body image and fear of weight gain; however, in cases with co-occurring autism, food restriction could be due to other reasons such as the texture or smell of foods instead of the calorie content, or discomfort associated with swallowing or chewing, anxiety about eating with other people, and rigidity around timing of meals or the way food is prepared and served. In these cases, focusing on conventional targets for ED treatment, such as fear of weight gain, overlooks what could be the true cause of the atypical eating behaviours, creating barriers for patients’ engaging in treatment.

> *“Atypical presentation- Enjoys calorie dense foods. ... i.e., oat milk, mash potato, peaches, rice pudding and rice, chocolate and ice cream.” (Case 9)*
>
> *“Food: small range at any time and then tires and stops eating them, resulting in the range of acceptable meals ever shrinking (This seems to be common within ASD patients).” (Case 16)*
>
> *“At home, [the patient] eats just a small range of foods, eating the same foods repeatedly until [the patient] tires of them.” (Case 2)*
>
> *“Highly anxious if something is presented differently than expected, i.e., crumbs falling off the Weetabix in [the patient’s] bowl. ... [Patient] has a preoccupation with numbers/measurements: i.e., precise measurements with fluid, weight, calories per day.” (Case 10)*

Noticing the patients’ atypical food preferences, dietitians developed an alternative menu (‘PEACE menu’) that is calorie-matched to the standard menu on the ward but consists of more bland tasting food items that are more homogeneous in texture. Most items were also pre-packaged for consistency. Food experiments and gradual exposure to new food were also helpful for patients who struggled with unfamiliar foods.

> *"Menu choices: Repetitive, bland foods, colours, textures and flavours. ...[the patient] has been utilising the alternative menu a lot." (Case 9)*
>
> *"Has found it very useful to have the alternative menu choices." (Case 15)*
>
> *"For [the patient] to explore food, sniffing/touching without having to eat it, [the clinician] has offered [the patient] to explore/play with a few new things from the menu which [the patient] would like to try." (Case 15)*

Cognitive rigidity

Cognitive rigidity was also documented as a major challenge, particularly in terms of difficulty coping with setbacks and unpredictable changes in the environment, such as the sudden shift to the virtual setting owing to the COVID-19 pandemic. Patients who were more inflexible and rigid also tended to find it harder to break routines and showed more extreme emotional responses to such changes. Cognitive rigidity also made therapeutic engagement more difficult, as helping to push the patient towards change is often key to making progress.

> *"[The patient] keeps a precise idea in [their] head of what each thing should look like and cannot seem to settle until [the patient] can see exactly how the staff have measured [the patient's] food out." (Case 10)*
>
> *"Change is a huge source of anxiety. [The patient] depends on routines, sameness and predictability." (Case 9)*
>
> *"[The patient] struggles with engagement because of rigidity; very concrete [thinking style] which makes it difficult for [the patient] to relate the CRT (Cognitive Remediation Training) exercises to real life. [Patient] attributes this to autism and says [the patient] 'is never going to change'." (Case 13)*

The team tried to help patients cope with changes by providing clear rationale for upcoming plans. Patients were notified of any plans or potential changes early on to manage uncertainty. Most administrative changes were also made in consultation with patients.

> *"Most changes are collaborative. If major changes, the implementation is with some notice rather than straight away." (Case 6)*
>
> *"What works well: providing rationale for changes, boundaries in place, being clear on timeframes." (Case 7)*

Clinicians sometimes found that their own approach could be influenced by their patients' rigid way of behaving and inadvertently also become increasingly detail focused within their own practice. They were able to use case discussion as an opportunity for reflection and calibration of the team's approach.

> *"[The patient's] rigid way of behaving has led the team into becoming rigid & detail-focused as well, adding detailed conditions to [the patient's] passes just to avoid [the patient's] disruptive behaviours on the ward. The team will need to resist giving in to this and try to move to bigger picture and planning." (Case 10)*

Emotional difficulties

In addition to some cases displaying more extreme emotional reactions to changes, some had difficulty identifying and articulating their emotions during therapy sessions, leading to poorer therapeutic engagement. Clinicians found that this made planning and delivering therapy more challenging, as they had to speculate about the patient's feelings and the best ways to proceed with therapy with limited patient input.

> *"Perhaps [the patient] would agree to goals because I'd suggested them so sometimes it was tricky to work out what was meaningful to [the patient], especially as [the patient] didn't report having emotional responses to many things." (Case 2)*
>
> *"Emotions were not described well. 'Don't know how to answer, not sure I can', 'don't know how I feel'." (Case 20)*

The team therefore incorporated an emotions list into their practice in order to help patients to identify and express their emotions. In addition, a "traffic light communication system" was used to help patients to express both their emotions and the ways in which they wished to be supported to the clinical team.

> *"Developed Traffic Light Communication System for wider team. [Patient] had cards on bedroom door to indicate how [the patient] was feeling: Red = I am really struggling, approach me with the emotions list and ask me to mark what I am feeling; Amber = Today is difficult, check in on me and ask me how I am doing; Green = I am ok, everyone carry on as usual." (Case 12)*

4.5 Discussion

This qualitative synthesis of PEACE huddle case notes and minutes provides a snapshot of the variety of challenges that clinicians face when treating complex patients with AN and autism, including communication difficulties, maintaining boundaries, issues related to autism screening, presence of comorbidities other than autism, sensory sensitivities, atypical eating behaviours, cognitive rigidity, and emotional difficulties.

4.5.1 Helping patients with communication and emotional difficulties

Research has pointed out that one of the key problems for individuals with autism is communication in a social context, particularly with peers (Doris et al., 2014; Paul, 2008). The case notes in this study further demonstrate how communication difficulties can, in practice, affect group participation as well as therapeutic engagement. Furthermore, patients' inability to maintain social relationships with peers can lead to over-dependence on carers (Kinnaird et al., 2021) and clinical staff, creating a major barrier to independent living after discharge.

Clinicians on the PEACE team tried different resources and treatment adaptations for communication difficulties. One example was the 'communication passport' (a copy is provided in Appendix 1.1), which is a one-page self-report document encompassing multiple aspects of communication, including a patient's preferred way to communicate, their sensory needs, their dislikes and their special interests and strengths. This worksheet was designed to help health professionals understand patients' preferred ways of communicating. Another adaptation described in the case notes was individual-level modification of communication style. For patients who struggled with open ended questions, which is not unusual in individuals with autism (Rapin & Dunn, 1997), multiple choice questions were sometimes used as an alternative.

Additionally, patients often found it challenging both to identify and to articulate their emotions. However, it should be noted that emotional difficulties are widely present in the overall ED population, rather than limited to those with autism comorbidity. Indeed, there is a large body of existing work on alexithymia in patients with ED (Westwood et al., 2017) as well as autistic individuals (Kinnaird et al., 2019c). Thus, the adaptations and resources used to address emotional difficulties may be helpful to all patients with ED, with or without co-occurring autism. To help patients identify their emotions, Cognitive Remediation and Emotion Skills Training (CREST; Tchanturia et al. 2015) was delivered in both individual and group formats. CREST interventions have been shown to significantly improve alexithymia and motivation in patients with AN and autism (Adamson et al. 2018). On the other hand, patients with difficulties articulating their thoughts and emotions were given options to use conversation cards or 'traffic light' communication system to indicate their emotions, or to represent their thoughts through art or diagrams instead. These methods received good feedback in several cases, but their validity should be explored further in future research.

4.5.2 Boundary maintenance in adapting treatment for autism and other comorbidities

Previous studies have discussed boundary crossings, which are defined as attempts to "adapt an existing therapeutic alliance to foster the patient's capacity to work in therapy" (Glass, 2003). Boundary crossings are usually benign modifications to accommodate reasonable requests and individualise treatment. They become problematic when there is a negative impact on patients, endangering their health, independence, and/or recovery (Johnston & Farber, 1996). In the setting of this study, clinicians were highly attuned to the different needs of patients with the comorbidity and were open and prepared to make adaptations. As a result, difficulties maintaining rules and boundaries spanned most of the case notes reviewed. Clinicians in this study often found themselves facing the dilemma of whether to continue encouraging change in patient behaviour for recovery from ED, or to make accommodations for autism-specific needs.

Rather than adhering rigidly to absolute boundaries in all situations, clinicians often endeavoured to compromise with patients. Furthermore, they worked with patients collaboratively to investigate what was driving the presenting difficulty before deciding whether treatment boundaries could be adapted: whether it was an ED symptom that should be addressed, an autism-driven need that could be accommodated, or an autism-related difficulty that nevertheless should be managed to facilitate independent living. Clarifying the cause of patients' problems was a crucial step to developing a corresponding care plan. Previous research on a framework for differentiating between clinical features of autism and ED could be a useful guiding tool for clinicians facing similar dilemmas (Kinnaird & Tchanturia, 2021). In some cases, however, comorbidities other than autism (e.g. anxiety, OCD and EUPD) were also present and intertwined with autism and the ED. This is consistent with existing evidence of overlap between EUPD and autism (Dudas et al., 2017) and OCD and autism (Kushki et al., 2019). These comorbidities and ED often fuelled each other by contributing to similar patterns of thoughts and behaviours, making recovery even more difficult. Therefore, more work may be required for clinicians to differentiate between the symptoms and identify the best way to help patients. This suggests the need for an extensive guiding framework for differentiating between difficulties caused by ED, autism, and other common comorbidities such as OCD and EUPD.

4.5.3 Sensory difficulties, cognitive rigidity and atypical eating behaviours

Both sensory difficulties and cognitive rigidity were linked to atypical eating behaviours in people with AN and autism, suggesting that their presentation may be driven by autism-related sensory and cognitive difficulties rather than common ED symptomatology such as fear of weight gain. Adaptations were necessary in these cases since conventional treatment at the ED services targeted typical ED symptoms and ED-driven cognition. In some cases, patients' preferences for certain foods were based on the texture, temperature, or even colour, instead of calorie content (e.g., preference for smooth-textured, high calorie foods like ice cream). Weight restoration, therefore, could be easier for these patients once a sensory friendly dietetic plan was in place, since their primary concern was not weight or body shape. This is consistent with previous research showing that inpatients with AN and high autistic characteristics showed more improvement in BMI after treatment than peers without autism (Li et al., 2020). On the other hand, it is important to consider that patients exhibiting atypical eating behaviours primarily driven by sensory factors may have Avoidant/Restrictive Food Intake Disorder (ARFID) rather than AN, even if ARFID was not initially diagnosed. ARFID is a relatively newly acknowledged ED driven by sensory sensitivities, fear of adverse consequences of eating, or a general disinterest in food. There is a possibility that ARFID remains underdiagnosed among patients admitted to the SLaM ED service, potentially due to a lack of recognition, especially considering that diagnostic interviews have only been recently established (Bryant-Waugh et al., 2019; Bourne et al., 2020). Future research efforts should be directed towards examining the prevalence of ARFID among admissions to ED services and understanding its clinical presentation.

In some cases, patients also had rigid rules around eating and could be exceedingly selective, such as limiting intake to a few categories of foods or only eating pre-packaged food. Clinicians found food experiments and gradual exposure to novel foods helpful when patients presented with selective eating behaviour. One such case has since been published (Webb et al., 2023), including detailed accounts of how food exposure was trialled with a PEACE autistic patient, aiming to increase nutrition and variety. Such interventions are mostly used with avoidant/restrictive food intake disorder (ARFID) and aim to reduce anxiety related to food and eating, and the extent of food neophobia (Dumont et al., 2019). People with autism share a similar presentation to people with ARFID, including a preference for familiar foods and an aversion to trying new things (Kinnaird et al., 2019a), which inspired the team to try food experiments with the patients. Recent research has also found that fussy eating partially mediates the associations between autism and the development of ED behaviours (Leno et al., 2022), suggesting that fussy eating may be a useful point for prevention and intervention.

One challenge, however, with introducing food experiments to an ED service, was its initial contradiction with usual practice where patients were expected to finish their meals instead of playing with food without eating it. Extensive team-wide discussions were held before all clinical staff reached consensus on which patients could utilise the food experiments and for how many sessions. The costs and resources required to deliver the intervention also need to be considered before food experiments can be made regular practice. Overall, although food experiments were found to be helpful with some of the cases with autism comorbidity, this is not yet validated and therefore warrants future testing.

4.5.4 Need for pragmatic autism screening tools suitable for ED services

This study also highlights a need for a pragmatic autism screening approach in ED services. The AQ-10 was used in the service for its brief format and convenience, and has the advantage of being a screening instrument to identify individuals who would benefit from a full autism assessment (Westwood et al., 2016a). However, its validity and reliability for use with this specific patient population are yet to be tested. Indeed, in some cases, patients previously had a formal autism diagnosis or deemed by clinicians to have a strong autistic presentation that would benefit from treatment adaptations, but still scored below the threshold on the AQ-10. Furthermore, it is still unknown whether the AQ-10 is specific enough to differentiate between autism and other common comorbidities such as social anxiety, given that certain items on the AQ-10 may tap into symptoms of social anxiety rather than autism. Clinical practice would benefit from future research focusing on pragmatic screening tools with higher specificity and sensitivity when used in this co-morbid population. Combined use of the AQ-10 with other self-report screening measures for increased validity, such as sensory sensitivity screening (Kinnaird et al., 2020) or more detailed self-report measures like the Social Responsiveness Scale (Kerr-Gaffney et al., 2020), should also be considered.

4.5.5 Limitations

This study focused on a relatively small number of cases and only half of the cases had formal diagnosis of autism, therefore, the findings of this case synthesis cannot be generalised to the wider population of patients with comorbid autism and ED. However, the clinical reality and challenges raised by the clinicians in this study provide important learnings for future treatment improvement and adaptations, as well as future research. The lack of a suitable autism screening tool was also noted for this clinical group. Future research should consider incorporating more valid screening tools, such as the longer version of AQ (Baron-Cohen et al., 2001), the Camouflaging Autistic Traits Questionnaire (CAT-Q; Hull et al., 2019), or the Sensory Processing Measure, Second Edition (SPM-2; Parham et al., 2013) that investigate more of the behavioural aspects in this population. Furthermore, as the cases concerned were de-identified, it was not possible to trace the patients' clinical records to identify outcomes such as BMI improvement, limiting the range of reportable measures to complement clinicians' reports of what was helpful. However, ongoing evaluation of the PEACE Pathway will provide evidence on effectiveness to support its wider implementation.

4.6 Conclusions

Clinicians face a variety of challenges when providing care to patients with comorbid ED and autism, including dealing with communication difficulties, boundary issues, problems with autism screening, managing and differentiating comorbidities, sensory difficulties, atypical presentation of eating behaviours, cognitive rigidity, and emotional difficulties. The exploratory findings of this synthesis serve to generate hypotheses for future investigation to identify ways in which health professionals can address these difficulties and develop protocols for dealing with clinical dilemmas in adapting treatment.

Chapter 5 Sensory workshop evaluation

This chapter includes the publication:
Li, Z., Holetic, V., Webb, J., Chubinidze, D., Byford, S., & Tchanturia, K. (2023). In-person and online sensory wellbeing workshop for eating disorders: updated case series. Journal of Eating Disorders, 11(1), 117.
The candidate (ZL) contributed to the data collection, data analysis, drafting and revising of the manuscript, together with co-first author VH (data collection, drafting and revising of the manuscript), co-authors JW (data collection, review of the manuscript), DC (drafting and review of the manuscript), and supervisors Prof Sarah Byford (review of the manuscript) and Prof Kate Tchanturia (review of the manuscript). The manuscript has been modified and expanded to incorporate into this thesis. A PDF version of the original publication is provided in the Appendix 5.1.

5.1 Preface

In Chapter 4, one of the clinical challenges in supporting adults with AN and autism was patients' sensory difficulties. This chapter aims to evaluate the sensory wellbeing workshop (hereafter 'sensory workshop'), a one-off psychology workshop developed by the PEACE Pathway to help patients manage sensory sensitivities.

The sensory workshop comprises of psychoeducation, discussion and hands-on exercises. During the COVID-19 pandemic, the workshop had to be fully adapted for online delivery. The candidate led this adaptation to online workshop. This chapter introduces how the PEACE team changed the format of the workshop in response to the pandemic, and explores the impact of the workshop format change on outcomes. This provides a helpful background for Chapter 6 (Clinical Evaluation) and Chapter 7 (Cost-savings Analysis), both of which highlight the impact of the COVID-19 outbreak on the PEACE Pathway outcomes.

5.2 Introduction

Sensory disturbances in patients with eating disorders (ED), particularly anorexia nervosa (AN), have been widely studied in recent years (Islam et al., 2015; Kinnaird et al., 2018). Some argue that sensations are commonly muted in individuals with AN, leading to increased reliance on other external cues and rules to regulate eating behaviour (Pollatos et al., 2008), whereas others have identified sensory hypersensitivities in AN (Zucker et al., 2013) which can lead to sensory avoidance. For example, studies have found that patients with AN had lower olfactory threshold (Stein et al., 2012) and increased smell capacity (Fernández-Aranda et al., 2016; Rapps et al., 2010) than controls, which could make certain sensations (e.g. strong smell of food) exceedingly intolerable. Moreover, difficulties in interpreting and tolerating these sensations can affect emotional regulation, as individuals may not be able to appropriately guide emotional reactions using body signals (Merwin et al., 2013). These individuals may then use the ED as a maladaptive coping strategy for negative emotions.

Among individuals with ED, research has also identified a subgroup with a comorbidity of autism that have a more complex presentation (Brede et al., 2020; Kinnaird and Tchanturia, 2021). There have been consistent findings of a relationship between sensory processing and eating behaviours in autistic individuals (Nimbley et al., 2022), as well as association between autism, sensory processing, and illness severity in individuals with ED (Saure et al., 2022a). Sensory difficulties are present in 90% of children and adults with autism (Leekam et al., 2007), which could exacerbate sensory issues when comorbid with ED. Indeed, patients with both conditions exhibit heightened sensory sensitivities in areas of smell, taste, vision, and texture (Kinnaird et al., 2020; Nimbley et al., 2022), leading to challenges adapting to treatment settings and active avoidance of certain foods (Li et al., 2022).

To support patients with hyper- or hypo-sensitivities, it is important to provide a space, psychoeducation and materials to explore their sensory needs. Therefore, a one-off sensory wellbeing workshop was developed by the PEACE Pathway (Tchanturia et al., 2020), based on an investigation of sensory preferences and difficulties in patients using a screener survey (Kinnaird et al., 2020) as well as perspectives of people with lived experience of sensory sensitivities (Kinnaird et al., 2019). Sensory wellbeing refers to the state of wellbeing that individuals experience when their sensory needs are adequately met and regulated. The one-off sensory wellbeing workshop combines psychoeducational materials and practical activities, with the aim to improve sensory awareness and provide sensory management strategies to support sensory wellbeing (protocol of the workshop published in Tchanturia et al., 2022). It starts with psychoeducation of the basic senses and discussion led by the facilitators about sensory experiences, followed by two exercises. In the first exercise participants explore a range of materials of different textures and senses to identify their own sensory preferences. The second exercise was a DIY activity for participants to make a self-soothing sensory item, for example a scented hand cream. Takeaway psychoeducation materials were also provided after the workshop.

Previously, a pilot evaluation of the sensory workshop has been conducted (Tchanturia et al., 2022) to examine its feasibility and discuss possible areas for development of the workshop. The candidate contributed to the data collection, analysis and revising of the manuscript in the pilot evaluation. Significant improvement was found in all post-workshop measures with large effect sizes, indicating possibility for the workshop to be delivered as part of ED treatment. Areas of improvement were also identified, including the need for longer workshop duration, more activities, collaboration across clinical services, and possibly introducing a follow up session. Given the limitations of sample size in the pilot study, we have since organised more workshops that are longer in duration, delivered online and in person across clinical services, and offering enriched psychoeducational content and activities based on the feedback we received from pilot workshops.

Psychological work should be based in evidence to ensure it is of significant clinical benefit for patients (Spring, 2007). Therefore, this follow-up study aims to:

- Generate more practice-based experience for the sensory workshop by conducting a case series with an increased sample size since the pilot evaluation (Tchanturia et al., 2022);
- Further investigate the impact of workshop format change by comparing the outcomes of face-to-face and online workshops.

5.3 Methods

5.3.1 Participants

All participants of the study were adult patients admitted to the South London and Maudsley NHS Foundation Trust (SLaM) National Eating Disorder Service and South West London and St George's Mental Health NHS Trust Specialist Eating Disorder Service. The workshop was advertised in community meetings and research advertisement board in the services. All patients (with or without autistic characteristics) who were interested to participate were invited to the workshop. Participants who did not complete the pre-workshop or post-workshop measures were excluded from analysis.

5.3.2 Measures

All participants were given a pre-workshop questionnaire to complete at the start (T1) of the workshop, and a post-workshop questionnaire at the end (T2). Full questionnaires can be found in the Appendix 5.2. The pre- and post-workshop questionnaires consisted three Likert scale items asking participants to rate their awareness of their own sensory wellbeing ("How aware are you of your sensory wellbeing?"), awareness of strategies to enhance sensory wellbeing ("How aware are you of the strategies to enhance your sensory wellbeing?"), and their confidence in managing their own sensory wellbeing ("How confident do you feel to manage your sensory wellbeing?"). The post-workshop questionnaire contained an additional question asking participants to rate the usefulness of the workshop ("How useful was this sensory workshop?"). All questions used a 5-point Likert scale ranging from 1 ("Not aware/confident/useful at all") to 5 ("Really aware/confident/useful"). By comparing participant responses before and after the workshop, we aimed to evaluate the change in participants' self-awareness and abilities to manage their sensory wellbeing. Furthermore, by including a question on usefulness in the post-workshop questionnaire, we can gauge participant satisfaction which is valuable for the workshop's future refinement.

5.3.3 Sensory wellbeing workshop procedure

Detailed procedure and protocol of the sensory workshop can be found on the PEACE website (peacepathway.org). To summarise, this one-off workshop aims to help patients increase knowledge and awareness about their sensory system, identify strategies that can enhance sensory wellbeing, and provide patients with tools to manage their sensory needs. The workshop was advertised to all patients in the ED service through poster and community meetings. Attendance was voluntary. The in-person workshop begins with psychoeducation of the different senses (touch, sight, hearing, smell, taste, proprioception, interoception) and discussion of sensory experiences, followed by two exercises: an exploration of different materials to identify one's own sensory preferences, and a do-it-yourself (DIY) activity of creating a sensory item of choice, for example a glitter jar, a scented hand cream or choose materials which have soothing effect when touched (fluffy, firm, soft textiles). Take home materials such as further psychoeducational worksheet and tools to communicate sensory preferences were also provided. At the start and end of the workshop, participants were asked to complete the pre (T1) and post (T2) workshop questionnaires. The in-person workshops lasted for a duration of two hours and were facilitated by two to three members of clinical staff.

During the COVID-19 pandemic, the sensory workshop was adapted for online delivery via Microsoft Teams and run from December 2020 to April 2022. The psychoeducational content was adapted to a PowerPoint presentation, and discussions were facilitated online. An interactive presentation software, named Mentimeter, was used to facilitate discussions. Following psychoeducation, the Mentimeter tool was utilised to prompt participants to write and post answers freely to two questions: 'what senses are comforting to me?' and 'what senses bother me?', and the answers were discussed as a group. For the DIY element, participants were encouraged to identify and prepare their own sensory items for the exercises. Participants who did not have items at hand would discuss and describe the sensory items they found helpful. Electronic versions of the pre- and post-workshop feedback questionnaires were distributed, and the take home materials were circulated after the workshop via e-mail. The online workshop ran for one and a half hours, shorter than the in-person workshop as material preparation time was deducted, and was facilitated by two to three members of the clinical team.

Overall, the two workshop formats differ most significantly in the provision of materials for the practical element. The in-person workshop includes a hands-on activity of making a sensory item using materials provided by facilitators, whereas in the online format participants were required to bring or discuss their favorite sensory items. To ensure participant engagement, break out rooms of smaller groups were used in online workshops, with one facilitator in each break out room leading the discussion.

5.3.4 Analysis

Within-group analysis was conducted using Wilcoxon signed ranks tests to examine improvement on each measure in in-person and online workshops individually. Furthermore, between-group analysis was conducted to investigate the effect of workshop format for each outcome measure (awareness of sensory wellbeing, awareness of strategies to enhance sensory wellbeing, and confidence in managing sensory wellbeing) using cumulative link mixed models fitted with the Laplace approximation, the most popular class of ordinal regression models, due to its suitability for repeated measures ordinal data analysis (Christensen, 2018). Group (online vs face-to-face) and time (T1 and T2) and the interaction between them were included as explanatory variables and individual identity as random variable. In addition, for the 'usefulness' measure which is only answered once at post-workshop, a Mann-Whitney U test is used to compare between online and face-to-face workshops. Data were analysed using IBM SPSS software (Version 28) and the clmm function in the ordinal package for R

(R Core Team, 2021). The majority of responses to open questions on the survey have already been analysed using thematic analysis in Tchanturia et al., 2022 and therefore were not analysed again in this study.

5.4 Results

In total, 14 workshops (4 online and 10 face-to-face) including 86 participants (26 online and 60 face-to-face) were run from February 2020 to May 2023. The number of participants for each workshop ranged from 2 to 10. Eighty-one patients (23 online and 58 face-to-face) submitted anonymous feedback at T1 and/or T2. Among them, feedback was partly missing (in either pre- or post-workshop measure) for 10 (43.5%) online participants and 5 (8.6%) face-to-face participants. These participants were excluded by case from analysis. As a result, a total of 66 valid responses (13 online and 53 face-to-face) were included in the analysis. Their baseline characteristics are summarised in Table 5.1. There was no significant difference between online and face-to-face participants in their baseline characteristics.

Table 5. 1 Baseline characteristics of participants in online and face-to-face (F2F) sensory wellbeing workshops

	Online (N=13)	**F2F (N=53)**
Age (years), mean (SD)	23.2 (4.1)	25.8 (7.9)
Missing	2 (15.4%)	7 (13.2%)
Diagnosis, n (%)		
AN restrictive	9 (69.2%)	32 (60.4%)
AN binge-purge	2 (15.4%)	9 (17%)
AN atypical	0	2 (3.7%)
Bulimia nervosa	0	1 (1.9%)
Binge eating disorder	0	1 (1.9%)
Other Specified Feeding and Eating Disorder (OSFED)	1 (7.7%)	1 (1.9%)
Missing	1 (7.7%)	7 (13.2%)
Gender, n(%)		
Female	13 (100%)	45 (84.9%)
Male	0	0
Other	0	1 (1.9%)
Missing	0	7 (13.2%)
BMI on admission, mean (SD)	16.35 (2.45)	15.35 (4.63)
Missing, n(%)	2 (15.4%)	7 (13.2%)
Ethnicity		
White British	12 (92.3%)	36 (67.9%)
White Irish	0	1 (1.9%)
White other	0	3 (5.7%)
Black Afro-Caribbean	0	2 (3.8%)
Black British	0	1 (1.9%)
Asian (Indian)	1 (7.7%)	0
Mixed	0	3 (5.7%)
Missing	0	7 (13.2%)

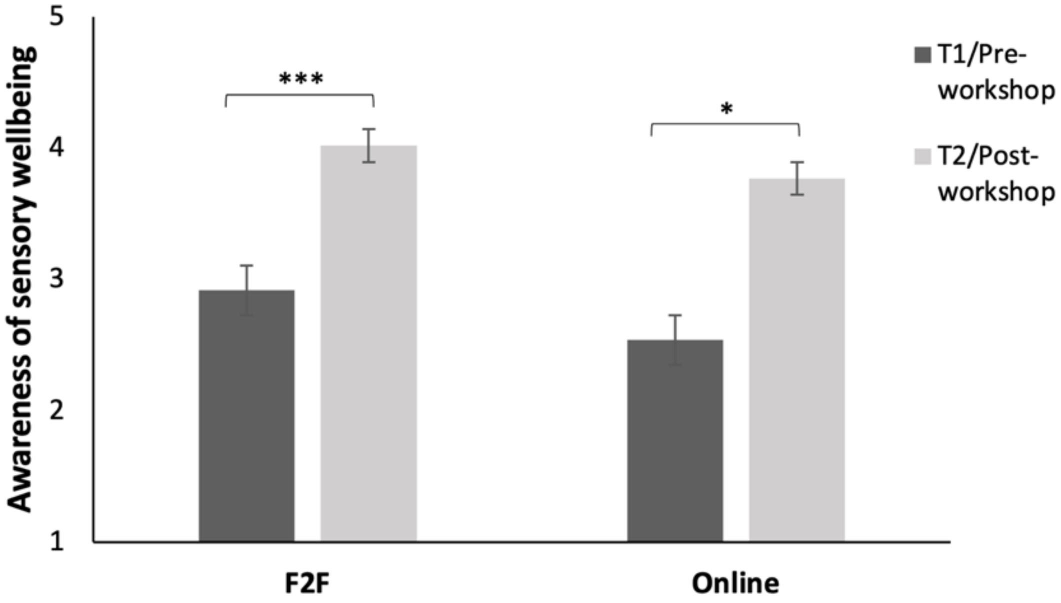
Outcomes are summarised in Table 5.2 and visualised in Figures 5.1(a) to 5.1(c). Both face-to-face and online workshops saw statistically significant improvement in all measures with large effect sizes.

Table 5. 2 Summary of pre-workshop (T1) and post-workshop (T2) participant feedback

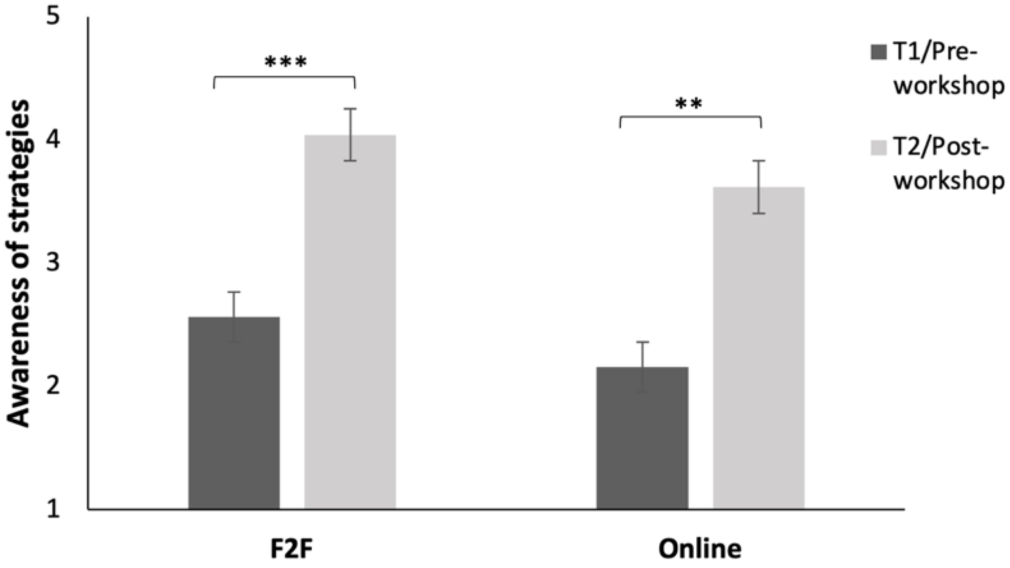
Measure	Workshop Format	T1		T2		Difference		
		M	SD	M	SD	*Z*	*P*	Cohen's *d*
Awareness of sensory wellbeing	F2F	2.92	1.03	4.00	0.76	-5.21	< 0.001	1.08
	Online	2.54	1.13	3.77	0.73	-2.55	0.011	0.95
Awareness of strategies	F2F	2.49	1.12	4.02	0.69	-5.65	< 0.001	1.25
	Online	2.15	0.90	3.62	0.77	-3.13	0.002	1.88
Confidence	F2F	2.38	0.88	3.51	0.80	-5.56	< 0.001	1.15
	Online	2.15	1.14	3.46	0.97	-2.85	0.004	1.27

Figure 5. 1 Comparison of face-to-face (F2F) and online workshop scores for (a) Awareness of sensory wellbeing (b) Awareness of strategies to enhance sensory wellbeing and (c) Confidence in managing sensory wellbeing

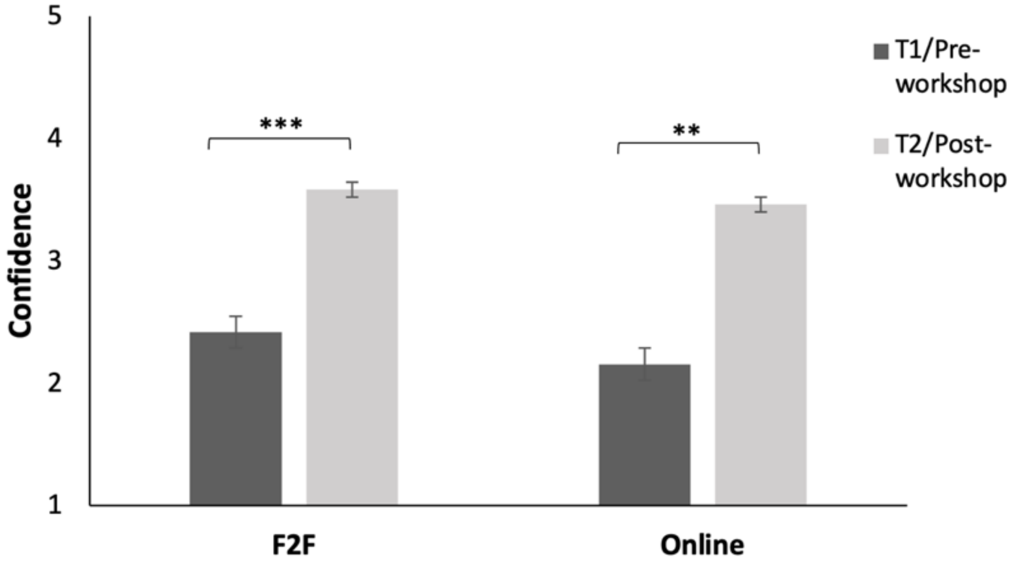
(a)



(b)



(c)



Note: $^{*}p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.001$

Table 5.3 shows the results of cumulative link models for all measures. Time had a significant effect on awareness of sensory wellbeing ($p = .019$), awareness of strategies to manage sensory wellbeing ($p < .001$), and confidence in managing sensory wellbeing ($p = .038$), suggesting that participants improved significantly on all measures. Neither workshop format nor the interaction between time and workshop format had a significant impact on the outcomes, suggesting that improvement on the outcomes was not significantly different between in-person and online workshops.

In terms of post-workshop ratings of usefulness, 51 (96.2%) participants of the face-to-face workshop and 12 (92.3%) participants of the online workshop rated it 3 (“Quite useful”) to 5 ("Really useful”). The mean rated usefulness was 4.01 for face-to-face and 3.77 for online workshops. Mann-Whitney test showed that the two workshop formats did not differ significantly in reported usefulness (U = 265, p = .366).

Table 5. 3 Summary of cumulative link models for all sensory workshop measures

	Awareness of sensory wellbeing			Awareness of strategies			Confidence		
	Coefficient	SE	*p*	Coefficient	SE	*p*	Coefficient	SE	*p*
Time (T1 vs T2)	2.66	1.14	.019*	3.87	1.13	<.001***	2.36	1.14	.038*
Format (F2F vs online)	-0.85	0.76	.266	-0.66	0.64	.302	-0.97	0.79	.224
Time x Format	0.14	0.87	.874	-0.39	0.81	.629	0.79	0.89	.372

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$; SE=standard error; F2F=face to face.

5.5 Discussion

In this chapter, we provide updated results for the sensory wellbeing workshop since the publication of its pilot evaluation (Tchanturia et al., 2022). Overall, the results are in line with the original paper, with participants reporting significant and substantial improvements in all measures (awareness of sensory wellbeing, awareness of strategies to manage sensory wellbeing, and confidence in managing sensory wellbeing) at post-workshop. Our results contribute to the growing body of literature that attests to the positive patient experiences and outcomes associated with group therapies (Ohmann et al., 2013; Sparrow et al., 2016; Tchanturia et al., 2016), and continues to demonstrate the feasibility of incorporating group workshops as adjunct elements within ED treatment programs (Tchanturia et al., 2022).

Furthermore, our results provide support for online provision, with no difference in outcomes between workshops delivered in person and online. This finding highlights the adaptability of the workshops and their potential for broader dissemination. However, it is essential to consider the practical differences between the formats. In-person workshops create a more hands-on and interactive environment, which facilitates better demonstrations of sensory items and encourages social interaction among participants. Conversely, online workshops may face challenges in achieving the same level of engagement and interaction as face-to-face sessions. This is evident in the significantly higher proportion of online participants who did not complete their feedback form compared to those attending in person. While this could be attributed to technological difficulties or distractions (such as email notifications and social media), it is worth investigating if the difference in response rate is due to different levels of engagement. Future studies comparing between the two workshop formats on the level of participant engagement are warranted. Despite these potential challenges, the online format offers increased accessibility and flexibility, particularly for those who may encounter barriers to attending in-person workshops. Furthermore, the following recommendations may help enhance the delivery of online sensory wellbeing workshops: (1) Streamlined material acquisition: It would be beneficial to offer pre-assembled material packs for participants who may encounter challenges in obtaining the necessary items themselves. This approach ensures that all attendees have the requisite resources for the online workshop. (2) Workshop automation: to aid item demonstrations in the online workshops, we suggest incorporating pre-recorded content, interactive tools, or self-paced activities in the workshop. This approach will foster a more streamlined and efficient experience while preserving engagement and interactivity. (3) Introducing breaks: As the focus on psychoeducation in online workshops can be mentally taxing for participants, regular short breaks could be introduced into the workshop, for example in between the psychoeducation and discussion sessions.

Research is sparse when investigating sensory processing within ED behaviours. However, previous studies have demonstrated that individuals with ED have more sensory disturbances than healthy controls (Zucker et al., 2013). For example, Gaudio et al. (2014) found that individuals with AN may have multisensory impairments regarding their body perception, including both tactile and proprioceptive sensory components. Other studies have demonstrated that individuals with ED may have higher sensory sensitivities or even avoid sensory experiences and appear less able to appropriately identify satiety sensations (Fassino et al., 2004; Pollatos et al., 2008) or recognise internal signals relating to stress such as increased heart rate (Zonnevylle-Bender et al., 2005). A more recent study showed that those with AN had significantly lower sensory registration and seeking behaviour, along with increased sensitivity and sensory avoidance compared to healthy controls (Saure et al., 2022a). It is worth noting that most of the work have a focus on participants with AN. We have included patients with all EDs in the current study but the majority of patients had AN, which reflects the patient demographics at the ED service. Future studies should consider including different patient groups to investigate the impact of addressing sensory difficulties in patients with bulimia nervosa or binge eating disorder.

Furthermore, understanding subjective body experience and its linkage with emotional awareness and regulation is crucial when challenging ED symptomology and cognitive distortion in patients with EDs. Previous work has linked sensory processing impairment with self-disgust in AN as well as BN (Bell, Coulthard, & Wildbur, 2017). It is important to note that as well as the relentless pursuit for the ‘perfect’ body, patients may also be motivated to maintain disordered eating to alter their body experiences (Zucker et al., 2013). There is also evidence that individuals with AN have deficits in integrating visual and proprioceptive information, which may contribute to the distorted body image in AN (Case, Wilson, & Ramachandran, 2012). Therefore, sensory processing difficulties could be a crucial target when addressing the maintenance factors of the illness. Following this early stage evaluation of the sensory workshop, further research is needed, perhaps on a more longitudinal scale, to measure the impact of addressing sensory experience on ED treatment outcomes.

The present study is limited by the sample size for online workshops as well as missing data. Furthermore, feedback was partly incomplete for 43.5% of online participants and 5.9% of face-to-face participants, suggesting that participants of the face-to-face workshops were more likely to fill in the outcome measures than those of the online workshops. Methods for online feedback collection may need to be improved, and findings comparing the two workshop formats therefore need to be interpreted with caution. More rigorous trials of the workshop need to be conducted in the future, incorporating a wider range of outcome measures (including ED symptom measures) as well as a control group to quantify outcomes.

5.6 Conclusion

Both online and face-to-face formats of the sensory workshop led to improvement in awareness of sensory wellbeing and confidence in managing sensory wellbeing for patients with ED. Future studies are warranted to investigate the impact of the workshop on ED treatment outcomes.

Chapter 6 Clinical evaluation of the PEACE Pathway

6.1 Introduction

The systematic review reported in Chapter 2 highlighted PEACE Pathway as the first systemic attempt in the UK to adapt an ED service for autistic people. The review also summarised previous literature on the impact of co-occurring autism on ED clinical outcomes. The results of the cluster analysis presented in Chapter 3 have then helped to provide a clearer understanding of the patients' presentation at the service where PEACE Pathway was developed and implemented – South London and Maudsley (SLaM) ED service. Patients at the service could be separated into a higher symptoms group and a lower symptoms group, where the higher symptoms group also had more autistic characteristics. Chapter 3 also gave a detailed introduction of the clinical audit at SLaM ED service, which is the data source for the clinical evaluation in this chapter and the cost-savings analysis in Chapter 7. Chapter 4 shifted the focus to the PEACE Pathway, providing a synthesis of the challenges in supporting people with the comorbidity and how these challenges were addressed by the PEACE team. This provided important background for the chapters that followed. Chapter 5 evaluated one component of the PEACE Pathway – the sensory wellbeing workshop, identifying significant improvement in patient's sensory wellbeing management in both online and in-person formats of the workshop.

This chapter presents a preliminary evaluation of the PEACE Pathway's clinical outcomes using audit data from the SLaM ED Service, where the pathway was rolled out. Specifically, this chapter aims to use naturalistic clinical data to evaluate the impact of the PEACE Pathway on patients' clinical outcomes at the service. The main hypothesis was that patients admitted after PEACE implementation would show superior improvement in treatment outcomes than patients admitted before PEACE was implemented. The objectives are as follows:

- Primary analysis: to compare the improvement in clinical outcomes upon discharge in patients admitted before PEACE implementation (2012-2016) versus admissions after the PEACE Pathway implementation has begun (2017-2022). (Objective 1)
- Secondary analysis 1: to compare the improvement in clinical outcomes upon discharge in autistic patients (those with a diagnosis of autism spectrum disorder or with autistic traits) admitted before and after PEACE implementation. (Objective 2)
- Secondary analysis 2: to regroup the participants in the primary analysis and compare the improvement in clinical outcomes upon discharge in patients admitted after the PEACE Pathway has been *fully implemented* (2019-2022) versus admissions *before and during* PEACE implementation (2012-2018). (Objective 3)
- Secondary analysis 3: to remove data from admissions during the period when PEACE was not fully implemented yet (2017-2018) and compare the improvement in clinical outcomes upon discharge in patients admitted after the PEACE Pathway has been *fully implemented* (2019-2022) versus admissions *before* PEACE implementation (2012-2016). (Objective 4)

Corresponding to each objective, the following hypotheses were tested:

- Objective 1: it was hypothesised that admissions after the PEACE Pathway implementation would see significantly greater improvement in clinical outcomes compared to admissions before PEACE implementation.
- Objective 2: it was hypothesised that autistic patients admitted after the PEACE Pathway implementation would see significantly greater improvement in clinical outcomes compared to autistic patients before PEACE implementation.
- Objective 3: it was hypothesised that patients admitted after full implementation of PEACE would show significantly greater improvement than patients admitted before and during the implementation period.

- Objective 4: it was hypothesised that patients admitted after full implementation of PEACE would show significantly greater improvement than patients admitted before the implementation period started.

6.2 Methods

6.2.1 The dataset

This chapter used clinical audit data at the SLaM NHS specialist inpatient ED service. See 3.3.1 in Chapter 3 for an in-depth introduction of the clinical audit.

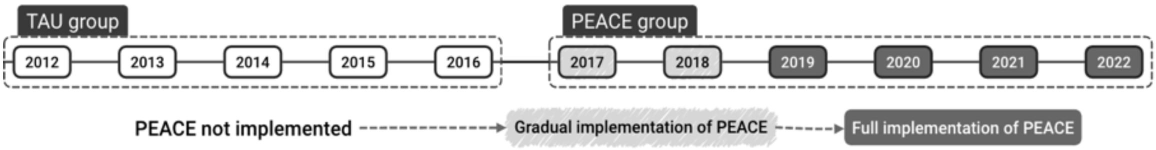
The audit consists of self-reported demographic and clinical data from patients. As part of the admission process to the SLaM ED inpatient service, patients are asked to complete a demographic questionnaire including age, gender, living condition, employment status, years of education, marital status, family history of autism, previous hospitalisation due to ED, leave from work or study due to ED, and illness duration of ED. Patients' height, weight, body mass index (BMI), ED diagnosis and medication use are recorded by a member of staff. As part of the audit, patients also complete a set of clinical measures once on admission (T1) and once on discharge (T2). The clinical measures included: Eating Disorder Examination Questionnaire (EDE-Q; Fairburn & Beglin, 1994), Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), Work and Social Adjustment Scale (WSAS; Mundt et al., 2002), and Autism Spectrum Quotient, short version (AQ10; Allison et al., 2012). On all of the clinical measures, higher scores indicate more severe symptoms. For a more detailed description of the audit measures, see 3.3.1.

6.2.2 Participants

Only patients with an ED diagnosis were included. Patients who were referred to the inpatient service but did not receive an ED diagnosis due to their difficulties not being ED-related were excluded. Patients with missing data in all five clinical measures (BMI, EDE-Q, WSAS, HADS, and AQ-10) on admission or on discharge were excluded, but those who had at least one complete clinical measure on admission and on discharge were preserved to minimise loss of power.

For the primary analysis and secondary analysis 1, admissions from January 2012 to December 2022 were separated into a PEACE group, comprising of patients admitted after PEACE was initiated, and a treatment as usual (TAU) group comprising of patients admitted before PEACE implementation (Figure 6.1). As the PEACE Pathway was implemented in a stepwise manner from January 2017 to January 2019, all patients discharged before January 2017 would have had no exposure to PEACE and therefore formed the TAU group, and all patients admitted after January 2017 would have had some exposure to PEACE implementation, and therefore formed the PEACE group (Figure 6.1).

Figure 6. 1 Patient grouping in the primary analysis and secondary analysis 1



Twelve patients were admitted before and discharged after January 2017 (whose admission therefore spanned PEACE initiation). These patients were grouped based on the percentage of their admission that took place before or after January 2017, such that those where the majority of their admission days (>50%) took place before January 2017 were grouped as a TAU patient, and those whose admission was mostly after January 2017 were categorised as a PEACE patient. For example, a patient who was admitted on 28 November 2016 and discharged on 26 May 2017 would have spent 19% (34 days) of their admission in with no exposure to PEACE and 81% (146 days) exposed to PEACE implementation, and therefore were allocated to the PEACE group. Of the 12 patients whose admission spanned PEACE initiation, five spent the majority of their admission (53% to 87%) with no exposure to PEACE (prior to January 2017) and were therefore allocated to the TAU group, and seven spent the majority of their admission (53% to 82%) with some exposure to PEACE (after January 2017) and were therefore allocated to the PEACE group.

For secondary analysis 2 and secondary analysis 3, patients were re-grouped based on their exposure to the PEACE Pathway. In secondary analysis 2 (Figure 6.2), only patients admitted after January 2019 had full exposure to the PEACE Pathway and therefore were included in the PEACE (full exposure) group, and all admissions before then were allocated to the TAU (partial or no exposure to PEACE) group. In secondary analysis 3 (Figure 6.3), all patients admitted during the period when PEACE was not fully implemented yet (2017-2018) were excluded; only patients with full exposure to the PEACE Pathway were included in the PEACE (full exposure) group, and patients with no exposure to PEACE were allocated to the TAU (no exposure) group.

Figure 6. 2 Patient grouping in secondary analysis 2

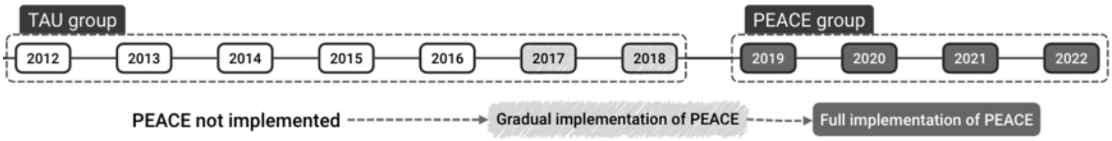
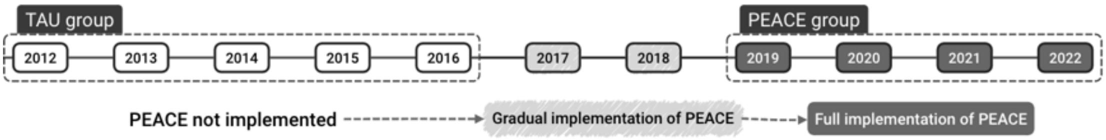


Figure 6. 3 Patient grouping in secondary analysis 3



6.2.3 Data analysis

All analyses were performed using IBM® SPSS® software Version 28 and jamovi Version 2.3 which is a data analysis software based on the R language. Difference between PEACE and TAU in baseline characteristics on admission was checked using t-tests, Mann-Whitney U tests, Chi-square or Fisher's exact tests where appropriate, and any differing variables were introduced in the analyses as covariates.

Statistical analyses followed from the five study objectives. In the primary analysis, the impact of PEACE implementation was evaluated by comparing improvement in clinical outcomes upon discharge for PEACE and TAU patients

(Objective 1). Linear mixed models were fitted with group (PEACE vs TAU) and time point (Admission/T1 and Discharge/T2) as main effects, a group x time point interaction effect, and a random intercept for participant. Using mixed models with maximum likelihood allows variables with missing data to be included in the model estimates. Because linear mixed models require that any missing data are missing at random, baseline predictors of missing outcome data were sought using binary logistic regression and any identified predictors of missingness were included in the mixed models as covariates. When investigating differences in BMI, only patients with an AN diagnosis were included in the analysis, as BMI improvement is a primary treatment goal for these patients but not for patients with other ED diagnoses. Patients with all diagnoses were included when investigating changes in other clinical measures such as EDE-Q, HADS, WSAS and AQ10. When reporting outcomes, Satterthwaite p-values and degrees of freedom were reported. Cohen's d effect sizes were reported for T1 to T2 differences for each clinical measure. Effect sizes were interpreted as small (d = 0.2), medium (d = 0.5), and large (d = 0.8) based on benchmarks suggested by Cohen (Cohen, 2013).

Secondary analysis 1 repeated the primary analysis but with autistic patients only, to compare the improvement in clinical outcomes upon discharge in autistic patients admitted before and after PEACE implementation (Objective 2). Secondary analysis 2 and 3 also repeated the process of primary analysis but using PEACE and TAU groups that were differently defined (see 6.2.2) to investigate if the degree of exposure to PEACE Pathway alters the results of the primary analysis (Objective 3 & 4).

6.3 Results

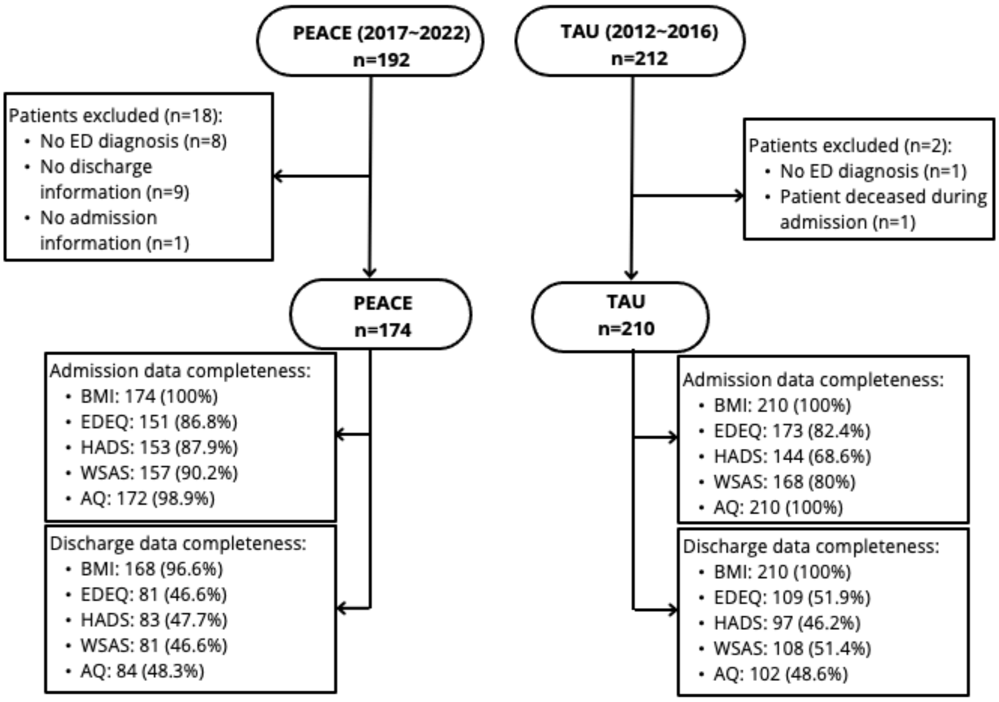
6.3.1 Participants

Figure 6.4 shows the participant flow for the sampling and data completeness in this study. In total, 192 patients were grouped as PEACE patients and 212 as TAU patients based on their time of admission and discharge. Twenty patients were excluded from the analysis for the following reasons:

- No ED diagnosis (PEACE: n=8; TAU: n=1).
- No discharge information on the record (i.e., missing data on all clinical outcomes on discharge; PEACE: n=9).
- No admission information on the record (i.e., missing data on all clinical outcomes on admission; PEACE: n=1).
- One patient deceased during admission and was therefore excluded (TAU: n=1)

This left a total of 174 patients in the PEACE group and 210 patients in the TAU group (Figure 6.4).

Figure 6. 4 Participant sampling chart



6.3.2 Primary analysis: Comparing improvement in clinical outcomes in PEACE versus TAU

6.3.2.1 Baseline characteristics

Table 6.1 shows the baseline characteristics of the PEACE and TAU groups in the primary analysis. There was no significant difference between PEACE and TAU regarding age, gender, BMI on admission, duration of illness, number of comorbidities, and length of admission. Diagnosis was significantly different between the two groups and was therefore introduced as a covariate in the mixed models.

Table 6. 1 Baseline characteristics: PEACE and TAU groups

	PEACE (n=174)	**TAU (n=210)**
Age [years], mean (SD)	29.2 (11.9)	27.9 (10.6)
Gender: female, n (%)	171 (98.3%)	210 (100%)
Diagnosis, n (%)		
AN-restrictive	135 (77.6%)	124 (59%)
AN-binge purge	33 (19%)	58 (27.6%)
AN-atypical	1 (0.6%)	14 (6.7%)
BN	3 (1.7%)	9 (4.3%)
EDNOS	2 (1.1%)	5 (2.4%)
BMI on admission, mean (SD)	13.88 (1.6)	14.24 (1.82)
Duration of illness [years], mean (SD)	11.2 (10.2)	10.7 (8.9)
Number of comorbidities, mean (SD)	1(1.3)	1(1.2)
Length of admission [weeks], mean (SD)	17.3 (13.8)	16.8 (14.1)

AN=anorexia nervosa; BN=bulimia nervosa; EDNOS=eating disorder not otherwise specified; BMI=Body Mass Index

6.3.2.2 Clinical outcomes

Table 6.2 records the clinical outcomes for the PEACE and TAU groups, effect sizes of the improvement from admission to discharge, and results of the linear mixed models including Satterthwaite p-values. For the comparison of BMI improvement between PEACE and TAU, only patients with an AN diagnosis were included because increase in BMI is a treatment goal only for patients with AN but not for other ED diagnoses. For other outcome measures, patients with all ED diagnostic subtypes were included. Each outcome measure is discussed in more details below.

Table 6. 2 Summary of outcome measures and linear mixed model results: primary analysis

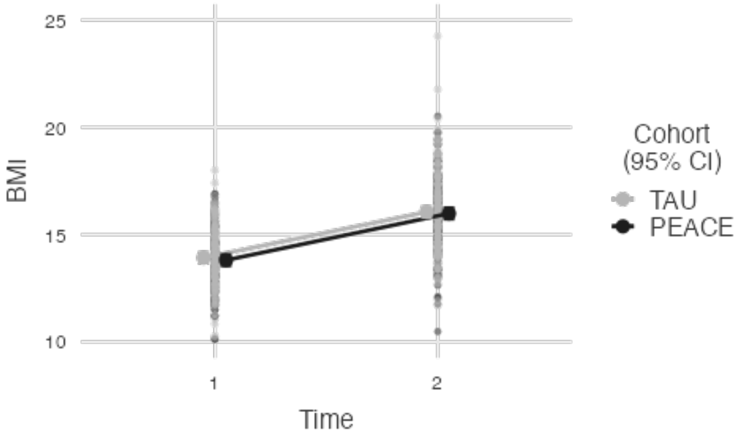
Outcome	Admission	Discharge	ES	LMM	
	Mean (SD)	Mean (SD)	Cohen's d	Time	Time x Group
BMI (AN only)					
TAU	13.95 (1.34)	16.08 (1.80)	1.45	F(1,360)=781.972	F(1,360)=0.085
PEACE	13.77 (1.35)	15.94 (1.73)	1.52	$p < 0.001$	$p = 0.770$
EDE-Q					
TAU	3.96 (1.58)	2.85 (1.64)	0.86	F(1,201)=129.07	F(1,201)=0.014
PEACE	4.50 (1.36)	3.28 (1.45)	0.96	$p < 0.001$	$p = 0.905$
HADS-Anxiety					
TAU	14.60 (4.47)	12.20 (5.09)	0.57	F(1,187)=45.734	F(1,187)=0.01
PEACE	15.34 (4.19)	13.00 (4.05)	0.60	$p < 0.001$	$p = 0.920$
HADS-Depression					
TAU	11.48 (5.04)	7.34 (5.04)	0.82	F(1,213)=92.26	F(1,213)=0.402
PEACE	12.33 (4.48)	8.82 (4.17)	0.78	$p < 0.001$	$p = 0.527$
WSAS					
TAU	25.68 (8.67)	20.02 (10.51)	0.44	F(1,313)=22.55	F(1,313)=2.26
PEACE	26.79 (9.76)	23.06 (9.36)	0.27	$p < 0.001$	$p = 0.134$
AQ-10					
TAU	3.53 (2.61)	3.43 (2.36)	0.04	F(1,223)=0.016	F(1,223)=0.091
PEACE	4.09 (2.65)	4.00 (2.19)	0.04	$p = 0.898$	$p = 0.763$

AN=Anorexia nervosa, AQ-10=Autism Spectrum Quotient, short version, BMI=Body Mass Index, EDE-Q=Eating Disorder Examination Questionnaire, ES=Effect Size, HADS=Hospital Anxiety and Depression Scale, LMM= Linear mixed models, WSAS=Work and Social Adjustment Scale.

6.3.2.2.1 Improvement in BMI: PEACE versus TAU (primary analysis)

Only patients with AN were included for comparing BMI improvement between PEACE versus TAU groups. Among the total sample, 169 (97%) PEACE patients and 196 (93%) TAU patients had an AN diagnosis. Both groups showed substantial improvement in BMI after finishing treatment with large effect sizes (Table 6.2). Below, figure 6.5 shows the estimated mean BMI by group (PEACE versus TAU) at time points T1 (admission) to T2 (discharge). The mixed-effects analysis showed that there was a significant positive relationship between time and BMI (F(1,360)=781.972, p <0.001) with no significant time x group interaction; therefore, the improvement in BMI was constant across both groups.

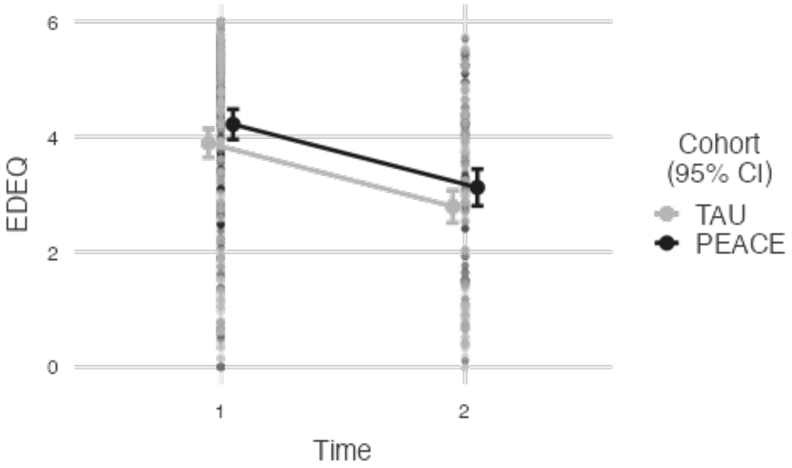
Figure 6. 5 Estimated mean BMI by group (PEACE vs TAU) at T1 (admission) and T2 (discharge)



6.3.2.2.2 Improvement in ED symptoms: PEACE versus TAU (primary analysis)

For the EDE-Q outcome, age was identified as a predictor of missingness (p =.003) and therefore was included in the mixed model as a covariate. Both PEACE and TAU saw substantial improvement in EDE-Q scores upon discharge with large effect sizes (Table 6.2). Below, figure 6.6 shows the estimated mean EDE-Q scores for the PEACE and TAU groups from T1 (admission) to T2 (discharge). The mixed-effects analysis showed that there was a significant negative relationship between time and EDE-Q (F(1,201)=129.07, p < 0.001) with no significant time x group interaction. The improvement in EDE-Q was constant across both groups. Over time, the marginal EDE-Q score was higher in the PEACE group (F(1, 352)=4.45, p= 0.036), suggesting generally higher EDE-Q in the PEACE group on admission and on discharge.

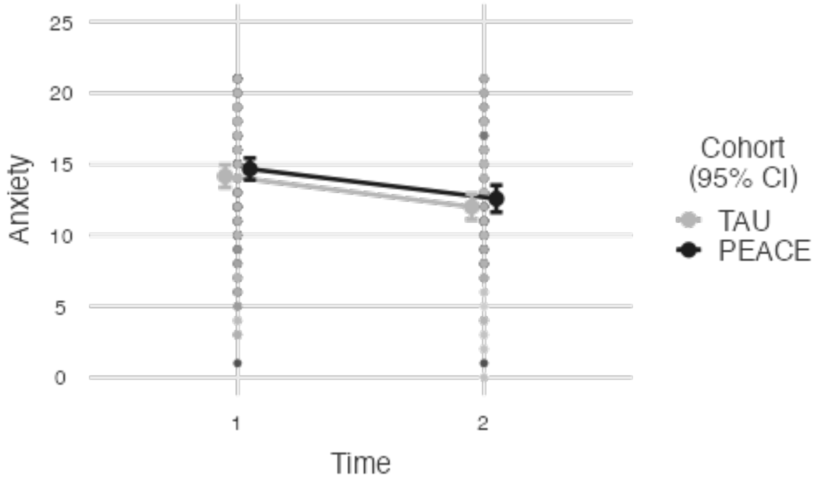
Figure 6. 6 Estimated mean EDE-Q scores by group (PEACE vs TAU) at T1 (admission) and T2 (discharge)



6.3.2.2.3 Improvement in anxiety symptoms: PEACE versus TAU (primary analysis)

No predictors of missingness were identified for the HADS anxiety measure. Both PEACE and TAU showed moderate improvement in anxiety scores upon discharge with medium effect sizes (Table 6.2). Figure 6.7 shows the estimated mean HADS anxiety scores for PEACE and TAU groups from T1 (admission) to T2 (discharge). The mixed-effects analysis showed that there was a significant negative relationship between time and anxiety (F(1,187)=45.734, $p < 0.001$) with no significant time x group interaction. The improvement in anxiety was constant across both groups.

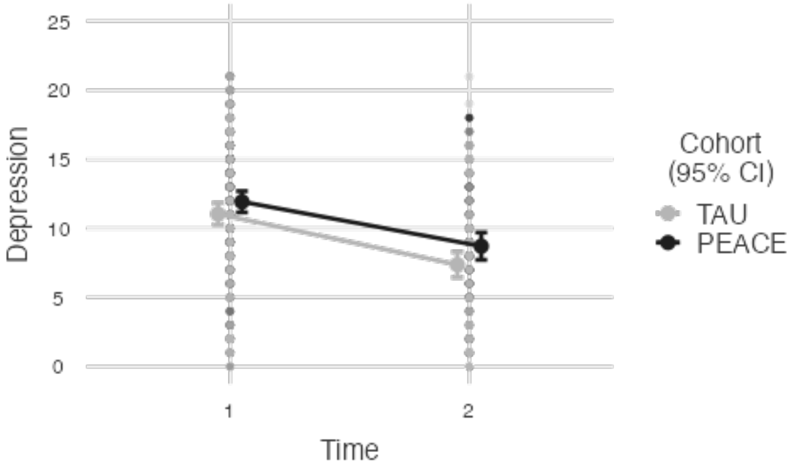
Figure 6. 7 Estimated mean HADS-anxiety scores by group (PEACE vs TAU) at T1 (admission) and T2 (discharge)



6.3.2.2.4 Improvement in depression symptoms: PEACE versus TAU (primary analysis)

No predictors of missingness were identified for the HADS depression measure. Both groups saw moderate improvement in depression with medium to large effect sizes (Table 6.2). Figure 6.8 shows the estimated mean HADS depression scores for the PEACE and TAU groups from T1 (admission) to T2 (discharge). The mixed-effects analysis showed that there was a significant negative relationship between time and depression (F(1,213)=92.26, p <0.001) with no significant time x group interaction. The improvement in depression was constant across both groups. Over time, the marginal depression score was higher in the PEACE group (F(1,323)=4.507, p=0.035), suggesting generally higher depression in the PEACE group on admission and discharge.

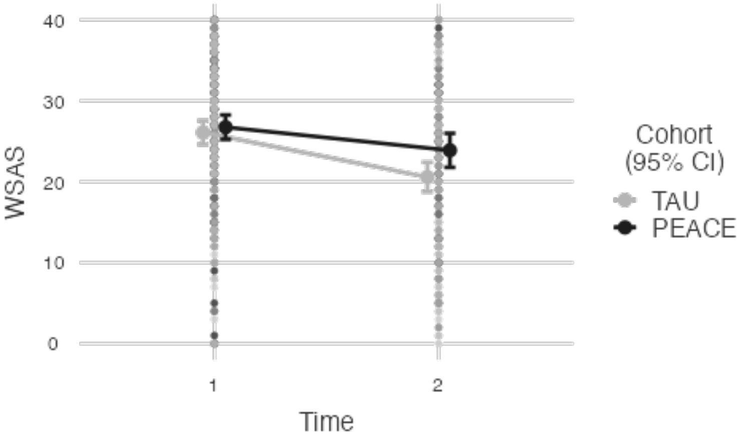
Figure 6. 8 Estimated mean HADS-depression scores by group (PEACE vs TAU) at T1 (admission) and T2 (discharge)



6.3.2.2.5 Improvement in work and social functioning: PEACE versus TAU (primary analysis)

No predictors of missingness were identified for the WSAS measure. Both PEACE and TAU patients showed some improvement in work and social functioning with small effect sizes (Table 6.2). Figure 6.9 shows the estimated mean WSAS scores for the PEACE and TAU groups from T1 (admission) to T2 (discharge). The mixed-effects analysis showed that there was a significant negative relationship between time and WSAS score (F(1,313)=22.55, p <0.001) with no significant time x group interaction. The improvement in WSAS was constant across both groups. Over time, the marginal WSAS was higher in the PEACE group (F(1,313)=4.80, p=0.029), suggesting generally higher work and social dysfunctioning in the PEACE group on admission and on discharge.

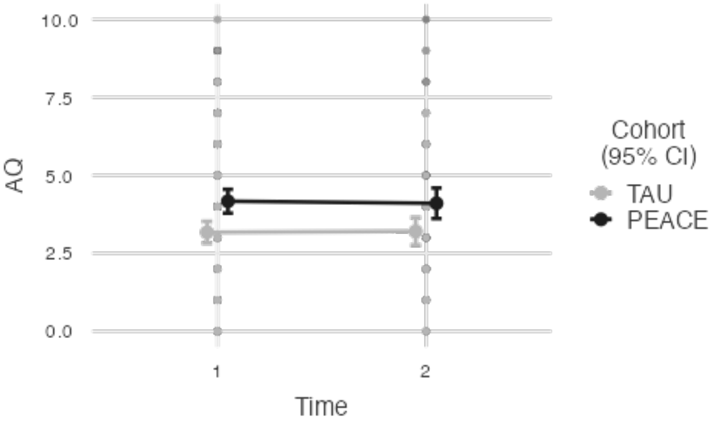
Figure 6. 9 Estimated mean WSAS scores by group (PEACE vs TAU) at T1 (admission) and T2 (discharge)



6.3.2.2.6 Change in autistic characteristics upon discharge: PEACE versus TAU (primary analysis)

No predictors of missingness were identified for the AQ10 autism screening measure. There was little change in AQ10 for both PEACE and TAU as can be seen from the small effect sizes (Table 6.2). Figure 6.10 shows the estimated mean AQ10 scores for the PEACE and TAU groups from T1 (admission) to T2 (discharge). The mixed-effects analysis showed no significant relationship between time and AQ10 score and no significant time x group interaction. The AQ10 stayed constant throughout treatment across both groups. Over time, the AQ10 was higher in the PEACE group (F(1, 411) =13.11, p <0.001), suggesting higher autistic characteristics overall in the PEACE group on admission and discharge.

Figure 6. 10 Estimated mean AQ10 scores by group (PEACE vs TAU) at T1 (admission) and T2 (discharge)



6.3.3 Secondary analysis 1: autistic patients only

6.3.3.1 Baseline characteristics

Secondary analysis 1 repeats the primary analysis but for autistic patients only. Among the total sample, there are 103 (26.8%) autistic patients in total. Table 6.3 shows the baseline characteristics of the autistic patients in the PEACE and TAU groups. There was no significant difference between the autistic patients in PEACE and TAU regarding age, gender, diagnosis, BMI on admission, duration of illness, number of comorbidities, and length of admission.

Table 6. 3 Baseline characteristics: autistic patients in PEACE versus TAU (secondary analysis 1)

	PEACE (n=56)	**TAU (n=47)**
Age [years], mean (SD)	29.3 (14.0)	27.4 (7.7)
Gender: female, n (%)	54 (96.4%)	47 (100%)
Diagnosis, n (%)		
AN-restrictive	40 (71.4%)	29 (61.7%)
AN-binge purge	13 (23.2%)	12 (25.5%)
AN-atypical	0 (0%)	3 (6.4%)
BN	2 (3.6%)	2 (4.3%)
EDNOS	1 (1.8%)	1 (2.1%)
BMI on admission, mean (SD)	14.22 (1.67)	14.65 (1.94)
Duration of illness [years], mean (SD)	11.7 (11.8)	11.3 (7.8)
Number of comorbidities, mean (SD)	1.3 (1.3)	1.1 (1.1)
Length of admission [weeks], mean (SD)	17.7 (15.1)	18.6 (14.5)

AN=anorexia nervosa; BN=bulimia nervosa; EDNOS=eating disorder not otherwise specified; BMI=Body Mass Index

6.3.3.2 Clinical outcomes

Table 6.4 records the clinical outcomes for secondary analysis 1 for the autistic patients in the PEACE and TAU groups, effect sizes of their improvement from admission to discharge, and results of the linear mixed models including Satterthwaite p-values. For the comparison of BMI improvement between PEACE and TAU, only patients with an AN diagnosis were included because increase in BMI is a treatment goal only for patients with AN but not for other ED diagnoses. For other outcome measures, patients with all ED diagnostic subtypes were included.

Table 6. 4 Summary of outcome measures and linear mixed model results: secondary analysis 1 (autistic patients only)

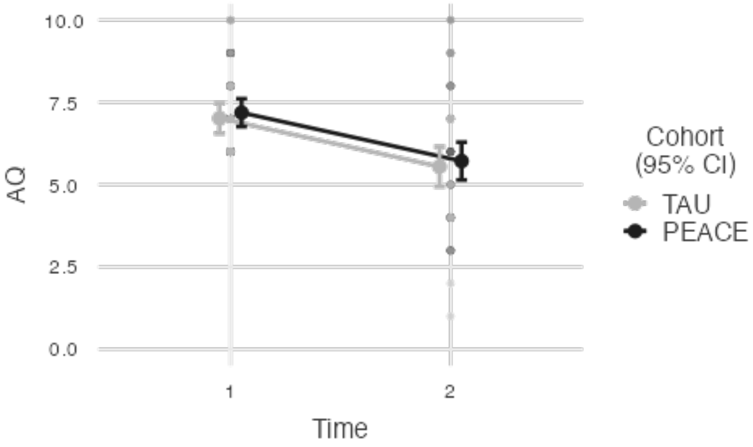
Outcome	Admission	Discharge	ES	LMM	
	Mean (SD)	Mean (SD)	Cohen's *d*	Time	Time x Group
BMI (AN only)					
TAU	14.59(1.91)	16.86(2.06)	1.29	F(1,93.7)=232.6	F(1,93.7)=0.094
PEACE	14.27(1.69)	16.72(1.95)	1.60	$p < 0.001$	p = 0.760
EDE-Q					
TAU	4.55(1.47)	3.24(1.66)	0.91	F(1,59.4)=59.5	F(1,59.5)=0.298
PEACE	4.94(1.01)	3.31(1.46)	1.31	$p < 0.001$	$p = 0.587$
HADS-Anxiety					
TAU	17.15(2.68)	14.20(4.72)	0.58	F(1,59.5)=20.472	F(1,59.5)=0.035
PEACE	16.93(3.42)	13.90(3.97)	0.82	$p < 0.001$	$p = 0.851$
HADS-Depression					
TAU	14.65(3.98)	9.20(4.50)	1.03	F(1,62.4)=42.52	F(1,62.4)=8.00e-6
PEACE	14.41(3.61)	9.55(3.98)	1.13	$p < 0.001$	$p = 0.998$
WSAS					
TAU	27.28(7.27)	23.40(9.97)	0.33	F(1,140)=6.46	F(1,140)=0.09
PEACE	27.50(8.17)	24.77(8.27)	0.22	$p = 0.012$	$p = 0.766$
AQ-10					
TAU	7.12(1.11)	5.58(2.28)	0.65	F(1, 89)=38.25	F(1, 89)=2.03e-4
PEACE	6.97(1.09)	5.66(2.04)	0.76	$p < 0.001$	$p = 0.989$

AN=Anorexia nervosa, AQ-10=Autism Spectrum Quotient, short version, BMI=Body Mass Index, EDE-Q=Eating Disorder Examination Questionnaire, ES=Effect Size, HADS=Hospital Anxiety and Depression Scale, LMM= Linear mixed models, WSAS=Work and Social Adjustment Scale.

Overall, the results (Table 6.4) were similar to the models using all patient data in the primary analysis (Table 6.2); in both PEACE and TAU, there were significant improvement in BMI, EDE-Q, HADS anxiety and depression, and WSAS, with no significant time x group interaction. They are not discussed in detail as the results and figures are similar to the primary analysis. One difference from the primary analysis was the AQ-10 measure. In secondary analysis 1, autistic patients in both PEACE and TAU groups showed substantial decrease in AQ-10 scores upon discharge with medium effect sizes (Table 6.4), whereas in primary analysis the AQ-10 stayed constant from admission to discharge for both groups (Table 6.2, Figure 6.10).

Below, Figure 6.11 shows the estimated mean AQ10 scores for the autistic patients in PEACE and TAU groups from T1 (admission) to T2 (discharge). The AQ10 decreased significantly over time ($F(1, 89)=38.25$, $p < 0.001$) with no significant time x group interaction.

Figure 6. 11 Estimated mean AQ-10 scores by group (PEACE vs TAU) at T1 (admission) and T2 (discharge) for autistic patients only (secondary analysis 1)



6.3.4 Secondary analysis 2: full exposure to PEACE versus partial to no exposure to PEACE

6.3.4.1 Baseline characteristics

Secondary analysis 2 regrouped the participants in the primary analysis to compare the improvement in clinical outcomes in patients admitted after the PEACE Pathway has been fully implemented (2019-2022; the full exposure group) versus admissions before and during PEACE implementation (2012-2018; the no or partial exposure group).

Table 6.5 shows the baseline characteristics for secondary analysis 2. There was no significant difference between the Full exposure group and the No or partial exposure group regarding age, gender, BMI on admission, duration of illness, number of comorbidities, and length of admission. Diagnosis was significantly different between the two groups and was therefore introduced as a covariate in the mixed models.

Table 6. 5 Baseline characteristics: patients in the 'full exposure' versus 'no or partial exposure' groups (secondary analysis 2)

	Full exposure (n=92)	**No or partial exposure (n=292)**
Age [years], mean (SD)	30.6 (13.0)	27.8 (10.5)
Gender: female, n (%)	89 (96.7%)	292 (100%)
Diagnosis, n (%)		
AN-restrictive	76 (82.6%)	183 (62.7%)
AN-binge purge	14 (15.2%)	77 (26.4%)
AN-atypical	0 (0.0%)	15 (5.1%)
BN	1 (1.1%)	11 (3.8%)
EDNOS	1 (1.1%)	6 (2.1%)
BMI on admission, mean (SD)	13.80 (1.49)	14.17 (1.79)
Duration of illness [years], mean (SD)	12.7 (11.2)	10.4 (8.8)
Number of comorbidities, mean (SD)	1 (1.4)	1 (1.2)
Length of admission [weeks], mean (SD)	17.2 (14.3)	16.9 (13.9)

AN=anorexia nervosa; BN=bulimia nervosa; EDNOS=eating disorder not otherwise specified; BMI=Body Mass Index

6.3.4.2 Clinical outcomes

Table 6.6 shows the outcomes for secondary analysis 2. For the comparison of BMI improvement, only patients with an AN diagnosis were included. For other outcome measures, all ED diagnostic subtypes were included. The results were all similar to the primary analysis (Table 6.2). Substantial improvement over time was observed in BMI, EDE-Q, HADS anxiety and depression, and WSAS in both Full exposure and No or partial exposure groups, with no significant time x group interaction. Similar to the primary analysis, there was little change in the AQ-10 upon discharge in either group with very small effect sizes, with no significant time x group interaction.

Table 6. 6 Summary of outcome measures and linear mixed model results: secondary analysis 2

Outcome	Admission	Discharge	ES	LMM	
	Mean (SD)	Mean (SD)	Cohen's *d*	Time	Time x Group
BMI (AN only)					
Partial/no exposure	13.91(1.36)	16.06(1.86)	1.49	F(1,360)=581.7	F(1,360)=0.002
Full exposure	13.74(1.29)	15.88(1.46)	1.46	$p < 0.001$	p = 0.964
EDE-Q					
Partial/no exposure	4.02(1.68)	3.09(1.65)	0.84	F(1,216)=97.54	F(1,217)=2.02
Full exposure	4.05(1.52)	2.79(1.43)	1.21	$p < 0.001$	$p = 0.157$
HADS-Anxiety					
Partial/no exposure	14.36(4.74)	12.72(4.97)	0.61	F(1,196)=33.27	F(1,196)=0.144
Full exposure	14.52(4.79)	11.97(4.27)	0.49	$p < 0.001$	$p = 0.704$
HADS-Depression					
Partial/no exposure	11.49(5.07)	8.19(4.90)	0.86	F(1,230)=57.66	F(1,230)=0.444
Full exposure	11.36(4.43)	8.19(3.88.)	0.57	$p < 0.001$	$p = 0.506$
WSAS					
Partial/no exposure	26.38(9.45)	22.18(10.16)	0.38	F(1,332)=20.07	F(1,333)=0.513
Full exposure	26.58(9.38)	20.89(10.24)	0.28	$p < 0.001$	$p = 0.474$
AQ-10					
Partial/no exposure	3.49(2.65)	3.77(2.31)	0.02	F(1, 232)=0.542	F(1, 232)=1.267
Full exposure	4.07(2.62)	3.49(2.45)	0.16	$p = 0.462$	$p = 0.261$

AN=Anorexia nervosa, AQ-10=Autism Spectrum Quotient, short version, BMI=Body Mass Index, EDE-Q=Eating Disorder Examination Questionnaire, ES=Effect Size, HADS=Hospital Anxiety and Depression Scale, LMM= Linear mixed models, WSAS=Work and Social Adjustment Scale.

6.3.5 Secondary analysis 3: full exposure to PEACE versus no exposure to PEACE

6.3.5.1 Baseline characteristics

In secondary analysis 3, all patients admitted during the period when PEACE was not fully implemented yet (2017-2018) were excluded, leaving only patients with full exposure to the PEACE Pathway in the Full exposure group, and patients with no exposure to PEACE were allocated to the No exposure group. Table 6.7 summarises the baseline characteristics for secondary analysis 3. There was no significant difference between the Full exposure group and the No exposure group regarding age, gender, BMI on admission, duration of illness, number of comorbidities, and length of admission. Diagnosis was significantly different between the two groups and was therefore introduced as a covariate in the mixed models.

Table 6. 7 Baseline characteristics: patients in the 'full exposure' versus 'no exposure' groups (secondary analysis 3)

	Full exposure (n=92)	**No exposure (n=210)**
Age [years], mean (SD)	30.6 (13.0)	27.9 (10.6)
Gender: female, n (%)	89 (96.7%)	210 (100%)
Diagnosis, n (%)		
AN-restrictive	76 (82.6%)	124 (59%)
AN-binge purge	14 (15.2%)	58 (27.6%)
AN-atypical	0 (0.0%)	14 (6.7%)
BN	1 (1.1%)	9 (4.3%)
EDNOS	1 (1.1%)	5 (2.4%)
BMI on admission, mean (SD)	13.80 (1.49)	14.24 (1.82)
Duration of illness [years], mean (SD)	12.7 (11.2)	10.7 (8.9)
Number of comorbidities, mean (SD)	1 (1.4)	1(1.2)
Length of admission [weeks], mean (SD)	17.2 (14.3)	16.8 (14.1)

AN=anorexia nervosa; BN=bulimia nervosa; EDNOS=eating disorder not otherwise specified; BMI=Body Mass Index

6.3.5.2 Clinical outcomes

Table 6.8 summarises the results for secondary analysis 3. For the comparison of BMI improvement between Full exposure versus No exposure groups, only patients with an AN diagnosis were included. For other outcome measures, all ED diagnostic subtypes were included.

The results were all similar to the primary analysis (Table 6.2). Substantial improvement over time was observed in BMI, EDE-Q, HADS anxiety and depression, and WSAS in both Full exposure and No exposure groups, with no significant time x group interaction. Similar to the primary analysis, there was little change in the AQ-10 upon discharge with very small effect sizes in either group, with no significant time x group interaction.

Table 6. 8 Summary of outcome measures and linear mixed model results: secondary analysis 3 (full exposure vs no exposure)

Outcome	Admission	Discharge	ES	LMM	
	Mean (SD)	Mean (SD)	Cohen's *d*	Time	Time x Group
BMI (AN only)					
No exposure	13.95 (1.34)	16.08 (1.80)	1.45	F(1, 284)=514.8	F(1, 284)=0.006
Full exposure	13.74(1.29)	15.88(1.46)	1.46	$p < 0.001$	$p = 0.938$
EDE-Q					
No exposure	3.96 (1.58)	2.85 (1.64)	0.86	F(1, 163)=97.39	F(1, 163)=1.467
Full exposure	4.05(1.52)	2.79(1.43)	1.21	$p < 0.001$	p = 0.228
HADS-Anxiety					
No exposure	14.60 (4.47)	12.20 (5.09)	0.57	F(1, 145)=28.63	F(1, 145)=0.074
Full exposure	14.52(4.79)	11.97(4.27)	0.49	$p < 0.001$	$p = 0.786$
HADS-Depression					
No exposure	11.48 (5.04)	7.34 (5.04)	0.82	F(1, 171)=48.62	F(1, 171)=0.389
Full exposure	11.36(4.43)	8.19(3.88.)	0.57	$p < 0.001$	$p = 0.534$
WSAS					
No exposure	25.68 (8.67)	20.02 (10.51)	0.44	F(1, 256)=24.10	F(1, 256)=0.004
Full exposure	26.58(9.38)	20.89(10.24)	0.28	$p < 0.001$	$p = 0.949$
AQ-10					
No exposure	3.53 (2.61)	3.43 (2.36)	0.04	F(1, 171)=0.692	F(1, 171)=0.896
Full exposure	4.07(2.62)	3.49(2.45)	0.16	$p = 0.407$	$p = 0.345$

AN=Anorexia nervosa, AQ-10=Autism Spectrum Quotient, short version, BMI=Body Mass Index, EDE-Q=Eating Disorder Examination Questionnaire, ES=Effect Size, HADS=Hospital Anxiety and Depression Scale, LMM= Linear mixed models, WSAS=Work and Social Adjustment Scale.

6.4 Discussion

This chapter investigated the impact of the PEACE Pathway on the clinical outcomes of patients admitted to the SLaM ED inpatient service. In the primary analysis comparing the improvement in clinical outcomes between the PEACE and TAU groups (Objective 1), patients in both groups showed substantial and significant improvement in all clinical measures including BMI, ED symptoms, anxiety and depression symptoms, and work and social functioning. Patients' autistic characteristics stayed constant from admission to discharge in both PEACE and TAU. However, the main hypothesis was not supported as there were no statistically significant differences in the improvement of outcomes between the PEACE and TAU groups.

It should be noted, however, that patients in the PEACE group had consistently higher autistic characteristics (6.3.2.2.6), more serious work and social functioning difficulties (6.3.2.2.5), and more severe ED symptoms (6.3.2.2.2) on admission and discharge. On one hand, it's important to acknowledge that the severity of ED symptoms measured by the EDE-Q may not be entirely reliable, as it relies on self-reporting. Patients may be in denial about their symptoms, as indicated by predominantly below-threshold scores in both the PEACE and TAU groups. On the other hand, the self-reported difficulties in work and social functioning, along with higher levels of autistic characteristics (some of which may overlap with symptoms of starvation), could suggest that patients in the PEACE group generally presented with more severe symptoms of illness. Considering that the PEACE group and TAU group are essentially admissions from two different time periods, this indicates that patients' presentation at the SLaM ED service has become more severe and complex throughout the period of the audit. There are several possible explanations for this. First, it should be noted that the SLaM ED service is a national specialist service, which tends to accept the most severe and/or medically complex cases of ED among adults, owing to the tier service model used. Less severe cases are seen in community ED services or general mental health services. With the incidence of ED rising in the UK (Micali et al., 2013; Devoe et al., 2023), it is possible that an increasing number of patients with more severe presentation are being referred to national specialist ED services, hence the increased severity and complexity in patients' presentation at the SLaM ED service over this time period.

It is also possible that the COVID-19 outbreak contributed to the increase in severity in patients' presentation in the PEACE group. The onset of the pandemic in the UK was in March 2020, shortly after PEACE had been implemented in full. Many factors about the COVID-19 outbreak have potentially detrimental impacts on the psychological wellbeing of patients with ED, including disruption to living situations (Branley-Bell & Talbot, 2020) such as disrupted routine and increased social isolation, reduced access to mental health services and usual support networks (Brown et al., 2021), increased preoccupation with food and body image concerns due to changes in physical activity frequency (Robertson et al., 2021), and increased exposure to anxiety-provoking media (Rodgers et al., 2020). Thus, the overall exacerbated patient presentation in the PEACE group could be associated with the COVID-19 outbreak.

In secondary analysis 1 focusing on autistic patients only, the results were generally similar to the primary analysis, except for the AQ-10 scores which decreased significantly in autistic patients from admission to discharge, in both PEACE and TAU groups. There are several possible explanations for this. First, it should be noted that some of the items on the AQ-10 questionnaire aim to gauge central coherence (the ability to focus on the whole picture rather than small details) and cognitive flexibility, both are treatment targets of the Cognitive Remediation Therapy (CRT) (Dandil et al., 2020), which is part of the standard treatment provided at the SLaM ED service. Therefore, patients' scoring on the AQ-10 might have improved after receiving treatment that targets central coherence and flexibility specifically. To confirm this, future studies could further investigate which items on the AQ-10 changed significantly from admission to discharge. Alternatively, it is possible that the high autistic traits observed on admission in these patients were due to starvation because of their ED, and the traits reduced after proper nourishment and/or improvement of ED symptoms. Indeed, some studies have proposed that starvation in patients with ED is associated with higher autistic traits including restricted and repetitive behaviours and reduced communication skills (Stewart et al., 2017; Westwood &

Tchanturia, 2017). There is also evidence suggesting that autistic traits decreased in patients with AN after they were weight-recovered (Karjalainen et al., 2019). Thus, it is possible that the patients' high AQ-10 scores in the beginning of treatment in this study did not signify genuine autism, but the severity of their ED and the effects of starvation. However, it should be noted that their AQ-10 scores on discharge were still close to the threshold of 6 for possible autism (PEACE 5.66; TAU 5.58). Prospective studies are needed to investigate if the reduction in autistic characteristics persist into the longer run after discharge. Studies should also examine patients' developmental history to see if ED is preceded by autism or autistic traits, to rule out starvation effects.

In both secondary analyses 2 and 3, regrouping of the patients in PEACE and TAU groups based on their exposure to PEACE did not affect the results of the primary analysis. It should be emphasised, however, that patients' exposure to the pathway implementation is impossible to gauge, especially during the period when PEACE was gradually rolled out on the ward. It would be impossible, for example, to quantify the percentage of PEACE implementation after one component (e.g., the PEACE menu) was introduced, since different components may have different levels of impact on patients. This chapter attempted to quantify patient exposure based on their dates of admission and discharge and in which group they spent the majority of their admission (6.2.2) to give a best estimate, however patients' exact exposure is impossible to decide. More rigorous, controlled trials are needed to investigate the impact of the full implementation of the PEACE Pathway.

Lastly, the nature of PEACE Pathway adaptations needs to be considered. As described in Chapter 1 (1.2.3), the PEACE Pathway focused on meeting patients' needs mostly through environmental adaptations, raising autism awareness among clinicians, supporting sensory needs including providing a sensory-friendly alternative menu, and providing communication support. Although some of the PEACE training focused on adapting the language used in therapy, it did not directly alter the treatment itself or provide a different treatment for the ED. Therefore, it could be that the PEACE Pathway had more impact on patients' engagement in therapy or overall emotional and sensory wellbeing (see Chapter

5 Sensory Workshop Evaluation), rather than on the standard ED treatment outcomes. Indeed, adapting for autism may have more impact on outcomes that the co-occurring autism is associated with. The systematic review in Chapter 2 found that co-occurring autism does not directly impact ED symptoms or physical outcomes in ED, but instead has a negative impact on patients' engagement in group therapy, and can also lead to longer hospitalisation and increased use of intensive treatment (see section 2.4.1). The impact of PEACE on patients' service use has been assessed in the cost-savings analysis in Chapter 7, where shorter lengths of admissions were observed for autistic patients in the PEACE group compared to TAU. An earlier preliminary study of cost-savings of the PEACE Pathway also reported similar results (Tchanturia et al., 2021). This finding, combined with results in this chapter, may suggest that PEACE leads to shorter admissions for autistic patients without compromising treatment effect (as the improvement in outcomes was substantial in the PEACE group and not significantly different from TAU), although more rigorous and longitudinal studies are needed to confirm this.

6.4.1 Limitations

This evaluation has several limitations. First, all data was collected in a naturalistic setting as opposed to a trial, therefore the conditions of PEACE and TAU groups were not controlled. The lack of randomisation inevitably introduces bias in factors such as age, sex, geography, and illness severity. Where differences at admission were evident, they were added to the mixed models to adjust for these differences in order to try and minimise the potential biases. It is important to note that the data used in this study span a period of 10 years, during which significant service-wide changes may have taken place, potentially influencing admission characteristics. For instance, policy adjustments affecting intake criteria could lead to variations in the severity of presentation among admitted patients over the years. Similarly, the COVID-19 outbreak only affected the PEACE group but not the TAU group, creating barriers to interpretation of the results. However, it is challenging to assess these factors solely based on the audit database, which was the data source for this study. Future research could employ a realist evaluation design, incorporating not only clinical data but also policy documents and, if accessible, ward records. This holistic approach would allow for a comprehensive examination of contextual factors and their impact on patient outcomes. Furthermore, the substantial amount of missing discharge data for measures other than BMI limited our power to investigate effects. Therefore, it would be of interest to examine whether the same outcomes are obtained in a larger study with more complete data. Finally, patients' actual exposure to PEACE Pathway implementation, in reality, is affected by many factors other than their date of admission, for example the number of PEACE trainings and workshops their clinicians have attended at the time. It is therefore impossible to ascertain the exact degree of exposure due to lack of controlled settings, and patients in the PEACE group can have varying levels of actual exposure. Future controlled trials with more rigorous design are needed to investigate the effect of PEACE Pathway in comparison to standard treatment.

6.4.2 Considerations for future data collection

Suggestions and considerations for future data collection through a trial are summarised in this section. First, collecting more person-centred, ED-related quality of life measures should be considered, such as the Clinical Impairment Assessment proposed by an international group of scholars as a standard measure of quality of life and social functioning (Austin et al., 2023), which may be a more appropriate measure of the impact of the PEACE Pathway. Furthermore, future studies should assess patients' group participation and therapy engagement, since the PEACE Pathway introduced various resources to aid communication and improve engagement. Each component of the PEACE Pathway (e.g., the alternative menu, communication passport, sensory tools) should also be evaluated individually, as it is impossible to evaluate all using a uniform set of measures.

For all outcome measures, more follow-up points in the longer run should be considered to gauge the sustainability of PEACE-related improvements. Recent findings suggest that although ED treatments generally yield some improvements in body weight and psychological functioning, these effects are not maintained at follow-up (Ambwani et al., 2020). Future trials should investigate if PEACE Pathway patients' improvement in outcomes maintained in the longer run.

Chapter 7 Cost-savings analysis of the PEACE Pathway

7.1 Introduction

Following the clinical evaluation in Chapter 6, this chapter considers the cost-savings brought by the PEACE Pathway through reduction in service use in autistic patients. The cost-savings analysis extracted patients' service use data from the same data source as Chapter 6 – the clinical audit database at the SLaM ED service, which is introduced in more depth in Chapter 3 (3.3.1). Together with Chapter 6 (Clinical Evaluation) and Chapter 8 (Qualitative Evaluation), these three chapters provide a comprehensive evaluation of the PEACE Pathway as a whole treatment adaptation pathway.

7.1.1 Service context

The PEACE Pathway is implemented at South London and Maudsley (SLaM) Eating Disorders (ED) service. The service consists of several treatment components including an outpatient service, an inpatient service, and two day-patient programmes (Step-up to Recovery programme and Day Care programme).

Outpatient service

The SLaM Eating Disorders Outpatient Service is located at the Maudsley Hospital. Outpatient therapy for ED includes mainly individual sessions such as cognitive behavioural therapy for eating disorders (CBT-ED), guided self-help and psychoeducation, and other forms of individual therapy and group sessions. The goal of treatment is to maintain patients within the community, reduce weight fluctuations, and improve ED symptoms. Patients whose health is severely compromised by ED are admitted to higher intensity services, such as inpatient or day care services, so that medical stabilisation and refeeding can be initiated, for example.

Inpatient service

The Eating Disorders Inpatient Unit is located at the Bethlem Royal Hospital, separate from outpatient and day services at the Maudsley Hospital. The inpatient programme starts at seven days a week, including all meals and snacks, and in some cases periods of home leave are introduced gradually. The majority of patients admitted to the inpatient unit have a low weight and are diagnosed with anorexia nervosa (AN), bulimia nervosa (BN) or diabulimia (a combination of diabetes and bulimia). Patients who require inpatient care generally fall into four categories: (1) patients with rapid weight loss with evidence of physical system failure; (2) patients for whom outpatient treatment has not been sufficient; (3) patients with low weight who are not able to manage in daily life and require help with weight stabilisation; and (4) patients suffering from severe and medically unstable BN. Key outcomes of inpatient treatment include weight gain, medical stabilisation, and improvement in ED behaviours. The daily structure therefore is built around meal management and support, individual sessions with psychologists and occupational therapists, and group sessions.

Step-up to Recovery service

The Step-up to Recovery service (hereafter ‘Step-up’) is a day programme that originally ran from 8am to 8pm Monday to Friday, based at the Bethlem Royal Hospital inpatient unit (see below for recent changes). Step-up’s patient group includes low weight patients (with a BMI of 14 or less) who are medically stable and: (1) have just finished their inpatient admission and feel unprepared for life after discharge and may benefit from relapse prevention; or (2) have longstanding presentation and have had several first line interventions but want to avoid inpatient hospitalisation. Patients at Step-up may not be working on weight restoration but instead may focus on other recovery goals such as increasing independence, physical health improvements and activities of daily living.

Day Care service

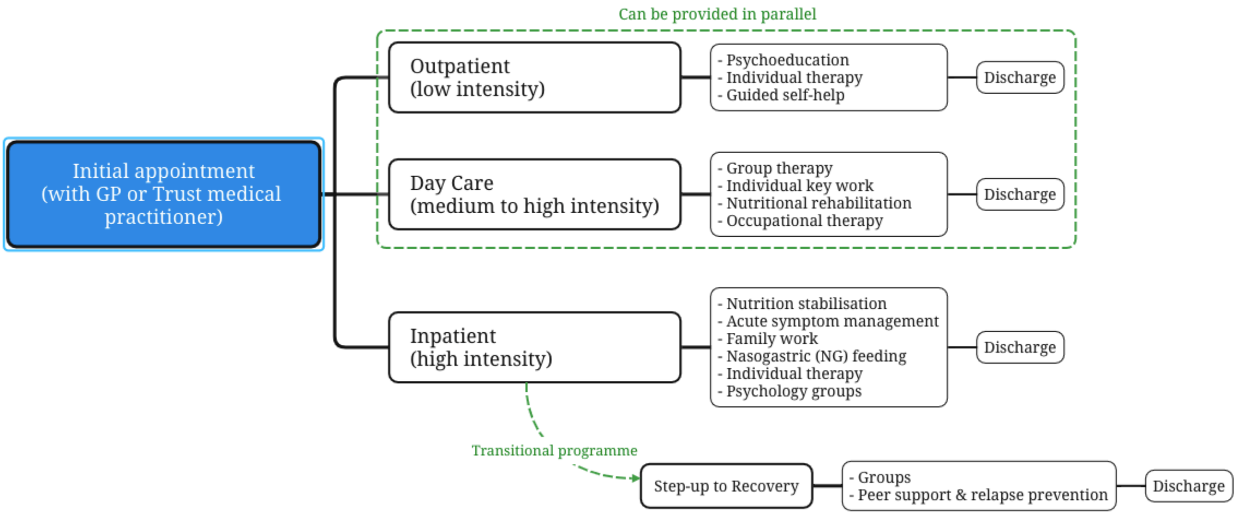
The SLaM Day Care service is a day programme based at the Maudsley Hospital that runs from 10am to 4pm Monday to Friday. The Day Care service accepts patients with a BMI of 16 or more (although people with a lower BMI can be accepted when appropriate) with any ED diagnosis who are medically stable and who: (1) are not showing progress in outpatient therapy and could benefit from intensifying the treatment; (2) are stepping down from inpatient treatment; (3) are deteriorating but not at a crisis point; or (4) have unaddressed needs that may benefit from intensifying treatment. Patients attending the Day Care service may be aiming for full weight restoration, or at a healthy weight with complex mental health needs. Typically, patients are offered a five-day-a-week therapy course for the first three months, dropping down gradually to two days per week by month six.

Day Services: integrating Step-up and Day Care

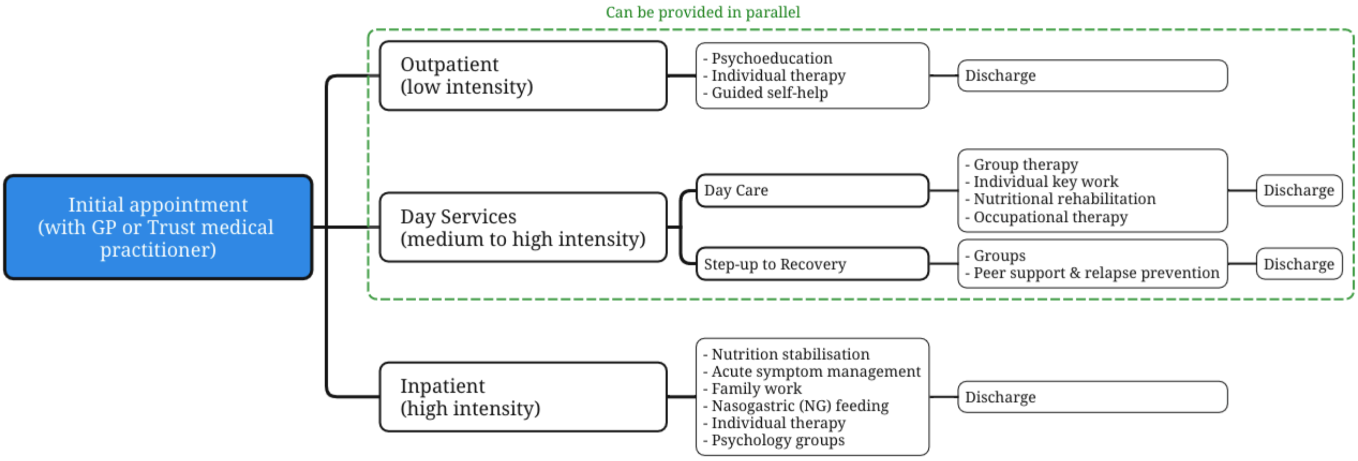
The Step-up and Day Care programmes were integrated in April 2021 to become the new ‘Day Services’, and both programmes relocated to a new building in the Maudsley Hospital, with the opening hours for Step-up changing to 10am to 4pm Monday to Friday to match Day Care hours. Their patient workloads stayed separate though, because of the difference in their treatment goals and patient weight thresholds; Step-up typically sees more patients at lower weight and/or with AN, whereas Day Care sees more patients with normal weight and a wider range of ED diagnoses (e.g., bulimia nervosa and binge-eating disorder). In terms of the course of treatment, both programmes mainly focus on group sessions while also providing one-to-one dietetic and occupational therapist sessions. Due to their similar structure and operating hours, Step-up and Day Care attendances are treated as a single Day Service for the purpose of costing.

Figure 7. 1 Pathway diagram

(a) Before integration of Step-up and Day Care:



(b) After integration of Step-up and Day Care:



7.1.2 PEACE Pathway implementation

PEACE was first developed at the SLaM Eating Disorder Service and King's College London and was funded by the Health Foundation (£75,000), an independent charity committed to bringing better healthcare for people in the UK (Ref: AIMS ID: 1115447) and the Maudsley Charity (£224,000). PEACE is the first systemic adaptation pathway for autistic people with ED (see Chapter 2 Systematic Review). Although the development and implementation of PEACE started in 2018 after funding was secured, training and research activities that raised autism awareness took place in the service in early 2017, including training on autism diagnosis, autism presentation in females, auditing outcomes, and assessment of 99 patients using the ADOS-2. More adaptations were introduced in 2018, and the full implementation of the PEACE Pathway started from January 2019.

Chapter 1 (section 1.2.3) provides a more detailed introduction to the development and components of the PEACE Pathway. In summary, the PEACE approach centres around autism friendly environmental adaptations, clinician training on autism assessment and knowledge, alternative sensory-friendly menu, and regular clinical 'huddles' (meetings) that promote case-by-case discussion and adaptations. Using guided materials (written and online at peacepathway.org), clinicians are supported to make individual adaptations in the structure and pace of sessions and around the individual's strengths that came with their autism. Expert guidance was also sought from the National Autistic Society (NAS) to ensure the treatment environment was autism friendly. In 2020, the inpatient unit became the first ED service in the UK to be accredited by NAS for providing high-quality care for autistic people, followed by accreditation of the Outpatient and Day Services in 2021. It was nominated for the 'Acute Service Redesign Initiative of the Year' in the 2021 Health Service Journal Value Awards.

In 2020, PEACE started to be rolled out to South-West London & St George's Adults Eating Disorders Service, where staff received training and started to join SLaM clinical huddles regularly. In 2022, Buckinghamshire, Oxfordshire and Berkshire West Sustainability Transformation Partnership started adapting and implementing the PEACE Pathway for young people. If the PEACE Pathway is found to be effective and cost-effective, national adoption of PEACE may be warranted to reduce the current "postcode lottery" in autistic people's access to adapted and individualised care.

7.1.3 Impact of Covid-19

It is necessary to consider the impact of the COVID-19 outbreak as PEACE implementation overlapped with the pandemic. In the beginning of the outbreak, the SLaM ED inpatient service went into official lockdown on 24 March 2020. This was in line with the national discharging requirements and closure of hospitals to all but urgent and emergency care. Clinical review of all admitted patients was conducted using revised discharge criteria (discharging patients who have not reached the level of severity requiring 24-hour care (NHS England, 2020)). Out of the 15 patients on the SLaM ED inpatient ward prior to lockdown, 10 were discharged early in preparation for ward closure. The remaining five patients were relocated to the Avalon Ward at South West London and St George's Mental Health NHS Trust which remained open with a limited capacity during COVID-19. The relocated patients continued to receive remote support from the psychology team at the SLaM inpatient service.

The SLaM inpatient service reopened in June 2020 with a staggered return of patients, prioritising severe and urgent cases. The ward did not reach full capacity (15 patients) until March 2021. During the staggered return period, physical distancing and other government containment strategies were still active. Ward visits were limited or banned from time to time, depending on the policy in force at the time. These disruptions inevitably affected the quality of care, in line with the challenges reported in other services in the UK (Chen et al., 2020) and globally (Li, 2020). In addition, professional and community support for autistic people was greatly limited during the pandemic (Oomen et al., 2021), further limiting options for clinicians when planning discharge for autistic patients at the ED service.

In addition to the immediate impacts of the pandemic, it is possible that the outbreak could have consequences that persist into the longer run (Propper et al., 2020). The reduced availability and quality of hospital care during the pandemic, when staff were focused on treating COVID-19 patients, led to significant backlogs and longer waits for patients. In addition, staffing shortages persisted, due to the diminished attractiveness of working in the NHS and difficulty in recruiting from overseas following Brexit (Propper et al., 2020). The latest figures in July 2023 showed that around 7.68 million people were waiting for NHS treatment, of whom around 390,000 had waited over a year, 308 times as many as in July 2019 before the pandemic began (British Medical Association, 2023). With EDs, long waiting times are particularly problematic, since they are linked to worsened symptoms while waiting and poorer treatment outcomes (Allen et al., 2023).

7.1.4 Previous evidence of cost savings

In 2020, a preliminary analysis of the impact of PEACE on hospitalisations and the associated cost of supporting patients with co-morbid autism in the SLaM ED service was conducted using existing audit data at the service and national average unit costs (Tchanturia et al., 2021). This work, which is reproduced in Appendix 7.1, was led and supported by my co-supervisors, KT and SB, drafted by co-author YD and reviewed by KS and ML, whilst I collected the data and carried out the analyses.

In this study, which used data for patients prior to the onset of COVID-19, we collected data on hospital admissions from clinical records for six years before PEACE was introduced (1st of January 2012 to 31st December 2017) and two years after PEACE was introduced (1st of January 2018 to 31st December 2019) for ED patients with diagnosed or suspected autism. Results indicated that the mean length of inpatient admission for autistic patients was 90 days after PEACE implementation compared to 133 days before PEACE implementation, resulting in estimated cost-savings of approximately £22,837 per patient and £275,000 per year for the service. Building on these preliminary results, the current analysis provides a more detailed estimate of costs and cost savings by collecting a broader range of mental health service use data (SLaM inpatient, outpatient, step-up, and day care) for a larger sample of patients who were followed up for 12 months after their admission.

7.2 Methods

7.2.1 Aims and objectives

The aim of this analysis was to explore the impact of the PEACE Pathway on length of inpatient admission, use of specialist day patient and outpatient ED services, and associated costs, for adults with ED admitted to SLaM inpatient service, both with and without autism. Participants were followed-up for 12-months from the point of inpatient admission. Based on the results of our preliminary analysis (Tchanturia et al., 2021), it was hypothesised that the PEACE Pathway would result in cost savings to the SLaM ED service for patients with ED and autism by reducing the length of inpatient admissions (the main cost driver in ED populations; Byford et al., 2007; Byford et al., 2019; Schmidt et al., 2016) for autistic patients. It was also hypothesised that the overall costs incurred by the service (inpatient, day patient and outpatient attendances combined) would be lower for autistic patients after PEACE was introduced compared with before. Costs related to non-autistic patients' service use before and after PEACE implementation were also explored, but without a pre-determined hypothesis due to the lack of relevant research evidence.

Specifically, the objectives were as follows:

1. To examine costs of service use (including inpatient, day services and outpatient attendances) over a 12-month period in autistic and non-autistic patients at SLaM ED service before and after PEACE implementation.
2. To investigate any cost savings generated over a 12-month period by reduced service use for autistic patients after PEACE implementation compared with before PEACE implementation.
3. To investigate objectives 1 and 2 in different hypothetical scenarios: (1) excluding admissions during the Covid-19 lockdown; and (2) alternative grouping of patients based on the degree of their exposure to PEACE implementation.

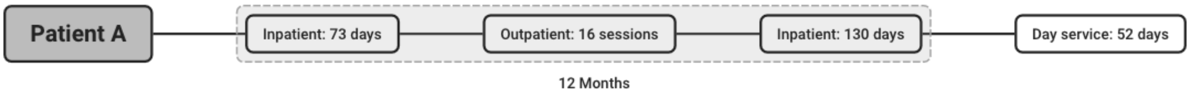
7.2.2 Service use data and unit costs

7.2.2.1 Service use

Patients' service use data was retrieved from clinical audit data at the SLaM inpatient ED service, including service use data for patients admitted to the inpatient ward during the five years before PEACE Pathway instigation (1 January, 2012 to 31 December, 2016) and the five and a half years after (1 January, 2017– 31 July, 2022). Each patient's service use was collected for the period 12 months since their index inpatient admission, to include any subsequent post-discharge admissions to the Step-up service, the Day Care service, the outpatient ED service, and inpatient readmissions within 12 months. This data was extracted by the audit data manager (ZL) from patients' clinical records. Length of inpatient admission was calculated from dates of admission and discharge on patients' records. Number of day service attendances was manually counted from clinical notes because days spent in day care changed over time as patients 'dropped-down' from 5 days per week to fewer, so it was not possible to rely on dates of admission and discharge. Similarly, number of outpatient attendances, which included outpatient psychology sessions such as CBT, one-off occupational therapy or dietetic sessions, or post-discharge follow ups and medical reviews, was manually counted from clinical notes.

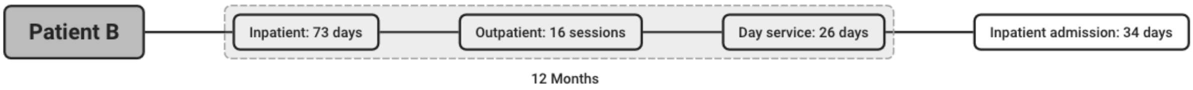
Only services received during the 12-months since index inpatient admission were recorded, thus inpatient admissions that continued beyond the 12-month period for an individual patient were truncated. For patients whose index inpatient admission exceeded one year, their inpatient days were recorded as 365 days because the remaining days exceeded follow up period. Below are some examples to illustrate this process (with the light grey window representing the 12-month follow up period):

Patient A:



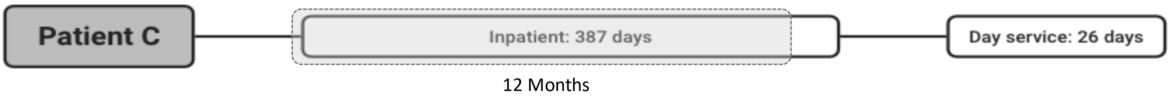
Patient A’s service use at 12-month follow up: 203 inpatient days (73+130) and 16 outpatient sessions. Day service attendance not counted as it occurred outside of the follow-up period.

Patient B:



Patient B’s service use at 12-month- follow-up: 73 inpatient days, 16 outpatient sessions, and 26 day service days.

Patient C:



Patient C’s service use at 12-month follow up: 365 inpatient days (the remaining inpatient days exceeded the 12-month follow up period and therefore were not counted).

7.2.2.2 Unit costs

In order to estimate the cost of these services, unit costs were needed for application to each category of service use data (inpatient, outpatient and day care). Our previous work applied unit costs from the NHS National Cost Collection (NHS England, 2019) to estimate costs of inpatient admissions at SLaM ED service (Tchanturia et al., 2021). However, the current evaluation required unit costs for a broader range of services, including day services, which are not recorded explicitly in the National Cost Collection. Rather, inpatient and day cases are not differentiated in the National Cost Collection which only gives one reference cost for both under ‘admitted patients’. Since it is unlikely that Day Care costs are as high as inpatient costs, and with no information on the relative percentage of inpatient versus day care (which would have allowed estimation of the unit cost of each service), the decision was made to use local costs sourced directly from SLaM. This included unit costs per day for inpatient admissions and day services (including Step-up and Day Care), and unit cost per attendance for outpatient services. All costs were for the 2022/2023 financial year and included:

- Inpatient admission at the SLaM ED service: £484 per night
- Day services at the SLaM ED service: £281 per day
- Outpatient attendance at SLaM ED service: £157 per attendance

7.2.3 Other data

7.2.3.1 Demographics

Patients' date of admission and date of discharge were extracted from the audit to enable grouping of patients into treatment-as-usual (TAU; before PEACE implementation began) and PEACE (after PEACE implementation began) groups. The method of patient grouping matches that described for the clinical evaluation (see Chapter 6, Section 6.2.2 for details).

7.2.3.2 Autism Spectrum Quotient, short version (AQ10; Allison et al., 2012)

The AQ10 is a short 10-item scale that measures traits of autism, such as auditory sensitivity and interpersonal difficulties. A score of 6 or higher indicates possible autism. Patients' AQ10 scores were extracted from the audit to separate patients into autistic and non-autistic groups, so that service use can be analysed separately for these two patient populations.

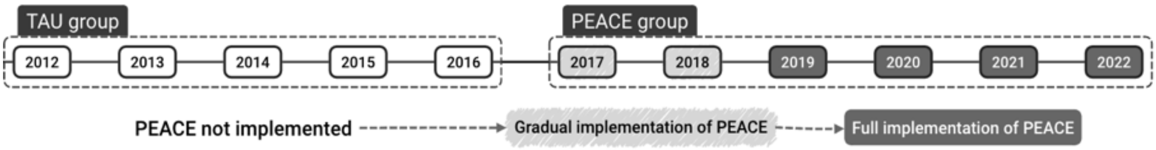
7.2.4 Data analyses

7.2.4.1 Service use and costs

All service use were costed for each individual participant by applying the unit costs described in Section 7.2.2.2, to estimate a total 12-month cost per participant (Objective 1). Both service use and the associated cost data in the dataset were first examined for extreme outliers. Any non-natural outliers (e.g., due to data entry errors) were corrected if possible (e.g., where the correct data was available in the clinical records) and deleted if not. Natural outliers (e.g., patients who engage with the service for a longer period of time) were kept because they were clinically meaningful in this naturalistic study.

7.2.4.2 Primary analysis

Patients were grouped into PEACE and TAU groups in the same approach as the clinical evaluation (6.2.2.2): Admissions from January 2012 to December 2022 were separated into a PEACE group, comprising of patients admitted after PEACE was initiated, and a treatment as usual (TAU) group comprising of patients admitted before PEACE implementation. For a comparison of baseline characteristics between PEACE and TAU groups, see Table 6. 1. Baseline characteristics: PEACE and TAU groups.



Data analysis was conducted separately for autistic patients (those scoring above or equal to 6 on the AQ10) and non-autistic patients (those scoring below 6 on the AQ10). This trait-focused approach aligns with the PEACE approach and prevents the exclusion of underdiagnosed patients. Underdiagnosis of autism is prevalent in adult women, who represent the majority of patients admitted to adult ED services. Previous studies have identified a gender disparity in autism diagnosis, highlighting that women and girls who meet the criteria for autism are at a high risk of not receiving a diagnosis (Loomes et al., 2017). Therefore, a trait-focused approach is favoured in this analysis rather than only including those with diagnosed autism, to prevent the exclusion of underdiagnosed patients who may otherwise be overlooked.

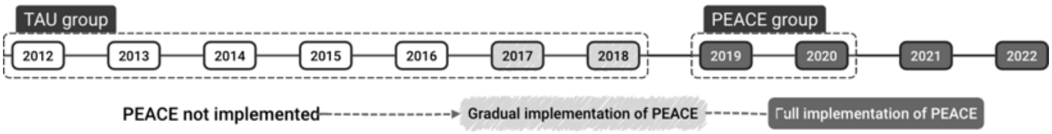
In the primary analysis, costs per patient at the 12-month follow-up were compared between the two patient groups (PEACE vs TAU) using standard T-tests (Objective 2), with the robustness of the results confirmed using non-parametric bootstrapping (1000 iterations). Cost data is often skewed as a result of a typically small proportion of patients who are very high cost, compared to a much larger proportion who are relatively low cost. The advantage of bootstrapping as a way to analyse such skewed data is that, unlike alternative approaches such as logarithmic transformation or non-parametric tests, the focus of the analysis is the arithmetic mean; the arithmetic mean is the most useful statistic for healthcare policy decisions, since only this will allow a policy maker to estimate the likely total cost, by multiplying the arithmetic mean by the population with a particular disorder (Barber & Thompson, 2000). Results therefore reported means rather than medians, given that means are generally preferred in health economic evaluations due to their suitability for parametric analyses and policy decision-making.

7.2.4.3 Secondary analyses

The naturalistic audit data used in this analysis is inherently prone to environmental influences, which create a lot of uncertainties. First, the COVID-19 outbreak affected all aspects of service use from admission, through treatment and to discharge. Second, the rolling out of the PEACE Pathway was a gradual process, making it impossible to gauge patients' exact degree of exposure during its implementation period. For the purpose of the evaluation, therefore, three scenarios have been considered in order to explore potential costs and cost savings that may be generated by PEACE, dependent on the assumptions made in the primary analysis (Objective 3). These assumptions were that: (a) the pandemic had no influence on the pattern of service use and thus the cost of participants in the study; and (b) that the impact of the PEACE Pathway would be the same irrespective of partial or full exposure (i.e., would be the same for those admitted at the very beginning of the implementation of the pathway as for those fully exposed to all elements of the pathway):

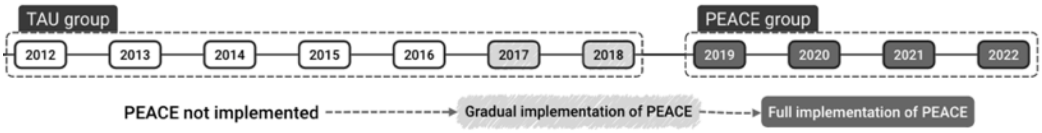
Secondary analysis 1: Adjusting for the impact of COVID-19

The SLaM ED service went into COVID-19 lockdown in March 2020, and its function and capacity did not recover until March 2021. Meanwhile, the long-term consequence of the pandemic persists into the longer run even after 2021. In order to adjust for the impact of these pandemic-related changes on the results of the current analyses, the primary analysis was repeated but excluded data for all patients discharged prematurely in March 2020 due to lockdown and all admissions after that. This approach provides an estimate of cost savings prior to the outbreak of COVID-19.



Secondary analysis 2: No or Partial exposure versus Full exposure to PEACE

The primary analysis grouped patients according to the date at which the PEACE Pathway began to be implemented (No versus Partial or full exposure to PEACE). The inclusion of those only partially exposed in the PEACE group may dilute the effect of the pathway and so a secondary analysis was carried out where the PEACE group only included patients admitted after PEACE was fully implemented in 2019 and admissions before that formed the TAU group (No or Partial exposure versus Full exposure to PEACE).



Secondary analysis 3: No exposure versus Full exposure to PEACE

A further comparison was undertaken to remove the impact of partial exposure to PEACE altogether by removing those participants who received only partial exposure – No exposure versus Full exposure.

7.3 Results

7.3.1 Participants

In total, there were 356 patients with complete service use data in the audit database. Three patients died during the 12-month follow-up period and thus were excluded. This left 353 patients to be included in the primary analysis

(PEACE n=169; TAU n=184). The sample size for the PEACE and TAU groups varied in secondary analyses depending on how patients were grouped. Table 7.1 reports the sample sizes for the PEACE and TAU groups in the primary analysis and the three secondary analyses, alongside the number and percentage of participants with and without autism according to the AQ10. Table 7.2 reports the number and percentage of participants with and without autism admitted each year from January 2012 to July 2022, which suggests that over this period, an average of 9 patients with autism and 25 patients without autism were admitted to the inpatient service each year.

Table 7. 1 Number (percentage) of autistic and non-autistic patients in the PEACE and TAU groups for the primary and secondary analyses

Total	Autism	No autism
Primary analysis		
PEACE (n=169)	PEACE (n=53)	PEACE (n=116)
TAU (n=184)	TAU (n=41)	TAU (n=143)
Secondary analysis 1		
PEACE (n=102)	PEACE (n=35)	PEACE (n=67)
TAU (n=184)	TAU (n=41)	TAU (n=143)
Secondary analysis 2		
PEACE (n=99)	PEACE (n=26)	PEACE (n=73)
TAU (n=254)	TAU (n=68)	TAU (n=186)
Secondary analysis 3		
PEACE (n=99)	PEACE (n=26)	PEACE (n=73)
TAU (n=184)	TAU (n=41)	TAU (n=143)

Table 7. 2 Distribution of autistic and non-autistic patients admitted each year from 2012 to 2022 (primary analysis)

Year	Autism	No autism
2012	11	29
2013	7	23
2014	9	29
2015	9	43
2016	12	22
2017	15	20
2018	5	24
2019	10	23
2020	7	16
2021	6	22
2022 (up to July)	3	8
Total	94	259
Mean	9	24

7.3.2 Primary analysis

7.3.2.1 Service use

Table 7.3 reports use of services over the 12-month follow-up for the total sample and for patients with and without autism, using the samples determined by the primary analysis. For the total sample, use of all services was higher in the period after PEACE had begun to be implemented (the PEACE group), compared to the period before PEACE (the TAU group). Results were similar for the non-autistic patients, who spent more time in hospital in the PEACE group compared to the TAU group (mean 131 versus 120 nights), attended more day services (mean 25 versus 13) and had more outpatient attendances (mean 6 versus 3 contacts). However, whilst autistic patients in the PEACE group also had more day service contacts (mean 22 versus 14 contacts) and more outpatient attendances (mean 9 versus 2 contacts) than the TAU group, the PEACE group spent less time in inpatient admission than the TAU group (mean 127 versus 141 nights).

Table 7. 3 Service use over the 12-month follow-up period (primary analysis)

Service	PEACE (n=169)	TAU (n=184)
Total sample		
Inpatient (nights)	130	125
Step-up (contacts)	17	8
Day Care (contacts)	7	4
Outpatient (contacts)	7	3
Autism		
Inpatient (nights)	127	141
Step-up (contacts)	14	10
Day Care (contacts)	8	4
Outpatient (contacts)	9	2
No Autism		
Inpatient (nights)	131	120
Step-up (contacts)	19	8
Day Care (contacts)	6	5
Outpatient (contacts)	6	3

7.3.2.2 Costs

Table 7.4 reports the mean total costs and costs by service type for the total sample and for patients with and without autism over the 12-month follow up period. For the total sample, all of the observed costs were higher in the PEACE group compared to TAU. This was mainly driven by the sample of participants without autism, where the observed costs of both inpatient and community services were higher in the PEACE group compared to TAU, resulting in overall higher total costs per participant (mean £71,434 PEACE versus £62,112 TAU), although this difference was not significant (mean difference £9,322, 95% CI [-884, 19528], p=0.073).

In the sample of autistic participants, mean observed costs per patient were higher for all community services (Table 7.4) but were lower overall (mean £69,438 PEACE versus £72,443 TAU) as a result of lower inpatient costs (mean £61,797 PEACE versus £68,456 TAU). However, these differences were only significant for outpatient costs (mean difference £1,137, 95% CI [411, 1863], *p*=0.003). On average total costs per patient were £3,005 lower in the PEACE group compared to the TAU group, producing estimated annual savings of approximately £27,000, given an average of nine patients with autism admitted per year (Section 7.3.1).

Table 7. 4 Cost (£) per patient over the 12-month follow-up period (primary analysis)

	PEACE			TAU					
Service	**Mean (SD)**	**Minimum**	**Maximum**	**Mean (SD)**	**Minimum**	**Maximum**	**Mean difference**	**95% CI**	**p-value**
Total sample	**PEACE (n=169)**			**TAU (n=184)**					
Inpatient	62952 (42587)	8712	176660	60358 (41703)	4840	176660	+2594	-6234, 11421	0.564
Step-up	4880 (11792)	0	62663	2372 (6585)	0	46646	+2508	482, 4534	0.015
Day Care	1907 (6596)	0	33439	1226 (4946)	0	34844	+681	-549, 1910	0.277
Outpatient	1069 (2215)	0	11618	458 (1132)	0	5809	+611	237, 985	0.001
Total	70808 (43343)	10164	176660	64414 (41788)	4840	176660	+6394	-2520, 15308	0.159
Autism	**PEACE (n=53)**			**TAU (n=41)**					
Inpatient	61797 (44393)	10164	176660	68456 (45611)	13552	176660	-6659	-25218, 11899	0.478
Step-up	3945 (10213)	0	57605	2721 (7983)	0	46646	+1224	-2622, 5069	0.529
Day Care	2322 (7067)	0	33439	1028 (4010)	0	18827	+1294	-1003, 3591	0.266
Outpatient	1374 (2540)	0	11304	237 (643)	0	2355	+1137	411, 1863	0.003
Total	69438 (45176)	10164	176660	72443 (45657)	13552	176660	-3005	-21753, 15743	0.751
No autism	**PEACE (n=116)**			**TAU (n=143)**					
Inpatient	63479 (41922)	8712	176660	58036 (40384)	4840	176660	+5443	-4665, 15551	0.290
Step-up	5308 (12465)	0	62663	2272 (6154)	0	32877	+3036	534, 5537	0.018
Day Care	1717 (6393)	0	29786	1283 (5195)	0	34844	+434	-983, 1852	0.547
Outpatient	930 (2047)	0	11618	522 (1232)	0	5809	+408	-18, 835	0.061
Total	71434 (42666)	12100	176660	62112 (40488)	4840	176660	+9322	-884, 19528	0.073

7.3.3 Secondary analysis 1: Adjusting for COVID-19

7.3.3.1 Service use

In this secondary analysis which attempted to remove the impact of COVID-19, the PEACE group consisted of 102 patients who were not affected by the pandemic outbreak, and the TAU group remains the same as for the primary analysis (184 patients). Table 7.5 reports use of services over the 12-month follow-up for the total sample and for patients with and without autism, using the samples determined by the secondary analysis to adjust for COVID-19 impact. For the total sample, there was no difference in the length of inpatient admission for the PEACE group compared to the TAU group (125 days for both groups). However, autistic patients in the PEACE group spent considerably less time in inpatient admission than the TAU group (mean 115 versus 141 nights) and had a greater number of day service contacts (mean 19 versus 14 contacts) and outpatient attendances (mean 7 versus 2 contacts). Non-autistic patients in the PEACE group spent more time in hospital than the TAU group (mean 131 versus 120 nights), attended more day services (mean 28 versus 13) and had more outpatient attendances (mean 5 versus 3 contacts).

Table 7. 5 Service use over the 12-month follow-up period (secondary analysis 1: adjusting for COVID-19)

Service	PEACE (n=102)	TAU (n=184)
Total sample		
Inpatient (nights)	125	125
Step-up (contacts)	16	8
Day Care (contacts)	9	4
Outpatient (contacts)	6	3
Autism		
Inpatient (nights)	115	141
Step-up (contacts)	9	10
Day Care (contacts)	10	4
Outpatient (contacts)	7	2
No Autism		
Inpatient (nights)	131	120

Step-up (contacts)	19	8
Day Care (contacts)	9	5
Outpatient (contacts)	5	3

7.3.3.2 Costs

Table 7.6 reports the mean costs for the total sample and for patients with and without autism over the 12-month follow up period. Similar to the primary analysis, mean observed costs per autistic patient were higher in the PEACE group for most community services (Table 7.6) but were lower overall (mean £61,998 PEACE versus £72,443 TAU) as a result of lower inpatient costs (mean £55,591 PEACE versus £68,456 TAU). However, these differences were only significant for outpatient costs (mean difference £799, 95% CI [81, 1517], p=0.03). On average, total costs per patient were £10,445 lower in the PEACE group compared to the TAU group, producing estimated annual savings of approximately £104,450, given an average of ten patients with autism admitted per year for this sample. In the sample of participants without autism, the observed costs of both inpatient and community services were higher in the PEACE group compared to TAU, resulting in overall higher total costs per participant (mean £71,855 PEACE versus £62,112 TAU). Similar to the primary analysis, this difference was not significant (mean difference £9,743, 95% CI [-2250, 21735], p=0.107).

Table 7. 6 Cost (£) per patient over the 12-month follow-up period (secondary analysis 1: adjusting for COVID-19)

	PEACE			TAU					
Service	**Mean (SD)**	**Minimum**	**Maximum**	**Mean (SD)**	**Minimum**	**Maximum**	**Mean difference**	**95% CI**	**p-value**
Total sample	**PEACE (n=102)**			**TAU (n=184)**					
Inpatient	60600 (40568)	8712	176660	60358 (41703)	4840	176660	+242	-9794, 10278	0.962
Step-up	4441 (11355)	0	62663	2372 (6585)	0	46646	+2069	-352, 4490	0.093
Day Care	2518 (7478)	0	33439	1226 (4946)	0	34844	+1292	-339, 2922	0.120
Outpatient	914 (1961)	0	11618	458 (1132)	0	5809	+456	38, 874	0.033
Total	68473 (41187)	10164	176660	64414 (41788)	4840	176660	+4059	-6043, 14161	0.430
Autism	**PEACE (n=35)**			**TAU (n=41)**					
Inpatient	55591 (39688)	10164	176660	68456 (45611)	13552	176660	-12866	-32579, 6848	0.198
Step-up	2665 (6551)	0	25571	2721 (7983)	0	46646	-55	-3430, 3320	0.974
Day Care	2706 (7318)	0	33439	1028 (4010)	0	18827	+1678	-1106, 4461	0.232
Outpatient	1036 (2016)	0	6594	237 (643)	0	2355	+799	81, 1517	0.030
Total	61998 (41077)	10164	176660	72443 (45657)	13552	176660	-10445	-30443, 9554	0.301
No autism	**PEACE (n=67)**			**TAU (n=143)**					
Inpatient	63216 (41071)	8712	176660	58036 (40384)	4840	176660	+5180	-6671, 17031	0.390
Step-up	5368 (13140)	0	62663	2272 (6154)	0	32877	+3097	-258, 6452	0.070
Day Care	2420 (7612)	0	29786	1283 (5195)	0	34844	+1137	-901, 3174	0.271
Outpatient	851 (1944)	0	11618	522 (1232)	0	5809	+329	-185, 843	0.207
Total	71855 (41145)	12100	176660	62112 (40488)	4840	176660	+9743	-2250, 21735	0.107

7.3.4 Secondary analysis 2: No or Partial exposure versus Full exposure to PEACE

7.3.4.1 Service use

In this secondary analysis, the PEACE (Full exposure) group consisted of 99 patients, and TAU (No or Partial exposure to PEACE) group consisted of 254 patients. Table 7.7 reports the use of services over the 12-month follow-up for the total sample and for patients with and without autism. For the total sample, patients in the PEACE group spent more time in hospital than the TAU group (mean 131 versus 126 nights), attended more day services (mean 26 versus 15) and had more outpatient attendances (mean 8 versus 4 contacts). However, autistic patients in the PEACE group spent less time in inpatient admission than the TAU group (mean 121 versus 139 nights), but had a greater number of day service contacts (mean 20 versus 18 contacts) and outpatient attendances (mean 11 versus 4 contacts). Non-autistic patients in the PEACE group spent more time in hospital than the TAU group (mean 135 versus 121 nights), attended more day services (mean 29 versus 15) and had more outpatient attendances (mean 7 versus 4 contacts).

Table 7. 7 Service use over the 12-month follow-up period (secondary analysis 2)

Service	PEACE (n=99)	TAU (n=254)
Total sample		
Inpatient (nights)	131	126
Step-up (contacts)	20	10
Day Care (contacts)	6	5
Outpatient (contacts)	8	4
Autism		
Inpatient (nights)	121	139
Step-up (contacts)	16	11
Day Care (contacts)	4	7
Outpatient (contacts)	11	4
No Autism		
Inpatient (nights)	135	121

Step-up (contacts)	22	10
Day Care (contacts)	7	5
Outpatient (contacts)	7	4

7.3.4.2 Costs

Table 7.8 reports the mean costs for the total sample and for patients with and without autism over the 12-month follow up period. For the sample of autistic participants, mean observed costs per patient were higher for Step-up and outpatient services (Table 7.8) but were lower overall (mean £65,763 PEACE versus £72,655 TAU) as a result of lower inpatient (mean £58,564 PEACE versus £67,048 TAU) and Day Care costs (mean £1,092 PEACE versus mean £2,012 TAU). The cost differences were not statistically significant. On average, total costs per autistic patient were £6,892 lower in the PEACE group compared to the TAU group, producing estimated annual savings of approximately £62,028, given an average of nine patients with autism admitted per year (Section 7.3.1). In the sample of participants without autism, the observed costs of both inpatient and community services were higher in the PEACE group compared to TAU, resulting in overall higher total costs per participant (mean £74,312 PEACE versus £63,138 TAU). This difference was not significant (mean difference £11,174, 95% CI [-94, 22,442], p=0.052).

Table 7. 8 Cost (£) per patient over the 12-month follow-up period (secondary analysis 2)

	PEACE			TAU					
Service	**Mean (SD)**	**Minimum**	**Maximum**	**Mean (SD)**	**Minimum**	**Maximum**	**Mean difference**	**95% CI**	**p-value**
Total sample	**PEACE (n=99)**			**TAU (n=254)**					
Inpatient	63428 (44231)	10164	176660	60887 (41291)	4840	176660	+2542	-7276, 12360	0.611
Step-up	5631 (13323)	0	62663	2770 (7404)	0	46646	+2861	55, 5667	0.046
Day Care	1768 (6549)	0	29505	1468 (5487)	0	34844	+300	-1052, 1653	0.663
Outpatient	1239 (2567)	0	11618	561 (1278)	0	6594	+678	143, 1213	0.013
Total	72067 (45323)	10164	176660	65686 (41444)	4840	176660	+6381	-3537, 16299	0.207
Autism	**PEACE (n=26)**			**TAU (n=68)**					
Inpatient	58564 (49025)	10164	167464	67048 (43242)	13552	176660	-8484	-29040, 12072	0.414
Step-up	4453 (12689)	0	57605	3012 (7672)	0	46646	+1441	-2822, 5702	0.504
Day Care	1092 (5566)	0	28381	2012 (6094)	0	33439	-920	-3648, 1806	0.504
Outpatient	1655 (3034)	0	11304	582 (1393)	0	6594	+1073	-192, 2337	0.093
Total	65763 (50479)	10164	167464	72655 (43214)	13547	176597	-6892	-27639, 13855	0.511
No autism	**PEACE (n=73)**			**TAU (n=186)**					
Inpatient	65161 (42623)	13552	176660	58634 (40440)	4840	176660	+6527	-4641, 17695	0.251
Step-up	6051 (13602)	0	62663	2681 (7323)	0	41869	+3370	31, 6708	0.048
Day Care	2009 (6885)	0	29505	1269 (5252)	0	34844	+740	-825, 2306	0.409
Outpatient	1090 (2386)	0	11618	553 (1237)	0	5809	+538	-46, 1121	0.071
Total	74312 (43494)	13552	176660	63138 (40599)	4840	176660	+11174	-94, 22442	0.052

7.3.5 Secondary analysis 3: No exposure versus Full exposure to PEACE

7.3.5.1 Service use

In this analysis, the PEACE (Full exposure) group consisted of 99 patients, and TAU (No exposure to PEACE) group consisted of 184 patients. Table 7.9 reports the use of services over the 12-month follow-up for the total sample and for patients with and without autism. In the total sample, patients in the PEACE group spent more time in hospital than the TAU group (mean 131 versus 125 nights), attended more day services (mean 26 versus 12) and had more outpatient attendances (mean 8 versus 3 contacts).

Table 7. 9 Service use over the 12-month follow-up period (secondary analysis 3)

Service	PEACE (n=99)	TAU (n=184)
Total sample		
Inpatient (nights)	131	125
Step-up (contacts)	20	8
Day Care (contacts)	6	4
Outpatient (contacts)	8	3
Autism		
Inpatient (nights)	121	141
Step-up (contacts)	16	10
Day Care (contacts)	4	4
Outpatient (contacts)	11	2
No Autism		
Inpatient (nights)	135	120
Step-up (contacts)	22	8
Day Care (contacts)	7	5
Outpatient (contacts)	7	3

However, the autistic patients in the PEACE group spent less time in hospital than the TAU group (mean 121 versus 141 nights). They had a greater number of day service contacts (mean 20 versus 14 contacts) and outpatient attendances (mean 11 versus 2 contacts). Non-autistic patients in the PEACE group spent more time in hospital than the TAU group (mean 135 versus 120 nights), attended more day services (mean 29 versus 13) and had more outpatient attendances (mean 7 versus 3 contacts). This contributed to the general trend in the total sample, the majority of which were non-autistic patients.

7.3.5.2 Costs

Table 7.10 reports the mean costs for the total sample and for patients with and without autism over the 12-month follow up period. For the sample of autistic participants, mean observed costs per patient were higher for all community services (Table 7.10) but were lower in total costs (mean £65,763 PEACE versus £72,443 TAU) as a result of lower inpatient cost (mean £58,564 PEACE versus £68,456 TAU). However, these differences were only significant for outpatient costs (mean difference £1,418, 95% CI [178, 2656], p=0.027). On average, total costs per autistic patient were £6,680 lower in the PEACE group compared to the TAU group, producing estimated annual savings of approximately £60,120, given an average of nine patients with autism admitted per year (Section 7.3.1). In the sample of participants without autism, all types of observed costs were higher in the PEACE group compared to TAU, resulting in significantly higher total costs per non-autistic participant (mean £74,312 PEACE versus £62,112 TAU; mean difference £12,200, 95% CI [426, 23973], p=0.048).

Table 7. 10 Cost (£) per patient over the 12-month follow-up period (secondary analysis 3)

	PEACE			TAU					
Service	**Mean (SD)**	**Minimum**	**Maximum**	**Mean (SD)**	**Minimum**	**Maximum**	**Mean difference**	**95% CI**	**p-value**
Total sample	**PEACE (n=99)**			**TAU (n=184)**					
Inpatient	63428 (44231)	10164	176660	60358 (41703)	4840	176660	+3070	-7382, 13523	0.564
Step-up	5631 (13323)	0	62663	2372 (6585)	0	46646	+3259	441, 6079	0.024
Day Care	1768 (6549)	0	29505	1226 (4946)	0	34844	+542	-822, 1906	0.435
Outpatient	1239 (2567)	0	11618	458 (1132)	0	5809	+781	243, 1317	0.005
Total	72067 (45323)	10164	176660	64414 (41788)	4840	176660	+7653	-2911, 18216	0.155
Autism	**PEACE (n=26)**			**TAU (n=41)**					
Inpatient	58564 (49025)	10164	167464	68456 (45611)	13552	176660	-9892	-33402, 13617	0.404
Step-up	4453 (12689)	0	57605	2721 (7983)	0	46646	+1732	-3304, 6768	0.495
Day Care	1092 (5566)	0	28381	1028 (4010)	0	18827	+64	-2275, 2402	0.957
Outpatient	1655 (3034)	0	11304	237 (643)	0	2355	+1418	178, 2656	0.027
Total	65763 (50479)	10164	167464	72443 (45657)	13552	176660	-6680	-30497, 17137	0.577
No autism	**PEACE (n=73)**			**TAU (n=143)**					
Inpatient	65161 (42623)	13552	176660	58036 (40384)	4840	176660	+7125	-4543, 18793	0.230
Step-up	6051 (13602)	0	62663	2272 (6154)	0	32827	+3779	454, 7105	0.026
Day Care	2009 (6885)	0	29505	1283 (5195)	0	34844	+726	-924, 2376	0.387
Outpatient	1090 (2386)	0	11618	522 (1232)	0	5809	+568	-22, 1160	0.059
Total	74312 (43494)	13552	176660	62112 (40488)	4840	176660	+12200	426, 23973	0.048

7.3.*6* *Trend* in length of stay for patients with and without autism

In addition, to visualise the trend in the length of inpatient admission by year for patients with and without autism, bar graphs are produced for the samples used in the primary analysis (Figure 7.2) and secondary analysis 1 (Figure 7.3) individually. These figures show variation in length of inpatient admission over time. However, the general trend for those without autism was for lengths of admissions to reduce over time between 2012 and 2015 and to increase over time from 2016 to 2020. Admissions dropped in the second year of the pandemic (2021), then showed an increase back to pre-pandemic levels in 2022. In contrast, admissions for those with autism remained relatively stable between 2012 and 2016 but showed a general reduction over time from 2017 up until the start of the COVID-19 pandemic. Admissions for patients with autism during the pandemic (2020-2021) were high but dropped back down to pre-pandemic levels in 2022.

Figure 7. 2 Mean length of inpatient admission by year for patients with and without autism (primary analysis; same sample used for secondary analyses 2 and 3)

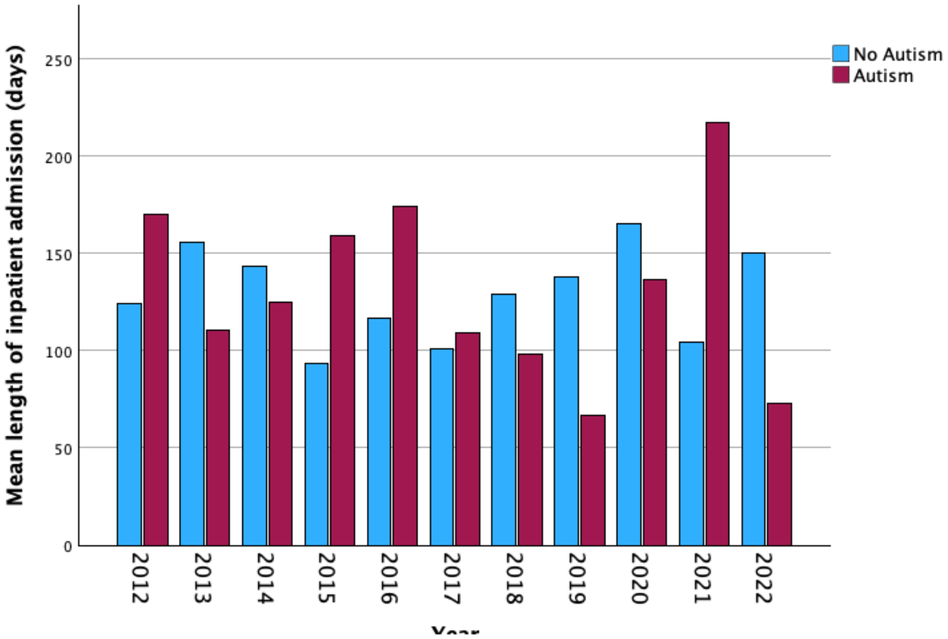
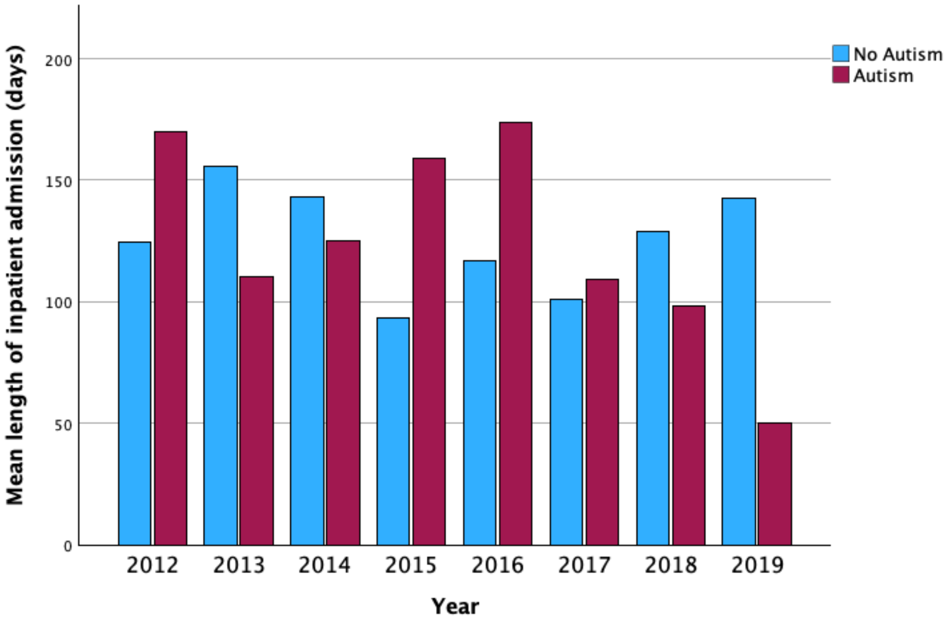


Figure 7. 3 Mean length of inpatient admission by year for patients with and without autism (secondary analysis 1)



7.3.7 Summary of results

Table 7.11 below summarise the results from the main analysis and the three secondary analyses for the total sample as well as for autistic and non-autistic patients individually. For autistic patients, the primary analysis and all secondary analyses show lower total costs in the PEACE group compared to the TAU group. Estimated cost savings were lowest for the primary analysis (approximately £3,000 per participant with autism) and highest when adjusting for the impact of COVID-19 (over £10,000 per participant with autism. Cost-savings were driven by lower lengths of inpatient hospitalisation after PEACE implementation, which were partially, but not wholly, offset by increases in day service and outpatient attendance costs. In contrast, total costs were higher for the non-autistic group after PEACE compared to before PEACE, as a result of increasing lengths of inpatient admissions over time.

Table 7. 11 Summary of cost differences for PEACE versus TAU

Service	N	PEACE Mean (SD)	N	TAU Mean (SD)	Mean difference	95% CI	p-value
Total sample							
Main analysis	169	70808 (43343)	184	64414 (41788)	+6394	-2520, 15308	0.159
Secondary analysis 1	102	68473 (41187)	184	64414 (41788)	+4059	-6043, 14161	0.430
Secondary analysis 2	99	72067 (45323)	254	65686 (41444)	+6381	-3537, 16299	0.207
Secondary analysis 3	99	72067 (45323)	184	64414 (41788)	+7653	-2911, 18216	0.155
Autism							
Main analysis	53	69438 (45176)	41	72443 (45657)	-3005	-21753, 15743	0.751
Secondary analysis 1	35	61998 (41077)	41	72443 (45657)	-10445	-30443, 9554	0.301
Secondary analysis 2	26	65763 (50479)	68	72655 (43214)	-6892	-27639, 13855	0.511
Secondary analysis 3	26	65763 (50479)	41	72443 (45657)	-6680	-30497, 17137	0.577
No autism							
Main analysis	116	71434 (42666)	143	62112 (40488)	+9322	-884, 19528	0.073
Secondary analysis 1	67	71855 (41145)	143	62112 (40488)	+9743	-2250, 21735	0.107
Secondary analysis 2	73	74312 (43494)	186	63138 (40599)	+11174	-94, 22442	0.052
Secondary analysis 3	73	74312 (43494)	143	62112 (40488)	+12200	426, 23973	0.048

Main analysis: Full+Partial PEACE versus No PEACE

Secondary analysis 1: Full+Partial PEACE versus No PEACE and excluding participants impacted by COVID-19 (will only affect PEACE sample)

Secondary analysis 2: Full PEACE versus No+Partial PEACE

Secondary analysis 3: Full PEACE versus No PEACE

7.4 Discussion

Using retrospective audit data of patients' service use at SLaM ED services, this analysis provided an estimate of costs associated with patients' ED service use over a 12-month period after the date of their hospital admission, and potential cost-savings for patients with co-morbid ED and autism resulting from the implementation of the PEACE Pathway and subsequent reductions in the length and cost of inpatient admissions for this population.

7.4.1 Costs and cost-savings: autistic patients

Based on the primary analysis, PEACE was estimated to generate total cost savings of £3,005 per autistic patient, or £6,659 per autistic patient if considering the cost of inpatient hospitalisations alone. Overall, the estimated cost-savings per year were £27,000. Shorter lengths and lower cost of admissions for autistic patients were observed despite increases higher use and cost of day and outpatient services and despite the general trend in the population as a whole for admission lengths to increase over time, which was also evident in the earlier analysis focused on inpatient admissions alone (Tchanturia et al., 2020a). The observed increase in the use of community services does not necessarily indicate heavier service burden or negative patient outcomes. Rather, day patient treatment has been shown to have financial and clinical advantages over inpatient care, being non-inferior and less costly (Fittig et al., 2008; Herpertz-Dahlmann et al., 2014; Zipfel et al., 2002). A previous randomised controlled trial (RCT) comparing inpatient treatment with specialist outpatient treatment, home treatment and three other services demonstrated similar improvement in symptoms across the services, but lower costs, greater patient satisfaction and fewer readmissions for services other than inpatient admissions (Kwok et al., 2016). Another RCT carried out in the UK, which evaluated specialist outpatient eating disorders services for children and adolescents compared with both inpatient admissions and generic child and adolescent mental health services, also concluded that specialist outpatient treatment had a higher probability of being cost-effective compared with inpatient treatment, as a result of lower costs alongside similar outcomes (Byford et al., 2007). Considering this evidence to suggest day services and outpatient treatments are non-inferior, less costly and potentially cost-effective compared to inpatient treatment, patients' increased engagement with day patient and outpatient services could be seen as a positive change following PEACE implementation.

However, these studies were focused on ED populations in general, rather than those with comorbid ED and autism, so it is important to consider whether non-inferiority of day or outpatient care compared with inpatient admissions is also true for autistic patients. A previous study using data from the SLaM ED service found that high autistic traits were a negative predictor of improvement in ED symptoms in day patient settings, but a positive predictor in inpatient settings (Li et al., 2020). The authors proposed two possible explanations: (1) the day service was essentially a group programme, and autistic individuals who struggle with social interactions and socio-emotional understanding may struggle with the group-oriented structure, and (2) the treatment protocol at day services maintains strict boundaries (i.e., weight, attendance and group contribution) that patients need to adhere to, and autistic individuals may find this challenging due to their heightened cognitive rigidity and preference for their own sets of routines. Indeed, studies have demonstrated that autistic adults' needs are not met adequately in traditional healthcare services (Gilmore et al., 2022; Kinnaird et al., 2019). It is possible that the implementation of the PEACE Pathway at the SLaM Day Care programme introduced an individualised approach that lowered boundaries for autistic patients to engage in treatment, therefore improving their attendance, but further research is needed to compare the impact of the Day Care programme on outcomes.

7.4.1.1 Secondary analyses

All three secondary analyses produced larger estimated cost-savings than the primary analysis. In secondary analysis 1, which excluded all admissions affected by COVID-19 (those discharged early in March 2020 due to lockdown and all admissions after March 2020), the estimated cost-savings per year were £104,450, more than 3 times larger than the cost-savings in the primary analysis. This suggests that the pandemic outbreak had a substantial impact on service use in autistic patients, possibly increasing their lengths of stay in hospital and driving up the costs. There are three possible ways that the pandemic can lead to longer hospitalisation for autistic patients in the ED service. First, previous studies reported that autistic individuals' mental health worsened during the pandemic (Bundy et al., 2022; Oomen et al., 2021; Pellicano et al., 2022), possibly due to increased levels of uncertainty and changes and disruptions to routines and self-regulation and barriers to fulfilling basic needs (Bundy et al., 2022). Similarly, increased severity of ED symptoms and increased risk and vulnerability have been reported during the pandemic for people with ED (Fernández-Aranda et al., 2020). Thus, autistic people who were admitted to the ED service during COVID-19 may already be in a worse condition than pre-pandemic times and needed longer periods of intensive support. Second, the pandemic disruptions may have altered the quality of care provided (Li, 2020); lockdowns, physical distancing and other containment strategies, staff shortages, and limiting/eliminating visits could all have a negative impact on the quality of care. This may lead to a slower recovery in patients. Third, professional and community support for autistic people was greatly limited during the pandemic (Oomen et al., 2021). The type of support that was interrupted ranged from medical and mental health support to household support. Therefore, clinicians in the ED service faced much more limited options for services to discharge patients to, and patients may therefore have been retained for longer on the ward to facilitate their recovery. Overall, the negative impact of COVID-19 on patient admissions at the ED service encompassed multiple aspects, making it impossible to estimate the impact of PEACE during the pandemic. The results of secondary analysis 1 suggest that PEACE may produce much larger cost-savings than the primary analysis, which included patients during COVID-19, implies.

The degree of PEACE Implementation may also play a role in the level of cost savings generated. With the exception of secondary analysis 1, which adjusted for the impact of COVID-19, secondary analysis 3 generated the largest inpatient cost-savings, when only including participants with full exposure to PEACE in the PEACE group, compared with participants with no exposure to PEACE. This suggests that the benefits of the PEACE Pathway are higher when PEACE is implemented fully. It should be noted however that the small sample sizes of autistic patients in secondary analyses 2 and 3 make it difficult to reach any firm conclusion. Considerations for future data collection are outlined in section 7.4.5.

7.4.2 Resource use and costs: non-autistic patients

Any trend in service use in non-autistic patients likely reflects the overall trend at the SLaM ED service, since non-autistic patients make up the majority of admissions (73.4% in the main analysis, 73.4-76.1% in the secondary analyses). In the primary and all of the secondary analyses, use of all services was higher for non-autistic patients after PEACE was implemented, compared with before implementation, in line with the results for the total sample overall. Considering that the PEACE group and TAU group are essentially admissions from two different time periods, this indicates that non-autistic patients' service use has increased at the SLaM ED service throughout the period of the audit. This is further supported by Figures 7.2 and 7.3 in section 7.3.6, where the length of hospitalisation for non-autistic patients showed an increasing trend from year 2015 to 2020. There is a temporary drop in both the length and number of non-autistic admissions (Table 7.2) in 2021, but this may be due to the surge in length of admission for autistic patients in the second year of the pandemic which may have contributed to limited capacity on the ward. Alternatively, it may be due to efforts to minimise lengths of admission as a result of COVID-19 restrictions and perhaps to deal with increased demand for admissions following the closure of inpatient wards in 2020.

This trend in length of admission at the SLaM ED service contradicts findings in previous work. For example, one study using time series analysis to examine routinely collected data on all NHS hospitals in England over 22 years found a reduction of 26.4% in length of stay for all common psychiatric disorders (ED included) from 1998/99 to 2019/20 (Degli Esposti et al., 2022). According to the same study, length of stay for ED decreased nationally by 12.5% from 2015/16 to 2019/20. Another study examined length of hospitalisation in AN globally using a systematic approach and found that overall length of stay decreased over time from 116 days to 85 days between 1990 and 2019 (Kan et al., 2021). Our findings in the opposite direction may be explained by several factors. Firstly, it should be noted that the SLaM ED service is a national specialist ED service, which tends to take on more severe and medically unstable patients than other general psychiatric services. With the rise in prevalence of ED and inpatient admissions in the UK (Micali et al., 2013; Devoe et al., 2023), it is possible that ED services and general psychiatric services nationally are facing increased pressure to discharge people quickly due to limited overall capacity. This may lead to an increasing number of patients with more severe presentation being referred to national specialist ED services, hence the increased average length of admission at the SLaM ED service over this time period.

Alternatively, it is possible that admissions in the PEACE group had a generally more complex presentation than the TAU group. Evident from the data in Chapter 6 (Clinical Evaluation; 6.3.2), patients admitted in the period 2017 to 2022 (the PEACE group) had generally more severe ED symptoms, more serious work and social functioning difficulties, and higher autistic characteristics at admission than admissions before 2017. The impact of COVID-19 should also be considered here. Previous work has suggested that the effects of the pandemic could persist into the longer run, with particular challenges around staff shortages and waiting times (Propper et al., 2020). Long waiting times are particularly problematic, since they are linked to worsened symptoms while waiting and poorer treatment outcomes (Allen et al., 2023). Therefore, the overall worse presentation and increased service use in the PEACE group for the total sample could be associated with the pandemic outbreak. This is also evident in the data in Table 7.11, where the difference between PEACE and TAU in the mean costs for the total sample decreased after excluding COVID-19 cases (Primary analysis: £6,394 versus Secondary analysis 1: £4,059).

It is unlikely that PEACE Pathway implementation itself would increase the length of admission of non-autistic patients. The focus of the PEACE Pathway is on adapting communication and sensory elements in treating autistic patients, and does not alter the structure of standard treatment provided at the SLaM ED service. Furthermore, the improvement in treatment individualisation and increased availability of support materials at the ED service could be beneficial to all patients, and not limited to autistic patients (see Chapter 8 Qualitative

Interview of Clinicians). The only additional time clinicians regularly allocate to PEACE-related activities is for the huddle meetings which run for one to two hours per month. This extra time dedicated to autism-specific discussions should not affect clinicians' capability to treat non-autistic patients, although future research should investigate the impact of PEACE implementation on resource allocation between autistic and non-autistic patients.

Since investigation of contributing factors for longer hospitalisation is beyond the scope of this study, data should be continuously collected at SLaM ED services to observe any changes in the trend in length of hospitalisation and its association with clinical characteristics. Nevertheless, autistic patients' reduction in length of stay after PEACE implementation may be more significant when viewed in the context of the generally increasing length of stay at the SLaM ED service.

7.4.3 Non-cash benefits

The estimated cost-savings in this study should be considered together with benefits of PEACE Pathway that are not immediately cashable. First, although increased engagement at day patient and outpatient services does not bring immediate cashable savings (except in so far as it is associated with reduced admission lengths), it contributes to a more cost-effective treatment network in the long run. The treatment environment at day patient and outpatient services also brings fewer disruptions to patients' life outside hospital than inpatient admission, including to their social life, family life, and to their studies or working life. From a government perspective, the flow of patients from inpatient to day/outpatient treatment may bring savings in incapacity benefits and extra taxes resulting from more people being able to work. Second, social benefits brought by PEACE through increasing autism awareness and advocacy across the service should be considered. In 2019, the NHS Long Term Plan (https://www.longtermplan.nhs.uk/) highlighted improving care for autistic people (with a focus on mental health) as a priority, recognising the stigma and barriers that autistic people face when accessing care. The PEACE Pathway's efforts in improving autism recognition and awareness, service user involvement, and evidence-based design are all important steps in systematically improving care for autistic people with ED. This benefit is hard to measure but may be of great importance nevertheless. Third, the impact of the PEACE Pathway on clinician and patient experience might not have an easily estimated value but can be considered through qualitative evaluation. For example, the qualitative review chapter (Chapter 5) provides a richer understanding of the PEACE Pathway's positive impact, including improved understanding of service user perspectives, improved patient engagement, increased flexibility and confidence in clinicians and increased team collaboration. All these benefits may not be easily monetised but are important to include in the full picture when considering the PEACE Pathway's impact on quality of care.

In addition, there may be other sources of cost-savings that are outside the scope of this analysis. ED is a chronic illness that has protracted complications and patients are often high consumers of health and social care services (van Hoeken & Hoek, 2020). This study only covers the use of SLaM inpatient, day patient and outpatient ED services, but use of community services, medical care or any services outside the SLaM trust, and their associated costs/cost-savings have been excluded and are therefore unknown. Apart from treatment costs, the costs of the disorder may also involve financial burden and loss of earnings for both patients and their carers. How these costs relate to PEACE implementation is unknown and should be assessed in future research, including the impact of the regular support provided to carers by the PEACE Pathway (Kinnaird et al., 2021).

7.4.4 Strengths and limitations

This study used naturalistic clinical data to explore costs and cost savings, which provides a more realistic insight into patients' service use. However, this also limits its ability to reach any firm conclusions about cost-effectiveness of the PEACE Pathway. It is important to acknowledge that the cost-savings identified in this study were relatively modest, and there was no significant difference observed between the PEACE and TAU groups regarding the reduction in length of admission for autistic patients. As such, it is crucial to interpret the study results cautiously. They primarily offer preliminary evidence of potential cost-savings and serve as a basis for generating hypotheses for future well-designed trials. Moreover, since the study was conducted solely in one setting (SLaM ED service), the generalisability of the findings to other clinical settings may be limited until more robust trials are undertaken. Furthermore, while lengths of inpatient admissions are straight forward to count, the way outpatient and day patient attendances are manually recorded by clinicians on electronic systems leaves room for inaccuracy. It is therefore recommended that more granular information should be collected from day patient and outpatient services when conducting future trials.

7.4.5 Considerations for future data collection

For future data collection through a trial, relevant data of interest includes: baseline patient characteristics, treatment use including any inpatient, outpatient and day patient attendances, use of other hospital and community health and social care services, and routine clinical outcome measures (such as body mass index and assessments of ED symptoms). To support assessment of cost-effectiveness, consideration should also be given to the inclusion of a health-related quality of life measure capable of generating quality adjusted life years (QALYs) (e.g. the EQ-5D measure of health-related quality of life (Herdman et al., 2011) preferred by the National Institute for Health and Care Excellence) . Alternatively, cost-effectiveness can be assessed using clinical outcome measures, such as a global functioning assessment (e.g., the Global Assessment of Functioning scale (Hall, 1995) or the Morgan-Russell outcome assessment schedule (Morgan & Hayward, 1988) which has been used in previous trials (Byford et al., 2007)). Although measures of ED symptoms, such as the EDE-Q, are already collected by the service, they would not be the most suitable outcome measure for an economic evaluation as the PEACE Pathway does not specifically target recovery from ED, hence a broader measure of functioning or quality of life is needed.

Lastly, when considering scaling up of the PEACE Pathway to other services, it is crucial to investigate whether other ED services are similar to SLaM and have adequate resources to implement PEACE. ED services vary greatly across UK. Previous multi-centre studies have highlighted the differences in demand, capacity and outcomes between specialist ED services in just one catchment area (e.g. Ayton et al., 2022). Therefore, future efforts in scaling up PEACE Pathway should consider these differences and plan the best methods for implementation.

Chapter 8 Qualitative evaluation of the PEACE Pathway: clinicians' perspective

8.1 Introduction

Following the clinical evaluation (Chapter 6) and cost-savings analysis (Chapter 7) of the PEACE Pathway, this chapter concludes the thesis with a qualitative evaluation of clinicians' experiences in PEACE implementation. The development of PEACE started with qualitative needs assessment with all stakeholders including clinicians (Kinnaird et al., 2017), carers (Adamson et al., 2020), and patients themselves (Babb et al., 2021; Brede et al., 2020; Kinnaird et al., 2019b). These early studies highlighted needs for environmental adjustments, clinician education and training in autism, refeeding programme adaptations to accommodate sensory sensitivities, tools to address communication difficulties and improve patient engagement, and improved recognition and understanding of autism within ED services. In an attempt to respond to these concerns, the PEACE Pathway introduced adaptations such as autism screening, environmental changes, sensory tools and psychoeducation, clinician training on autism assessment and autism awareness, alternative menus, and communication support (see 1.2.3 for details). To ensure consistent implementation of the adaptations, PEACE also introduced regular 'huddle' meetings to facilitate communication and case discussions between the multidisciplinary health professional teams at the ED service (Smith & Tchanturia, 2020). Preliminary evaluation of survey feedback has shown that 92% of trained clinicians agreed that their knowledge and skills improved and 97% agreed that the training sessions should be recommended to other ED clinicians (Tchanturia et al., 2020). Five years into PEACE implementation, it is imperative that the practicalities and challenges in PEACE implementation are fully explored in this evaluation. This chapter, therefore, aims to investigate the clinical team's experience of implementing the PEACE Pathway in greater depth through qualitative interviews.

When introducing adaptations to evidence-based interventions, transparent reporting of what does or does not work is essential, to ensure that the adapted intervention is acceptable, feasible and maximises benefits for patients. Seeking feedback from clinicians is critical to this process (Duggleby et al., 2020), especially since clinicians delivering the intervention are the default decision-makers regarding fidelity and adaptation once an intervention has been implemented. In the development of PEACE Pathway, qualitative feedback from stakeholders is regularly consulted to ensure that the adaptations made are acceptable and appropriate (Adamson et al., 2020; Kinnaird et al., 2019b; Kinnaird et al., 2017). However, adapting an intervention is often a dynamic process, as the context in which adaptations are made constantly changes (Campbell et al., 2020). In this study, specifically, we investigated multidisciplinary clinicians' thoughts about the following:

- Objective 1: Benefits of the PEACE Pathway;
- Objective 2: Barriers in the PEACE Pathway;
- Objective 3: Areas where further improvement is needed.

8.2 Methods

8.2.1 Participant selection

Semi-structured interviews were conducted with multidisciplinary clinicians who worked at the SLaM ED service between 2017 and 2022, when the PEACE Pathway was implemented at the service. A meeting was conducted first with the principal investigator of the PEACE Pathway (KT) to identify clinicians working at the service during this time period with good knowledge and involvement with the PEACE Pathway (i.e., participated in PEACE Pathway training and regular meetings). A list of potential interviewees with varied roles representative of the multidisciplinary team was identified (for example, counselling psychologists, consultant psychiatrists, psychology assistants, dietitians, family therapists, and occupational therapists). All potential interviewees identified were invited by ZL by email to participate in the study. The invitation email explained the purpose of the study and that clinicians were invited based on their involvement with the PEACE Pathway. Clinicians who expressed interest then received an information sheet and a consent form to be signed if they agreed to be interviewed. Written consent was acquired prior to interviews, including consent for the interview to be recorded. Copies of the information sheet and consent form are available in the Appendix 8.1. Ethical approval was granted by the College Research Ethics Committee at King's College London (Reference: MRSP-21/22-28800).

8.2.2 Interviews

Participants were interviewed face to face or online, depending on clinicians' preference. During the interview, a topic guide was used to ask participants the following questions:

1. Could you tell me about your involvement with the PEACE Pathway? (Gatekeeping question to gauge participant's involvement and identify focus points for follow-up questions)
    - Follow up: how did you find the [PEACE component that the participant mentioned in their reply to Question 1]? Helpful (Objective 1) or unhelpful (Objective 2)?

2. Was there anything from the training that really stuck with you? (To gauge participant's exposure to PEACE Pathway training)

3. Have you used the [communication passport/PEACE menu/sensory tools/autism screening/PEACE website/PEACE book] during clinical practice? (To ask about PEACE resources other than those mentioned by the participant in their reply to Question 1)
    - Follow up: how helpful (Objective 1) or unhelpful (Objective 2) did you find them?

4. Do you have any suggestions for how the PEACE Pathway can be improved? (Objective 3)

The interviewer also used follow up questions asking for elaboration and examples to obtain further details after asking the main interview questions. All interviews lasted between 30 minutes and one hour. Recordings of the interviews were then transcribed verbatim with all identifying information removed at the point of transcription. The interviews continued until no new information emerged, indicating data saturation.

8.2.3 Analysis

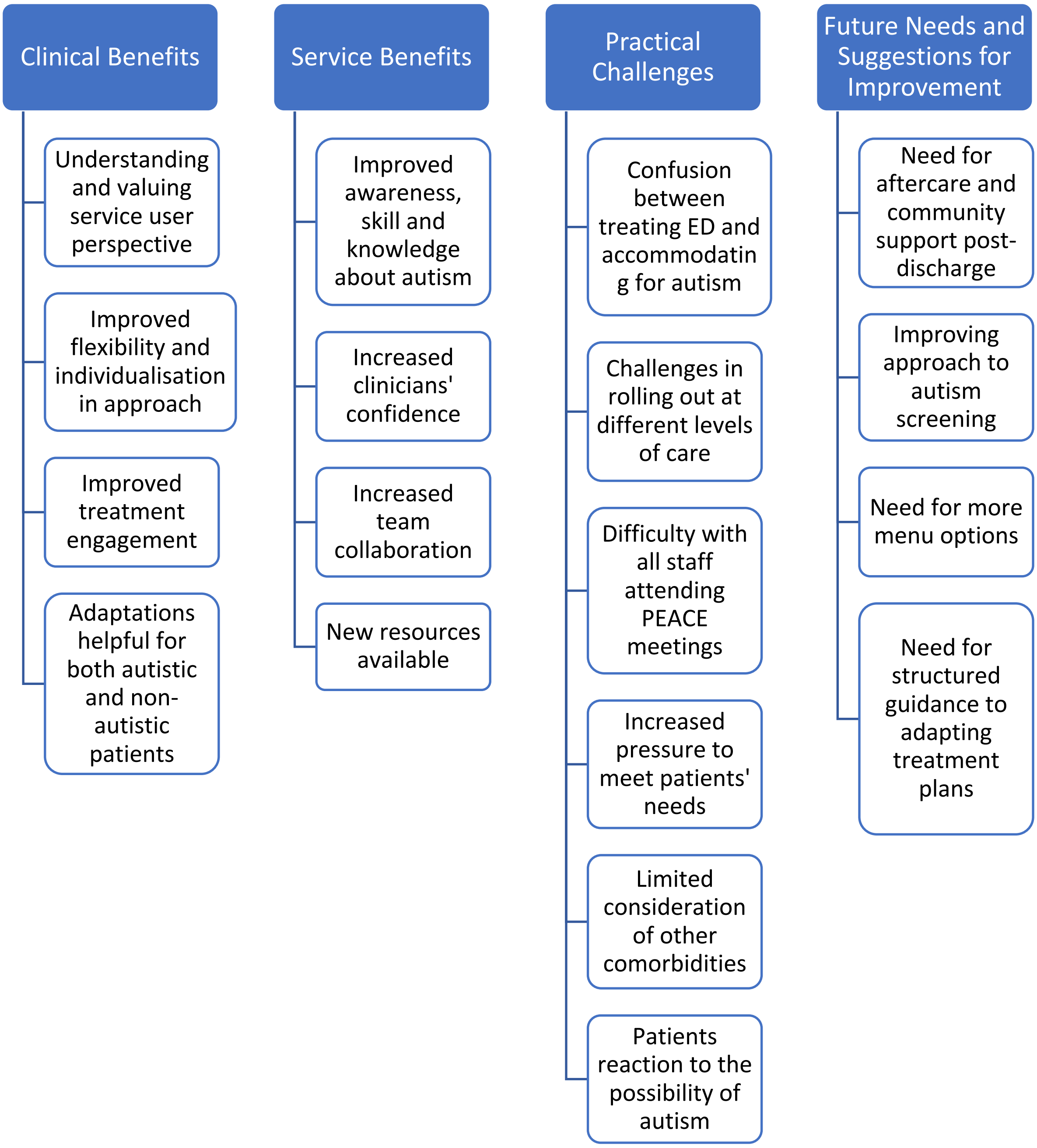
Interview data were analysed in NVivo 12 using thematic analysis (Braun & Clarke, 2006, 2021). Firstly, transcripts were read and reread by ZL and Chloe Hutchings-Hay for content familiarisation. Initial codes and preliminary themes were generated independently and then discussed by ZL and Chloe Hutchings-Hay. Preliminary themes were then reviewed and modified by scrutinising the data associated with each theme in the context of the entire data set. Finalised themes were re-worded for clarification where appropriate, and the relationship between themes and subthemes were checked for overlap. All results are reported according to the Consolidated Criteria for REporting Qualitative studies (COREQ) checklist (Tong et al., 2007).

8.3 Results

In total, 16 clinicians were approached, consented and interviewed before data reached saturation. The sample consisted of 4 psychology assistants (2 from inpatient setting and 2 from outpatient and day service), 2 counselling psychologists (both from inpatient setting), 2 consultant psychiatrists (1 from inpatient and 1 from outpatient and day service), 2 family therapists (1 from inpatient and 1 from outpatient and day service), 2 occupational therapists (both from outpatient and day service but with previous experience in the inpatient setting), 3 dietitians (2 from inpatient setting and 1 from outpatient and day service), and 1 clinical psychologist (from inpatient setting), representing the multidisciplinary team structure at the SLaM ED service. Clinicians all had experience treating patients with co-occurring ED and autism. Among the participants, 12 (75%) were female and 4 (25%) were male.

Four main themes emerged from the analysis: clinical benefits, benefits to the service, practical challenges, and areas where improvement is needed. All themes and sub-themes are presented in a thematic map (Figure 8.1). Key findings are reported below, supported by participant quotes. All quotes are anonymised with participant numbers.

Figure 8. 1 Thematic map of clinicians' views



8.3.1 Clinical benefits

Clinicians described several clinical benefits of the PEACE Pathway on their treatment approaches. Firstly, they highlighted the collaborative nature of the pathway development and how this helped them understand and value service users' perspectives. Patient involvement in the decision-making process was highlighted as particularly beneficial in the earlier stages of pathway development. Clinicians described seeking patient feedback on their preferred sensory adaptations (e.g., introducing silent key caps to reduce the sound of the ward keys and decluttering ward environment), communication needs (e.g., designing and giving out the communication passport for patients to fill in and having conversation cards available in public area on the ward), and preferred colour scheme for environmental adaptations.

> *"This wasn't, sort of, 'okay, this is a clinician project', or 'this is a carers' [project]', this was our project in terms of the patients, the carers and the clinicians all working together in deciding and making sure they had a voice about how would they want the sort of dining room, or the sort of corridors to kind of be. I remember even doing the psychology board with them, and we've kind of done that all together, as well, sort of during Christmas break that time, designing it together. So, making sure that they were very involved." – Participant 3*

> *"We talked to them about kind of their communication style, what kind of-, how do they seek support, what they find helpful, not helpful and tried to adapt it in such way." – Participant 4*

Participants also described improved flexibility and individualisation in their approach to meeting unmet needs of patients. Firstly, this was reflected in clinicians creating autism-friendly version of documents that were given out, such as colour-coding menus or adding bullet points and using concise language on information pamphlets and post-session summaries. Secondly, adaptations were made on an individual basis during sessions, such as adjusting environmental settings (e.g., lighting or seating positions), using clearer language and reducing metaphors, giving advanced notice about changes taking place, covering fewer topics in one session, as well as adjusting the structure and pace of the sessions (e.g., having shorter sessions that are more frequent). Participants also highlighted the importance of clarifying patients' sensory needs and communication needs at the start of treatment using PEACE resources such as the communication passport (https://www.peacepathway.org/download/16) to ensure that appropriate adaptations are made. Thirdly, participants described being able to tailor treatment goals and make informed clinical decisions based on patients' autistic characteristics. This involved establishing realistic expectations of what patients can achieve in treatment, and how the care plan can be adjusted to accommodate patients' needs while ensuring safe recovery from ED. For patients whose autistic needs interfered with treatment, some clinicians would discuss the PEACE approach (e.g., sharing information from the PEACE book) with them during sessions and try to establish priorities (e.g., "What is your/the? priority for change?", "What do you actually want to work on?" and "What's realistic?").

> *"And it's so easy to do, it takes like, three, four minutes just to, you know, turn the lights off, open the blinds, or close the blinds, or windows, you know, either sit side by side, lots of people like that, rather than like giving all that eye contact. And yeah, just like the length of the session, you know, some people wanted shorter sessions, some people wanted more regular sessions, some people wanted less regular [sessions]. So, you could be a little bit more bespoke." – Participant 10*

> *"For example, in one case, we talked about, you know, sensory and taste difficulties and also other hypersensitivities the patient had, for example with the sunlight, and that we made some adaptations like closing the curtains. We also discussed whether she should be allowed to go on walks in the evening when it was already quite dark. Yeah, so that was balancing the autistic needs and the safety of the patients and also health aspects as this patient needed vitamin D supplementation because she didn't have enough sunlight." – Participant 5*

Meeting unmet needs of patients led to better engagement. Clinicians gave examples of patients who were disengaged in the past but came into treatment more once their needs were met by individualised support, and of patients who were able to go on to more complex psychological work with appropriately adapted communication methods. Novel adaptations that led to better engagement were often shared in case discussions at PEACE meetings to ensure other staff were also aware of the approach, and could use it in their practice.

> *"She never engaged in psychological therapy, […] because: one, her, she said her needs weren't being met; and also it was rather, sort of sensory sensitivities, she was experiencing. So she never felt like both her autism and eating disorder were taken to consideration; she felt like it was just her eating disorder at that point in previous services. So we were making sure that we were thinking about things much more holistically. […] It was a lot of adaptations, she engaged in all our sessions together. And even after that, we were able to kind of go on to more complex psychological work with her such as, like, cognitive behavioral therapy, because she felt like we were listening and her needs were being met." – Participant 3*

> *"He wanted to do work with his parents, but he had had family therapy before and he hated being in the room and he found it really daunting. So I sort of tried to think outside the box and I said, let's do an experiment. And we'll do like a telephone conference. So we can all dial in. And then that will take away some of like the social, overwhelming social nature of it. I mean, it was very interesting because he loved it. And he really got a lot out of it and kept coming back as he disengaged in the past." – Participant 11*

Clinical benefits of PEACE Pathway adaptations were not limited to autistic patients only. Some of the resources such as the communication passport and sensory tools are available to all patients admitted to the service, and this was helpful as even patients without autistic characteristics can have communication preferences and/or sensory needs. It was also highlighted that sensory adaptations were particularly useful for trauma informed approaches, as sensory sensitivity is commonly seen in patients who had experienced trauma.

> *"Everyone is different and everyone has different sensory needs, whether you're on the autistic spectrum or not." – Participant 4*

> *“We wanted it to be a peaceful calming environment for, for everybody. And I think that's the important thing – it is for everybody because we know that, that that would suit an awful lot for the folks we work with with eating disorders, not just those with a diagnosis of ASD.” – Participant 7*

8.3.2 Benefits to the service

Participants also reflected on PEACE Pathway’s impact on the service overall, and highlighted improvement in the clinical team’s knowledge, skill, and awareness of autism in their daily practice. Many participants mentioned the benefits of attending PEACE training sessions, which covered a wide range of topics, including autism assessment and formulation, which helped clinicians identify autistic characteristics such as camouflaging that could interfere with treatment, and therapeutic and environmental adaptations for autism, which supported the development of strategies for individualising treatment approaches. Moreover, participants mentioned that PEACE raised the level of autism awareness across the team, and it was easier to have autism-related discussions when the team overall became better informed about autism.

> *“We would have a lot of experts in the field, come in and teach us and train us, whether that was to do with formulations, adapting CBT, it was all so helpful.” – Participant 3*

> *“The fact that the team as a whole was becoming better informed about autism, it was really helpful because then there were various sort of places that you could go, people that you could discuss things with.” – Participant 6*

With improved knowledge and skills, clinicians felt more confident and credible working with people with autism. As a result, they displayed more interest in patients’ autistic characteristics and were more willing to have autism-related discussions with patients, which improved therapeutic relationship and trust.

> *"I feel more confident working with people with autism because I have that background. And I also think I'm more credible to working with them." – Participant 7*

Participants highlighted PEACE Pathway's positive impact on team collaboration. This was mainly achieved through PEACE huddles, which are brief, regular meetings for case discussions and updates joined by clinical teams across the ED service. It was described as a valuable forum for hearing different perspectives from multidisciplinary team members, collective problem solving, and sharing formulations and dilemmas about patient cases.

> *"It really brought the team together across the services. You've got people from day care, from outpatient, inpatient, step up." – Participant 11*

> *"It was also a good space to know about what was happening where, because like I said, I'm a little bit out of touch with what's happening on the ward. But that was a place where I could find out what they were doing, and vice versa." – Participant 13*

Lastly, many participants highlighted that the PEACE Pathway has made available a wide variety of resources (see 1.2.3 for details) to use flexibly in practice. Participants appreciated the low stimulus room, the autism-friendly introduction packages for patients, the sensory psychoeducation materials, and the communication passport. The PEACE website (peacepathway.org) and book were also highlighted by most participants as good sources of information for themselves as well as for signposting patients and families to.

> *"I think there's some useful information and signposting on there. And I know [...] from having discussed with patients that they found it helpful. They've used it and have spoken about it in therapy. One patient in particular said that they wish this had been, this had been known sooner." – Participant 10*

8.3.3 Practical challenges

Many participants described their dilemma between treating ED and accommodating for autism. Disentangling what is ED and what is autism can be difficult, especially when patients' restrictive behaviours are influenced by factors from both conditions, such as body image concerns combined with a need for routine and predictability. Clinicians often worried that making accommodations for autism would inadvertently exacerbate the ED. This issue was highlighted particularly with the use of the PEACE menu, which is an alternative autism-friendly menu mainly consisting of bland tasting food with homogeneous texture that is calorie-matched with the regular menu used at the service. Food items on the PEACE menu are also photographed and pre-packaged where possible to maximise predictability and reduce patient anxiety. However, clinicians expressed concerns that some patients would choose the alternative menu not necessarily because of autism, but out of the desire to restrict because although the alternative menu is calorie-matched, some of the items may be perceived as lower calorie due to their blandness. There were also concerns that patients who chose the alternative menu all the time in order to avoid the standard menu would risk being on a restrictive and rigid diet with limited variety. Some clinicians noted that reasonable adaptations should be made in the beginning of treatment, but suggested that therapeutic challenges need to be introduced in the process to encourage improvement, for example to increase variety in food intake or to challenge rigid behaviours. Such challenges can be crucial to ensuring good transitioning into everyday life, but it is difficult to conclude from PEACE Pathway guidance when to reduce adaptations and introduce these challenges.

> *"In the beginning, we make a lot of adaptations to not challenge [the patients] too much with the texture of food, with the sunlight or with a, with the noise, etc. But there also needs to be some improvement and some therapeutic challenges. And it's not always clear for me from the information I get from the PEACE huddles etc. how quick we should make improvements and challenge these things." - Participant 5*

> *"The [PEACE] menu doesn't represent what's available in cafes, and [supermarkets] and stuff like this. And I think it is difficult with the eating disorder patients who tried to elicit… using all of the adaptations, because then effectively, they're just facilitating a very restricted diet." - Participant 12*

Clinicians' uncertainty between ED treatment and autism adaptations was intensified when PEACE was rolled out to different levels of care, where treatment goals and service structures can vary. For example, participants noted that implementation of the PEACE Pathway was stronger on the inpatient unit than it is in the outpatient unit. Differences in treatment goals were also highlighted by participants, with inpatient services noted as prioritising weight restoration, whereas day service and outpatient teams aim to support weight stabilisation and transition into the community. As a result, clinicians in outpatient and day care services tend to prioritise therapeutic challenges and may be more focused on manualised sessions rather than making adaptations. Lastly, participants pointed out differences in treatment format, where day services are essentially a group programme, which presents greater difficulties for clinical staff to support patients individually. Clinicians described that as much as they would like to tailor to individual needs, this also has an impact on the group elements of the treatment. For example, a clinician described that when one group member gets adapted treatment and is allowed to wear headphones during mealtimes, other members would be aware and would question the fairness of this. The impact of adaptations on patient dynamics in a group can be particularly challenging.

> *"I do think it's such an important thing to hold in mind the comorbidity and the crossover of traits, but I guess there is also sometimes the adjustment of what can be adapted on the inpatient ward to then when they come to day services, or outpatients, [where] we are not able to meet that level of adaptation. Or we are a bit more hesitant to." – Participant 12*

> *"In day service, the nature of the intervention is that you are going to be raising people's anxiety. They are confronting anxiety provoking situations around food and around*

> *emotions. And that's the nature of the intervention. And I suppose sometimes people might say in their [communication] passport, you know, don't, don't say this or that to me. But that might be something that we need to speak to them about, in order to sort of challenge the eating disorder, or challenge unhelpful ways of communicating." – Participant 13*

Participants also discussed difficulties with not all staff members being able to attend PEACE huddle meetings. Despite the importance of multidisciplinary team cohesion for disseminating clinical innovations to team members, participants highlighted the struggle for all disciplines to attend the meetings regularly given their already demanding workload.

> *"It can be hard in terms of sort of staff time. It can be a struggle for, say, for instance, some disciplines to find the time to attend these, due to various other demands on the ward as well." – Participant 3*

In addition, clinicians mentioned that some PEACE adaptations have increased the pressure they are under to meet patients' needs, which sometimes can be unrealistic and unhelpful in terms of recovery:

> *"I think, another thing about the communication passport, I would say that it needs to be used with caution, and also to think together with the patients. I don't think it's humanly possible for us to remember, in such fine details, some communication passports are so detailed in terms of how they like and not like to be spoken to, and so on. And to hold all these patients in mind is going to be very difficult. So I think it's helpful to have an idea, but we also need to invite the patients to think about how can we be more flexible with it? And some patients will say in the communication passport, I don't, I don't ask for support. And we can't just accept that, because that's not going to be helpful for them." – Participant 4*

Some participants raised concerns that there can be a lot of crossover between potential diagnoses in complex cases, for example personality disorder and autism, or complex PTSD and autism. Focusing prematurely on autism can lead to overshadowing of other possible diagnoses, stopping patients from getting appropriate treatments. This is exacerbated by the fact that waiting lists for a formal autism assessment in the UK are long, often exceeding two years, thus there is a danger of premature suggestions of autism.

> *"The PEACE Pathway – although I think it's really good, and it has lots of resource and it has helped loads of people – I think runs the risk of having an autism bias to the extent where it gets over thought about at the cost of being able to distinguish other stuff." – Participant 12*

In addition, suggestions of possible autism are sometimes met with negative reactions from patients and families. Some may reject the idea, and some may not be prepared to receive a suggestion of autism from an ED service. Disclosing this possibility to patients and families may therefore be a stressful experience for clinicians.

> *"But her parents, well, her mum is very rejecting of the diagnosis and is embarrassed about it. So I think you might have, yeah, just be prepared that some people might not be as understanding. ... You know, it's been really upsetting for her. Whilst it's like an epiphany, it's also really upsetting because she's like, ah, so like, I've got this thing, and it's about me, and it's with me." – Participant 11*

8.3.4 Suggestions for improvement

In the context of the challenges of and barriers to PEACE implementation, participants also reflected on potential areas of improvement in the future. The need for aftercare and community support was highlighted by many, not only as a suggestion for PEACE but more as a national urgent need for support for autistic individuals. Clinicians mentioned that the discontinuation of adaptations once patients leave the ED service is worrying. The PEACE Pathway therefore needs to be developed further, taking into account aftercare needs.

> *"So I think management of the aftercare needs to be improved, because you create a lot of expectations in the patients if you*

> *offer ASD and anorexia nervosa service on the ward, and the patients think this really continues afterwards. And it doesn't. Where the patient then has identified all the problems with the therapists, but will become a bit hopeless, if those identified needs are not met, after the treatment on the ward.” –* *Participant 5*

Participants also pointed out that the autism screening approach needs to be improved. The PEACE Pathway uses the Autism Spectrum Quotient short version (AQ10; Allison et al., 2012; Westwood et al., 2016) questionnaire to screen for autistic characteristics, and those who score over the threshold on admission are discussed in PEACE huddles and adaptations are made accordingly. In some cases, where there are uncertainties about a possible autism presentation, follow up measures are used; the team would enquire more about family history of autism, developmental milestones, further observe the patient’s presentation at the service, and/or follow up with the Social Responsiveness Scale 2nd Edition (SRS-2; Kerr-Gaffney et al., 2020) which is a longer questionnaire investigating autistic difficulties in more depth. However, participants raised several concerns about this process. Firstly, the participants cautioned against exploring autism with patients immediately after they score over the threshold on the AQ10 without seeking further evidence. Participants pointed out that there is need for structured guidance and clear decision points for the follow up procedure after the initial AQ10 screening, for example what additional features to look for in patients’ presentation, and when to mention the possibility of autism with patients. Secondly, participants were concerned that the AQ10 is not accurate enough with possible overlap with other diagnoses and starvation effect. The result therefore requires careful interpretation.

> *“I think with women as well, [AQ10] is not quite, I think, if you look at its psychometric properties, it's never, the internal consistency is never that high.” – Participant 11*

> *“So [score on the AQ10] was just flagged up as being positive. And then it's not as clear what do we then do with it? Often, we then decide to do something with it if we're really struggling with management, and we thought, actually, we need to think*

> *more about autism, then it becomes kind of more, more kind of on the forefront of our mind." – Participant 4*

Clinicians also mentioned that the PEACE menu could be improved to include more options, for example a version with more vegan options. It was also noted that a version for people with sensory hyposensitivity could be developed, in addition to the current version which is for people with hypersensitivity and dislike strong smells or tastes. The hyposensitivity version, for example, could include food items that have stronger smells and tastes and would satisfy sensory seeking needs.

> *"I think quite a lot of that group are vegan. So if they were to be another vegan option on the PEACE menu that might actually support them having more than just one food every single day, maybe there'd be two." – Participant 9*

Some participants preferred more structured, step-by-step treatment plans from PEACE, instead of general guidance on how to adapt sessions. Two benefits were proposed for this structured approach: easier and more specific treatment planning for clinicians, and clearer structure for patients with high rigidity.

> *"For example, in CBT for depression, you have these manuals where you will see in, in week one, you make this formulation. Week two, you talk about positive activities. Week three you implement the first change, etc. And then at the end people, so after 10 weeks people have made changes to their work environment, have met with friends, have learned how to give themselves more time to relax... And we don't have such a clear plan developed for people with ASD and anorexia. And so this is my impression. We have identified the challenge, we have been given some guidance, but let's say for someone who starts on the ward, very specific guidance would be good. I think that would also make sense to the to our patients. Because if you say to them, that is the way to go, they think oh, this is well thought through and there's something you know, because they, with this rigidity they want the clear structure and the clear advice that works quite well with them. So, coming from general guidance to a more specific treatment plan - I think that would be helpful." – Participant 5*

8.4 Discussion

8.4.1 Overview

The findings of this qualitative evaluation highlighted a broad range of benefits of and challenges in the PEACE Pathway from the perspective of multi-disciplinary clinicians working in the SLaM ED service where the PEACE Pathway had been implemented. Before discussing benefits, challenges and areas of improvement subsequent to the implementation of the PEACE Pathway, it is useful to reflect on the challenges identified in previous needs assessments conducted with stakeholders prior to and during PEACE Pathway development, which are summarised in Table 8.1. In 2017, Kinnaird and colleagues interviewed clinicians in the same SLaM ED service about their views on working with patients with the ED and autism comorbidity, which highlighted a lack of clinician confidence, a lack of clear pathways for autism assessment referrals, problems with patient/therapist communication, difficulties identifying and articulating emotions, and lack of systematic guidelines and staff training on adapting treatment (Kinnaird et al., 2017). A subsequent study involved interviews with patients and found that people with the comorbidity struggled with the typical time frames for treatment and could not engage well in refeeding due to sensory difficulties (Kinnaird et al., 2019b). The same study also highlighted the importance of involving patients in deciding how to adapt services to support patients with autism. A third study with carers raised issues such as difficulty getting an autism assessment, sensory difficulties, a need for a tailored approach to treatment and difficulty getting services to adapt treatment (Adamson et al., 2020).

Table 8. 1 Stakeholders' needs versus what has been achieved

Stakeholder	Need	Achieved by PEACE
Clinician	Need to improve confidence supporting the co-morbidity (Kinnaird et al., 2017)	Increased clinician confidence
Clinician	Need to improve expertise and experience, and sharing of expertise (Kinnaird et al., 2017)	Increased team collaboration through huddle meetings and case studies

Clinician	Need to improve understanding of autism and willingness to adapt (Kinnaird et al., 2017 & 2019b; Adamson et al, 2020)	Improved overall awareness, skill and knowledge about autism
Clinician	Need to improve communication challenges	Flexible and collaborative approach leading to improved treatment engagement; new resources developed (communication passport, conversation cards)
Patient	Need to develop better relationships with clinicians and to feel better understood (Kinnaird et al., 2019b)	Flexible and collaborative approach leading to improved treatment engagement
Patient	Need to feel listened to and able to influence adaptation of their treatment (Kinnaird et al., 2019b)	Collaborative approach focused on understanding and valuing the patient perspective
Patient	Need for a flexible, tailored and individualised approach (Kinnaird et al., 2019b; Adamson et al., 2020)	Improved individualisation and flexibility in treatment format, structure, tools and goals
Patient	Need to improve response to sensory and communication difficulties (Kinnaird et al., 2019b; Adamson et al., 2020)	Environmental and sensory adaptations and new resources available (e.g., communication passports and alternative menus)
Carer	Need for improved access to autism assessment (Adamson et al., 2020)	Autism screening tools introduced as standard screening procedure for all admissions; clinicians received training in assessing and recognising autism
Carer	Need to improve support for sensory difficulties (Adamson et al., 2020)	Environmental and sensory adaptations and new resources available (e.g., service environment re-designed, sensory workshop introduced and sensory toys available)
Carer	Need for a tailored approach to treatment and for service-wide adaptations to treatment (Adamson et al., 2020)	Improved individualisation and flexibility in treatment format, structure, tools and goals; improved team collaboration and awareness

Table 8.1 summarises stakeholders' needs assessed by previous studies in parallel with relevant themes arising from the current evaluation. Themes from the current evaluation suggest that many of the previously identified challenges

and needs have been addressed: clinicians reported an increase in their confidence; new resources, such as communication passports, alternative menus and sensory aids, have been developed and disseminated to help with communication and sensory difficulties; patients are now receiving a more tailored and individualised approach to treatment, with adjustable time frames and pace for treatment that better suits their needs; and clinician skills and knowledge about autism improved as a result of training. The PEACE Pathway also incorporated autism screening in order to meet the need for clear guidance on autism assessment; this was however both appreciated by clinicians and also highlighted as an area where improvement is still needed, discussed in more detail in section 8.4.3. Furthermore, some of the benefits highlighted in the current evaluation exceeded previously identified needs, for example PEACE Pathway adaptations and resources were beneficial not only to autistic patients, but to all patients with communication or sensory needs.

8.4.2 Benefits and challenges

Clinicians reported many benefits of the PEACE Pathway, such as improved understanding of service users' perspective, improved flexibility and individualisation in approach, increased treatment engagement, and provision of resources that are helpful to all patients, with or without autism. PEACE also brought benefits to the service overall, increasing general awareness and knowledge about autism, boosting clinicians' confidence in treating the comorbidity, providing platforms for team-wide collaboration, and making the service overall more resourceful. These findings may be linked to autistic patients' reduced use of intensive treatment after PEACE implementation in Chapter 7 (cost-savings analysis), suggesting that PEACE clinicians are making appropriate changes to meet the needs of autistic people. Indeed, PEACE adaptations align with the general recommended adaptations for working with autistic people by the NICE guidelines (NICE, 2012), including having breaks in therapy, increased use of written and visual information, involving carers, and avoiding ambiguous language. In addition, PEACE also introduced aspects that are similar to CBT adaptations that have been tested by other studies to be clinically effective for common mental health problems in autistic people, for example adjusting the structure and pace of therapy, and including materials and skills training to enhance patients' understanding of emotions (Spain et al., 2015). A systematic review by Walters, Loades and Russell (2016) found that interventions that were effective for autistic young people tended to use more modifications than those recommended by NICE. It was also found that such interventions tended to use more disorder-specific modifications i.e., tailoring to the specific psychological disorder being treated. Overall, the benefits and strengths of PEACE highlighted by clinicians in this study are encouraging, as they may be pertinent for enhancing engagement, acceptability and utility of ED treatment.

Clinicians also identified areas of confusion in the process of implementation, due to the difficulty in incorporating autism adaptations into existing ED treatment protocol and goals. For example, accommodating for patient's sensory needs by providing noise-blocking earbuds during mealtimes conflicted with the general requirement of social eating in inpatient and day patient treatment settings. Similarly, supporting patients with nutritional rehabilitation using their preferred option of an alternative bland menu conflicted with the typical goal of increasing the variety of food choices in ED treatment. At the core of these individual-level challenges lies the difficulty of distinguishing between ED and autism, and clinicians' hesitance to deviate from standard intervention protocols. Indeed, although patients with unmet needs have been told to 'leave the autism at the door' and focus on changing ED behaviours only (e.g. Adamson et al., 2020; Kinnaird et al., 2019b), in reality this is impossible, as autism is a neurodevelopmental condition that is part of a patient's identity and can be intertwined with ED presentation, sometimes even exacerbating ED behaviours (Kinnaird et al., 2019a). It is therefore important that adaptations are constantly discussed in supervision and clinical meetings on a case-by-case basis to ensure peer support for clinicians during decision making. Recent studies have also started to shed some light on distinguishing between common features in anorexia nervosa and autism (Westwood & Tchanturia, 2017). A framework was recently proposed to outline clinical features associated with autism that are also common in AN, and highlights the potential differences in presentation and mechanism which can provide helpful guidance in clinical practice (Kinnaird &

Tchanturia, 2021). However, more detailed guidelines are needed to distinguish between autism and other types of EDs such as bulimia nervosa or binge-eating disorder, and to clarify priorities for treatment in different clinical scenarios where treatment protocols may be in conflict.

Further dilemmas were highlighted in relation to the rolling out of adaptations in day service or outpatient setting, where team structures and approaches differ from those in inpatient settings, with greater emphasis placed on patients' flexibility and independence in preparation for full recovery. Indeed, it was highlighted that implementation of the PEACE Pathway was stronger and happened faster in inpatient settings compared to day service and outpatient settings. This may be due to the size of the team (the inpatient team is smaller than the day/outpatient teams and therefore barriers to communication may be lower), the nature of the psychological intervention (where the inpatient service provide more one-to-one interventions compared with the group based programme in the day service, which presents more difficulties for clinical staff to adapt care for individual patients), limits on the number and time of outpatient sessions provided to each patient (and so it may become challenging to meet the needs of an autistic person in a fixed number of sessions), and frequency of team communications (team meetings are run almost daily in the inpatient service and weekly in day/outpatient services). As a result, adaptations that worked in an inpatient setting may be less meaningful in other levels of care and constant tailoring, reviewing and supervision is required to align with core goals and the structure of alternative treatment settings. Appropriate evaluation is highlighted by previous research as a crucial step in this process (Lee et al., 2008), and future evaluation studies are warranted to gauge the impact of the implementation of the PEACE Pathway into daycare or outpatient settings.

The development of the PEACE Pathway adopted an iterative Plan, Do, Study, Act (PDSA) methodology (Tchanturia et al., 2020) to ensure best practice for service improvement (NHS England, 2021), and involved collaboration with patients, clinicians and carers to ensure that all stakeholder values and needs were considered. This approach closely reflects the recommended models for making adaptations to evidence-based practice in implementation science (Lee et al., 2008; von Thiele Schwarz et al., 2019). Nevertheless, clinicians in the ED service are supporting patients rather than testing theoretical models, and individual patient differences create a variety of dilemmas which are unlikely to be fully resolved through research. Instead, it is likely that sustained use, testing, modification, and evaluation of the PEACE Pathway is essential to support clinicians navigating these dilemmas. This highlights the importance of providing continuous support for clinicians. More resources should therefore be allocated but not limited to: regular clinician training to improve their confidence and skills, lowering barriers to multidisciplinary team decision-making regarding how to manage the dilemmas, and establishing emphasis on value in addition to effects across the services.

8.4.3 Future directions

Clinicians in this study also expressed a need for more structured, preferably manualised guidance. At the ED service, clinicians are used to using a range of structured, evidence-based ED treatment protocols in their daily practice (Lock & Le Grange, 2015; Schmidt et al., 2014; Tchanturia et al., 2013). For treatment of coexisting disorders like ED in autistic people, however, current guidelines recommend offering interventions for the specific disorder, not for autism (NICE, 2012), while only listing possible adaptations for autism without specifying the order of priority or structure in which the adaptations should be made. Whilst a PEACE Pathway guide to adapting treatment for autistic people with ED has been published, which includes practical examples and guidance written in multidisciplinary perspectives (Tchanturia, 2021) and was highlighted as helpful by many participants, some called for more structured, step-by-step guidance. However, it is not currently clear whether a more structured guideline would be feasible to manualise the PEACE approach, as a result of the complex interactions between the co-morbid conditions. Evident in this study was participants' perception of contradictory benefits and challenges. For example, the PEACE menu may reduce anxiety in patients and therefore be welcomed by staff providing mealtime support, but this may contradict dietitian guidance to increase food variety. Similarly, noise-reducing tools such as earbuds that aim to ease a patient's sensory sensitivity might also create barriers for 'social eating', which is one of the goals of ED treatment. One strategy suggested by previous work for challenges like this is to develop complex interventions that are flexible and allow for variations (Duggleby & Williams, 2016). The structure of PEACE resembles such an intervention: it includes a wide range of resources and adaptation guidelines that can be flexibly used to tailor to the individual on a case-by-case basis. However, this also creates barriers for clinicians who prefer structured guidance. Sustained use and testing of the PEACE Pathway, alongside development and testing of more structured guidance, is warranted.

Clinicians in this study also expressed uncertainties about the screening procedure for autism. Prior to PEACE implementation, interviews with clinicians at the same service suggested that there was no clear pathway for ED clinicians to refer their patients for an autism assessment (Kinnaird et al., 2017). The PEACE Pathway therefore introduced autism screening into standard practice using the AQ10, as it is the only measure recommended by NICE for initial assessment of autism in adults (NICE, 2012). However, previous work has shown that the AQ10 is not a good predictor of diagnosis in clinical samples (Ashwood et al., 2016). The screening tool's poor specificity was highlighted, reflecting high rates of false positives. In addition, there are specific challenges of screening for autism in people with ED, due to overlapping features such as cognitive rigidity and social difficulties (Kinnaird & Tchanturia, 2021). These overlaps make it more difficult for autism screening tools to distinguish between autistic characteristics and ED symptoms. Therefore, a more suitable autism screening tool for an ED service is needed. Previous work has suggested adding subscales on auditory sensitivity, social compensation and externally orientated thinking to the AQ10 to improve its ability to distinguish between ED and autism (Adamson et al., 2022). However, this model is yet to be tested further. Another challenging aspect of the screening process is deciding how to proceed with a positive result on the AQ10. Currently, this decision relies on the clinical expertise and experience of senior clinicians, who factor in follow-up assessments and clinical observations, including evidence of sensory sensitivities, management of social interactions, body language and eye contact, special interests, and other aspects. However, this process is not yet fully operationalised. A structured guide for decision making when a person scores on initial screening could be developed to aid this process, although it should leave enough room to consider individual differences between patient cases.

A need for improvement in aftercare for autistic people was also highlighted. This is highly relevant but exceeds PEACE Pathway's span of influence, and rather reflects a national need for destigmatising autism and improving diagnostic pathways and community support. Over the past 20 years, there has been a 7-8 times exponential increase in recorded incidence of autism diagnoses with the greatest rises among adults (Russell et al., 2022), yet current service provision for autistic adults is in its infancy compared to health and education services for autistic children (Lipinski et al., 2022; Murphy et al., 2016). The COVID-19 outbreak further increased NHS backlog of autism assessment referrals by 169% from pre-pandemic level (England, 2023; Society, 2023). This systemic gap in support for autistic people affects clinicians' decision making in a range of areas. Some clinicians hesitate to discuss the possibility of autism with patients, knowing that resources and support become very limited once patients are discharged, and patients could spend years on the waitlist for a formal assessment of autism. Some are faced with negative reactions and denials from patients and families due to stigma on autism. Some worry that the adapted environment at the ED service inadvertently creates a gap with the 'real world', and once a patient is discharged, the discontinuance in autism-friendly adaptations could lead to deterioration. This affects both discharge planning and clinicians' readiness to make adaptations. Therefore, improvement in the implementation of PEACE Pathway requires a system integrated with efficient autism diagnostic and aftercare services. Research on strategies to improve adult autism services in the UK, including assessment and diagnostic services and support networks, is currently underway (Brede et al., 2022; Riese & Mukherjee, 2022; Wigham et al., 2022).

8.4.4 Limitations

Nursing staff were not interviewed in this study due to their lower level of engagement with the development and/or implementation of PEACE Pathway. It was acknowledged that nursing staff did not participate in PEACE huddles and training, often due to schedule conflicts. However, their feedback could be invaluable as they have direct daily contact with patients, and should be investigated by future studies focusing on gaps and areas of improvement in implementation. The heterogeneity of this study sample, however, should strengthen the credibility of the study, as participating clinicians varied in gender, age, seniority, and discipline. Future studies should also aim to investigate patients' experiences. While conducting patient interviews would be beneficial, it was not feasible within the scope of this PhD due to time constraints and the lengthy ethics application process. To provide a comprehensive evaluation of the PEACE pathway, it is essential to conduct patient interviews which would allow for a deeper understanding of patients' perspectives on each component of the PEACE pathway, thereby enriching the overall evaluation process.

8.5 Conclusion

The implementation of PEACE Pathway has benefitted clinicians’ approach with patients and improved service-wide knowledge and awareness of autism, while also bringing practical challenges reflecting fidelity-adaptation dilemmas. Future areas of improvement are highlighted for PEACE resources as well as in the national support system for autistic individuals.

Chapter 9 Summary of findings and discussion

9.1 Summary of aims and objectives

The aims of this dissertation were to critically review evidence of clinical effectiveness and cost-effectiveness of any existing service-level or treatment-level adaptations to support patients with ED and autism (Chapter 2), to investigate the impact of autism comorbidity on ED outcomes (Chapter 2), to explore patterns in a range of ED symptoms and severity indicators in patients at the SLaM inpatient ED service (Chapter 3), to explore the clinical challenges associated with supporting people with the comorbidity and outline the approach of the PEACE Pathway in adapting treatment (Chapter 4), and to evaluate the outcomes of the PEACE Pathway clinically (Chapter 5 and Chapter 6), economically (Chapter 7), and qualitatively (Chapter 8).

9.2 Current evidence base for treatment adaptations for co-occurring autism and ED

Exploration of existing literature (Chapter 1) found a wealth of research on the overlapping behavioural and cognitive features between ED and autism. Among all subtypes of ED, AN has the most substantial evidence base in terms of this overlap. The prevalence of autistic characteristics in AN is reported to be 7% to 40% (Bentz et al., 2017; Kinnaird et al., 2020a; Postorino et al., 2017; Stewart et al., 2017; Tchanturia et al., 2016; Tchanturia et al., 2013; Westwood et al., 2017b; Westwood et al., 2018), assessed by a variety of autism screening tools in different studies. In this dissertation, the prevalence of autistic characteristics was 26.8% in the clinical sample in Chapter 6 (Clinical Evaluation; see 6.3.3.1), which mainly consisted of inpatients with AN. Overall, the inconsistency in the evidence suggests that currently there are needs for further investigation of autism in ED subtypes other than AN, a standardised autism assessment tool suitable for the ED population, and validation of current findings with larger samples and more sensitive measures.

Autism in AN is associated with major cognitive, social and behavioural difficulties and often leads to exacerbated severity and worse treatment outcomes (Saure et al., 2020; Leppanen et al., 2022; Nielsen et al., 2015), raising the need for treatment adaptations to standard ED treatment programmes. NICE guidelines for autism (NICE, 2012) recommend that clinicians delivering interventions for coexisting mental disorders to autistic adults should have an understanding of the core features of autism and make adaptations accordingly. Existing literature on making adaptations for autism mainly focus on building a sensory-friendly environment (Babb et al., 2021) and adaptations to cognitive behavioural therapy (CBT) which have demonstrated efficacy in reducing anxiety symptoms in autistic individuals (Spain et al., 2015; Spain and Happé, 2020; Ung et al., 2015). However, no protocol-specific recommendation has been proposed for adapting treatment for autistic people with ED.

Indeed, despite employing a very broad search strategy, the systematic review (Chapter 2) only identified three studies that described or evaluated treatment adaptations for comorbid ED and autism (Smith & Tchanturia, 2020; Tchanturia et al., 2020a; Tchanturia et al., 2020b), indicating that few such treatment adaptations have been developed. All of the included articles (Chapter 2, Review 1) were related to the same intervention – the PEACE Pathway. Therefore, the PEACE Pathway was the only intervention for patients with ED and comorbid autism that has been described and evaluated in published manuscripts. These PEACE-related studies, one focusing on the value of a single component of the pathway (PEACE huddles), as perceived by clinicians (Smith & Tchanturia et al., 2020), and one focusing on the impact of the pathway on length of hospital stay and associated costs (Tchanturia et al., 2020a), have produced positive indications to hypothesise that the PEACE Pathway may generate benefits for autistic patients. Results from the cost-savings analysis (Tchanturia et al., 2020a), in particular, may suggest that the PEACE Pathway is better able to support patients with comorbid autism, leading to reduced lengths of hospital stay, however further research is needed to confirm this.

9.3 Impact of co-occurring autism on clinical outcomes in ED

The second review in Chapter 2 investigated the impact of co-occurring autism on clinical outcomes in ED. The studies identified were predominantly cross-sectional or case series and all were published in the past decade. Although we included search terms for all ED diagnoses, almost all of the included studies focused on AN, with two studies further including patients with Eating Disorders Not Otherwise Specified (EDNOS). This again highlights the scarcity of research on autism in ED subtypes other than AN.

According to the included studies (Chapter 2, Review 2), autistic characteristics have no direct impact on physical outcomes or ED symptoms (Huke et al., 2014; Nazar et al., 2018; Stewart et al., 2017). However, a negative impact was found on Morgan-Russell outcomes (Anckarsäter et al., 2012; Nielsen et al., 2015) which encompass an individual's food intake, weight concern, mental state, psychosexual state and social relationships. This finding has implications for choosing outcome measures when evaluating treatment outcomes in patients with autistic features. Social-emotional processing difficulties and cognitive rigidity are common features of autism (Davies et al., 2016; South et al., 2007) which might be reflected negatively on the Morgan-Russell assessment or other measures that tap into social relationships and cognitive flexibility, but would not have an impact on ED measures that gauge ED symptoms only, for example the Eating Disorder Examination Questionnaire (EDE-Q). Hence, when evaluating outcomes for autistic patients, the measure should be chosen and interpreted with caution.

Furthermore, the included studies (Chapter 2, Review 2) found that autistic patients fared worse in group settings but showed favourable outcomes when receiving individual support (Dandil et al., 2020; Tchanturia et al., 2016). There was also a positive association between autism and other comorbid disorders and symptoms in ED, such as personality disorders (Anckarsäter et al., 2012), depression and anxiety symptoms (Li et al., 2020; Stewart et al., 2017), obsessive compulsive symptoms (Stewart et al., 2017), and social and psychosexual impairment (Li et al., 2020; Nazar et al., 2018; Nielsen et al., 2015). Co-occurring autism in ED often also leads to treatment augmentation, either through greater use of intensive day-patient or inpatient treatment (Nazar et al., 2018; Stewart et al., 2017) or longer hospital admissions (Tchanturia et al., 2020a) compared to neurotypical patients. Given the same review also identified that autism does not affect ED symptoms or BMI change directly, the associated treatment augmentation could potentially be explained by (1) the standard treatment not meeting autistic people's needs (for example, preferring individual support to group settings), and/or (2) their higher rates of comorbid symptoms such as depression, anxiety, obsessive-compulsive symptoms or social impairment could have an impact on treatment effectiveness. Indeed, in one of the included studies, autism stopped predicting treatment augmentation once levels of depression had been adjusted for (Stewart et al., 2017). Thus, the need for treatment augmentation in autistic patients may be a result of untreated comorbidities and/or unfulfilled needs that are autism related.

This may suggest that treatment adaptations for this comorbid population may not directly impact on ED symptoms, but may provide better support for the complex needs of autistic patients, thus reducing subsequent need for intensive support. Nevertheless, controlled studies utilising a robust longitudinal design and following stringent diagnostic criteria are clearly needed to further elucidate the relationship between autistic characteristics and treatment outcomes in ED. A universal screening tool for autism in ED is also needed to establish consistency across studies.

9.4 Symptom patterns and severity indicators in patients at the SLaM inpatient ED service

The cluster analysis of symptom patterns and severity in presentation in patients at the SLaM inpatient ED service, reported in Chapter 3, separated the patients into two groups of similar sizes: one group (the "higher symptoms cluster") with higher average BMI, reporting more severe eating pathology, higher anxiety and depression, and more autistic characteristics; and another group (the "lower symptoms cluster") with lower BMI, lower ED symptoms, lower anxiety and depression, and fewer autistic characteristics. The higher symptoms cluster also reported lower self-efficacy to change, more previous hospitalisations, comorbid diagnoses, binge eating and purging behaviours and use of psychotropic medication than the lower symptoms cluster.

It was found that the more severe group of patients at the SLaM inpatient ED service also had more autistic characteristics – this echoes the findings from the systematic review (Chapter 2, Review 2), where autism was linked to more depression, anxiety, obsessive-compulsive symptoms and social impairment in ED. This link between autism and illness severity suggests that treatment adaptations for autism have potential to benefit the more severe and vulnerable patients at the SLaM inpatient ED service.

The contributing weight of BMI as a variable in the formation of severity clusters was very low, suggesting that BMI did not make substantial contributions to the cluster formation. This suggests that weight alone may not be a significant severity indicator amongst inpatients at the SLaM ED service, most of whom have very low BMI. This is consistent with previous work showing that improvement in psychopathology in AN does not correlate with BMI improvement (Mattar et al., 2012), suggesting the need for a better indicator of illness severity such as comorbid symptoms and purging behaviour, rather than BMI alone.

9.5 Clinical challenges associated with supporting people with the comorbidity

Supporting patients with the comorbidity who have complex needs and more severe symptoms brought unique challenges to the staff at the SLaM ED service. The qualitative synthesis of case study minutes and clinical notes (Chapter 4) provides a snapshot of the challenges that clinicians face, including communication difficulties, maintaining treatment boundaries, issues related to autism screening, presence of comorbidities and complications other than autism, sensory sensitivities, atypical eating behaviours, cognitive rigidity, and emotional difficulties. Recognising these challenges, team collaboration to problem solve was a crucial step in the development of the PEACE pathway.

Some of the difficulties, such as those that are communication, cognition or sensory-related, are fundamentally linked to patients' special needs due to autism, which can interfere with therapy engagement when not acknowledged and supported properly. Communication difficulties, for example, are common in autistic individuals in a social context (Doris et al., 2014; Paul, 2008). Clinicians on the PEACE team tried to address patients' communication needs by modifying their communication style to reduce Socratic questioning and use more direct language when helpful. Resources such as the communication passport (Chapter 1, 1.2.3.5) were also developed to help clinicians understand patients' communication needs better. Other attempts to adapt treatment included increasing the use of visual communication, introducing food experiments (Webb et al., 2023), emotion skills training, and sensory adaptations. Qualitative interviews with PEACE clinicians (Chapter 8) demonstrated that these adaptations brought clinical benefits and improved patient engagement.

Another type of challenge is rooted in the difficulty to distinguish between ED, autism, and other complex comorbidities. ED symptoms and autistic characteristics are often similar and sometimes fuelling each other (for example, autism-related rigidity makes ED symptoms harder to change). Clinicians were often caught in the dilemma between addressing an ED symptom and accommodating an autism-driven need. Moreover, ED is a highly comorbid disorder, often co-occurring with depression, anxiety disorders, obsessive-compulsive disorder (OCD), substance abuse and personality disorders (Hudson et al., 2007; Keski-Rahkonen, 2021; Pearlstein, 2002; Swinbourne et al., 2012). Conditions such as OCD and emotionally unstable personality disorder can also share common features with autism, for example cognitive rigidity and emotional difficulties, which makes it more challenging for clinicians to distinguish, plan and prioritise treatment. Qualitative evaluation of PEACE (Chapter 8) showed that clinicians were able to use PEACE huddle meetings for case-by-case considerations and care planning. However, a more established framework is still needed for distinguishing between ED and comorbidities to aid clinical decision making.

Another challenge was the need for a pragmatic autism screening approach in ED services. Similarly, the lack of an appropriate autism screening tool for ED population was also highlighted in the systematic review (Chapter 2), where it was difficult to synthesise evidence from studies that used inconsistent screening methods for autism. The AQ-10, being a screener for clinical populations recommended by the NICE guidelines, has its advantage of being quick and pragmatic, but its validity and reliability for use with the ED population are yet to be tested. Clinical practice would benefit from future research focusing on pragmatic screening tools with higher specificity and sensitivity when used in this co-morbid population. Combined use of the AQ-10 with other self-report questions for increased validity, such as sensory sensitivity screening (Kinnaird et al., 2020) or developmental history questions, should also be considered.

9.6 Evaluation of outcomes of the PEACE Pathway

This thesis includes a pilot clinical evaluation (Chapter 6), a cost-savings analysis (Chapter 7), triangulated with a qualitative evaluation of clinicians' experiences (Chapter 8) of the PEACE Pathway. Additionally, one component of the PEACE Pathway – the sensory wellbeing workshop – was evaluated separately (Chapter 5) as the workshop outcomes were collected and analysed separately from the clinical evaluation. The evaluation compared online and face-to-face formats of the sensory workshop and found that both formats led to significant improvement in awareness of sensory wellbeing and confidence in managing sensory wellbeing for patients with ED. Furthermore, the findings highlighted the adaptability of the workshop and its potential for broader dissemination.

9.6.1 Meeting patients' needs, generating cost-savings without compromising treatment outcomes

For the clinical evaluation (Chapter 6) and cost-savings analysis (Chapter 7) of the PEACE Pathway, this dissertation used naturalistic audit data at the SLaM ED service, which included patient data and clinical outcomes collected routinely five years before (admissions in 2012-2016) and six years after (admissions in 2017-2022) the PEACE Pathway was implemented. In total, 384 patients with adequate completeness of clinical outcome data were included in the clinical evaluation, and 353 patients with complete service use data were included in the cost-savings analysis. It was found that both patients admitted before PEACE implementation (the treatment as usual group; TAU) and admissions after PEACE implementation (the PEACE group) showed substantial and significant improvement in all clinical measures upon finishing inpatient treatment, including improvement in BMI, ED symptoms, anxiety and depression symptoms, and work and social functioning. There was no significant group difference between PEACE and TAU.

The improvement in clinical outcomes in the PEACE group should be interpreted in light of the cost-savings analysis (Chapter 7). Previous literature has found that co-occurring autism commonly leads to longer hospitalisation and increased service use (see section 2.4.1). The cost-savings analysis in Chapter 7 assessed patients' service use in the 12 months following their inpatient admission at the SLaM ED service and observed reduced lengths of hospitalisation for autistic patients in the PEACE group compared to TAU. An earlier preliminary study of cost-savings of the PEACE Pathway reported similar results (Tchanturia et al., 2021). This reduction in length of hospitalisation for autistic patients may be linked to the positive impact of PEACE reported in the qualitative evaluation (Chapter 8): increased autism awareness in the service, improved understanding of service users' perspective, improved flexibility and individualisation in approach, increased treatment engagement, and incorporation of new resources. Overall, the PEACE Pathway has value as a treatment adaptation pathway that meets patients' needs through an individualised approach without compromising

ED treatment outcomes, while reducing the length of hospitalisation for autistic patients to bring cost-savings to the service.

9.6.2 Growing severity in patients' presentation at the SLaM ED service and the impact of COVID-19

It should be noted that compared to patients in the TAU group, patients in the PEACE group had consistently higher autistic characteristics (Chapter 6, 6.3.2.2.6), more serious work and social functioning difficulties (6.3.2.2.5), and more severe ED symptoms (6.3.2.2.2) on admission and throughout treatment. Admissions in the PEACE group may therefore have an overall more severe presentation. Considering that the PEACE group and TAU group are essentially admissions from two different time periods, this indicates that the severity and complexity in patients' presentation have grown over time. A similar trend was observed in the cost-savings analysis (Chapter 7), where non-autistic patients, who make up the majority of admissions (73.4% of the total sample in the analysis), showed increasing service use at the SLaM ED service throughout the period of the audit. Several explanations were proposed for this potentially growing severity in patients' presentation at the SLaM ED service. First, the SLaM ED service is a national specialist ED service, which tends to take on more severe and medically unstable patients than other general psychiatric services. With the rise in prevalence of ED and inpatient admissions in the UK (Micali et al., 2013; Devoe et al., 2023), it is possible that services nationally are facing increased pressure to discharge people quickly due to limited overall capacity. This may lead to an increasing number of patients with more severe presentation being referred to national specialist ED services, hence the increasing patients' severity and service use at the SLaM ED service over this time period.

Alternatively, the impact of the COVID-19 should be considered. The onset of the pandemic in the UK was in March 2020, therefore only affected the data in the PEACE group. The negative impact of COVID-19 on patient admissions at the ED service encompassed multiple aspects. First, previous studies reported that autistic individuals' mental health worsened during the pandemic (Bundy et al., 2022; Oomen et al., 2021; Pellicano et al., 2022), possibly due to increased levels of uncertainty, disruptions to routine and barriers to fulfilling basic needs (Bundy et al., 2022). Similarly, increased severity of ED symptoms and increased risk have been reported during COVID-19 for people with ED (Fernández-Aranda et al., 2020). Thus, autistic people who were admitted to the ED service during COVID-19 may be in a worse condition than pre-pandemic times and needed longer periods of intensive support. Second, the pandemic disruptions such as physical distancing, lockdowns and staff shortages may have an impact on the quality of care provided (Li, 2020) which may lead to a slower recovery in patients. There are also longer-term consequences such as significant backlogs and longer waiting lists for patients (Propper et al., 2020), which are linked to worsened symptoms and poorer treatment outcomes in ED (Allen et al., 2023). In this dissertation, the negative impact of COVID-19 is probably most evident in the data for secondary analysis 1 in the cost-savings analysis (Chapter 7), where after excluding all admissions affected by the pandemic, the estimated cost-savings by PEACE more than tripled compared to the original analysis (£104,450 compared to £27,000 in the primary analysis). Therefore, the overall worse presentation and increased service use in the PEACE group could be associated with the pandemic outbreak.

9.6.3 Considerations for future research strategies

The findings presented in this dissertation may be helpful to generate hypotheses and guide future research strategies for evaluating PEACE or similar clinical pathways. Suggestions and considerations for future data collection are summarised in this section.

Firstly, the nature of the PEACE Pathway adaptations needs to be considered. As described in Chapter 1 (1.2.3), the PEACE Pathway focused on meeting patients' needs mostly through environmental adaptations, raising knowledge and awareness among clinicians, and introducing resources to support sensory and communication needs. PEACE did not aim to directly alter the ED treatment itself or provide a different treatment for the ED. Therefore, the impact of the pathway may be best measured by patients' engagement in treatment, increase in social functioning, improvement in skills such as emotion regulation and independent living, or improvement in overall emotional and sensory wellbeing. Preferably, each component of the PEACE Pathway (e.g., the alternative menu, communication passport, sensory tools) should also be evaluated individually, as each may be best evaluated using a customised set of measures (as with the sensory wellbeing workshop evaluation in Chapter 5).

For future trial data collection, standard ED treatment outcomes such as BMI and ED symptom measures would not be the most suitable outcome measure, as the PEACE Pathway does not specifically target recovery from ED, hence a broader measure of functioning or quality of life is needed, such as the Clinical Impairment Assessment proposed by an international group of scholars as a standard measure of quality of life and social functioning for ED (Austin et al., 2023). To support further assessment of cost-effectiveness, it may also be beneficial to include a health-related quality of life measure capable of generating quality adjusted life years (QALYs) (e.g. the EQ-5D measure of health-related quality of life (Herdman et al., 2011) preferred by the National Institute for Health and Care Excellence). Alternatively, cost-effectiveness can be assessed using clinical outcome measures, such as a global functioning assessment (e.g., the Global Assessment of Functioning scale (Hall, 1995) or the Morgan-Russell outcome assessment schedule (Morgan & Hayward, 1988) which has been used in previous trials (Byford et al., 2007)). However, this approach is limited as it doesn't support comparison across different disorders, making relative cost-effectiveness harder to demonstrate against the NICE standards.

For all outcome measures, more follow-up points in the longer run should be considered to investigate if patients' improvement in outcomes maintained in the longer run. This is also important for studies that aim to investigate if autistic characteristics in patients with ED are due to starvation effects. In this dissertation, patients' autistic characteristics measured by the AQ-10 remained stable from admission to discharge, suggesting that they are a trait rather than an ED complication. However, this needs to be tested in longitudinal studies with more follow-ups.

Lastly, when considering scaling up the PEACE Pathway to other services or levels of care, it is crucial to investigate whether other ED services are similar to SLaM and have adequate resources to implement PEACE. Previous multi-centre studies have highlighted the heterogeneity of ED services across the UK, including their differences in demand, capacity and outcomes (e.g. Ayton et al., 2022). Furthermore, this dissertation focused primarily on the inpatient setting. Implementation of PEACE in other levels of care such as day service or outpatient service may face challenges related to the difference in service structure, including but not limited to: programme length, patient's degree of contact with the multidisciplinary team, treatment goal and protocol used, limits on the number and time of sessions provided to each patient, staff team size and frequency of communication. Therefore, future efforts in scaling up PEACE Pathway should consider these differences and plan the best methods for implementation.

9.7 Clinical implications

This dissertation has implications for improving guidelines for treatment adaptations for people with co-occurring ED and autism. First, the review of clinical notes (Chapter 4) and the interviews with clinicians (Chapter 8) both highlighted the need for better clinical guidelines for distinguishing between autism and ED. This is particularly important given the current lack of a standardised autism assessment suitable for identifying potentially undiagnosed autism in the ED population. The AQ-10 short screener (Allison et al., 2012), although pragmatic for screening autism in adults and is recommended by the NICE guidelines (NICE, 2012), may lack specificity in ED populations where symptoms such as anxiety and cognitive rigidity can contribute to false positives on the AQ-10 (Adamson et al., 2022). Recent studies have just started to address the need for distinguishing between common features in autism and ED for clinical guidance. Kinnaird and Tchanturia (2021) published a comprehensive framework of shared features in autism and AN, and highlighted differences in the behavioural presentation, severity, cognitive process, and underlying mechanism of these shared features between the two conditions. However, the differences and similarities theorised in this framework were derived from studies examining autism population and AN population separately. At present, there is a scarcity of research examining commonalities and underlying differences between ED symptoms and autistic features in a clinical sample with the comorbidity.

Indeed, disentangling ED and autism can be much more complicated in a clinical setting, especially when certain presentations are influenced by factors from both conditions, for example restrictive eating could be due to body image concerns (rooted in ED) combined with an autistic need for routine and predictability (see Chapter 8, section 8.3.3). This was one of the major barriers for clinicians to decide whether they should make adaptations. Helpfully, Brede and colleagues (2020) proposed a model of autism-specific mechanism underlying ED difficulties, including how autistic traits could lead to restricted eating directly, through sensory sensitivities and/or cognitive factors, or indirectly, through increasing negative emotions which leads to restricted eating as a coping mechanism. This model is yet to be empirically tested, but it provides a helpful theory for clinicians to consider, or even discuss with patients. Indeed, examination of PEACE case study notes in this dissertation highlighted the usefulness of working with patients collaboratively to investigate what was driving the presenting difficulty before deciding whether or how treatment could be adapted (Chapter 4, section 4.5.2). Autistic patients should be supported to understand their experiences and difficulties: whether a certain difficulty is an ED symptom that should be addressed, an autism-driven need that could be accommodated, or an autism-related difficulty that nevertheless should be managed to facilitate independent living after discharge. Working collaboratively with patients to clarify the cause of their problems using research-informed frameworks, therefore, is a crucial step to developing a care plan for adaptations.

Another core element of the PEACE Pathway was skill training, teaching autistic patients to cope with their sensory needs (see Chapter 5 for details about the sensory wellbeing workshop), voice their communication needs (see Appendix 1.1 PEACE communication passport), plan daily eating and routines (Williams, 2021), and become more aware of their dislikes and special interests (using the communication passport; Appendix 1.1). This is often lacking in standard ED treatments, which do not focus on teaching essential skills for daily tasks, communication, or sensory regulation, as it is expected that ED symptoms and associated cognitive difficulties would improve with weight restoration (Lozano-Serra et al., 2014; Meehan et al., 2006). For people with co-occurring autism and ED, however, their autism related needs are likely to persist given that it is a lifelong neurodevelopmental condition (Sonido et al., 2020). Therefore, treatment adaptations for people with this comorbidity should consider incorporating essential skill teaching to standard ED treatment. Individual elements of the PEACE Pathway that teach specific skills for coping with autistic needs are still to be evaluated. While this dissertation has demonstrated the feasibility of the sensory wellbeing workshop, future research should investigate the effect of other PEACE components, such as the communication passport, for autistic people with ED.

Providing consistent support for clinicians was also highlighted as essential to adapting treatment (Chapter 8, section 8.4.2). In their attempt to individualise and adapt treatment, clinicians are often caught in the interface between patient's needs and organisational structures/goals: specialist ED services (especially outpatient services with heavier patient loads) often have limits on the number of sessions provided to each patient with protocol-specified treatment goals, and so it may become challenging for clinicians to meet the needs of an autistic patient in a fixed number of highly protocolised sessions. It is therefore essential to provide platforms for team supervision (such as the PEACE huddles, see Chapter 1, section 1.2.3.2) where clinicians can discuss challenges and adaptations on a case-by-case basis to ensure peer support for decision making. More resources should also be allocated to regular clinician training to improve their confidence and skills.

Lastly, a need for systemic improvement in aftercare for autistic people was also highlighted in this dissertation. This exceeds the PEACE Pathway's current span of influence and rather reflecting a national need for destigmatising autism, improving diagnostic pathways, and improving community support. The incidence of autism diagnoses among adults in the UK has increased exponentially over the past decades (Russell et al., 2022), yet current service provision for autistic adults is in its infancy compared to services for autistic children (Lipinski et al., 2022; Murphy et al., 2016). The COVID-19 outbreak further limited professional and community support for autistic people and increased backlogs (Oomen et al., 2021). This systemic gap in support for autistic people affects clinicians' decision making in a range of areas (Chapter 8; section 8.4.3), including whether and when to explore autism with patients, how to bridge the gap between adapted environment on the ward and the 'real world' with low support, low autism awareness once a patient is discharged, or how to prevent the potential deterioration post-discharge due to the lack of community support. These factors heavily affect clinicians' readiness and willingness to make adaptations. Therefore, implementing a treatment adaptation pathway requires a system integrated with efficient autism diagnostic and aftercare services. Research on strategies to improve adult autism services in the UK, including assessment and diagnostic services and support networks, is warranted and ongoing (Brede et al., 2022; Riese & Mukherjee, 2022; Wigham et al., 2022).

9.8 Limitations

A number of the included studies in the systematic review in Chapter 2 suffered from small sample sizes, which may have led to a lack of power to identify true differences between patients with and without autism. Most of the clinical studies included in the Review 2 also reported missing data and high attrition rates at follow-up, making the results less reliable. Nevertheless, the results synthesised from these early studies are hypothesis generating and warrant future research with more robust study designs. It should also be noted that the review used a very broad search strategy with minimal limits, and the recentness and relative scarcity of studies investigating the comorbidity meant that a significant proportion of the abstracts retrieved by the search were not relevant to the review. Therefore, the manual shortlisting of articles was a time-consuming process that has potential for human error.

In studies using data from the service audit database at SLaM ED service (Chapter 3, Chapter 6 and Chapter 7), common limitations are rooted in the measures used in the audit. The audit used self-report questionnaires, it is therefore possible for individuals to deny or minimise ED symptoms on measures such as the Eating Disorder Examination Questionnaire (EDE-Q). Moreover, the specificity of autism screening tools such as the AQ-10 in the ED population has been controversial. The internal consistency for AQ-10 in the audit database (Cronbach's $\alpha = 0.78$) was acceptable but not excellent. Future studies should consider combining assessment interviews with self-report measures of ED symptoms, as well as developing and using measures of autistic characteristics that are more suitable for the ED population. The audit does not record which patients had premature disengagement from treatment by self-discharge; including these patients may have affected the outcomes in this evaluation. Missing data is another common limitation for naturalistic clinical audit data. However, this does not affect the robustness of the clustering in Chapter 3, given that Bayesian inference was used for its enhanced interpretability in observational data; whereas the clinical evaluation in Chapter 6 used mixed models with maximum likelihood to allow variables with missing data to be included in the model estimates. Still, it would be of interest to examine whether the same outcomes are obtained in larger, controlled studies with more complete data.

Another limitation is in regards to participant grouping. In Chapter 6 (Clinical Evaluation) and Chapter 7 (Cost-savings Analysis), all data was collected in a naturalistic setting as opposed to a trial. The PEACE and TAU groups were essentially admissions from two time periods and the conditions were not controlled. This lack of randomisation inevitably introduces bias. Furthermore, the COVID-19 outbreak affected the PEACE group but not the TAU group, creating further barriers to interpretation of the results. To facilitate interpretation, sensitivity analyses were therefore conducted to investigate outcomes excluding the data points affected by the COVID-19. Lastly, although patients are grouped to PEACE and TAU based on exposure to PEACE, their actual exposure to PEACE Pathway implementation is impossible to gauge. Because PEACE was implemented gradually in a stepwise manner, patients' exposure could be affected by many factors, for example the amount of PEACE training their clinicians have attended at the time. This dissertation attempted to quantify patient exposure based on their dates of admission and discharge and in which group (PEACE or TAU) they spent the majority of their admission to give a best estimate. However, future controlled trials with more rigorous design are needed to investigate the effect of PEACE Pathway in comparison to standard treatment. Considerations for measures to be included in future trials are included in 9.6.3.

For the qualitative studies in this dissertation (Chapter 4 and Chapter 8), we acknowledge that researcher bias may affect the results to some extent. To control for this, a second coder who is from a clinical background (and therefore very different from the candidate's own research background) analysed data independently with the candidate for both qualitative studies. Another limitation for Chapter 8 was the lack of nursing staff in the sample. Nursing staff's feedback could be invaluable as they have direct daily contact with patients, and should be investigated by future studies. However, the heterogeneity of the study sample should strengthen the study, as participating clinicians varied in gender, age, seniority, and discipline.

Lastly, it should be noted that in all analyses in this dissertation, autistic patients refer to those who scored over the threshold on the short screener AQ-10, rather than patients with a confirmed diagnosis of autism. Therefore, outcomes of the PEACE Pathway for people with a confirmed diagnosis remain to be evaluated. However, using a trait approach in ED comorbidity studies has its value, especially when autism is commonly underdiagnosed in this predominantly female population (Loomes et al., 2017).

9.9 Conclusions

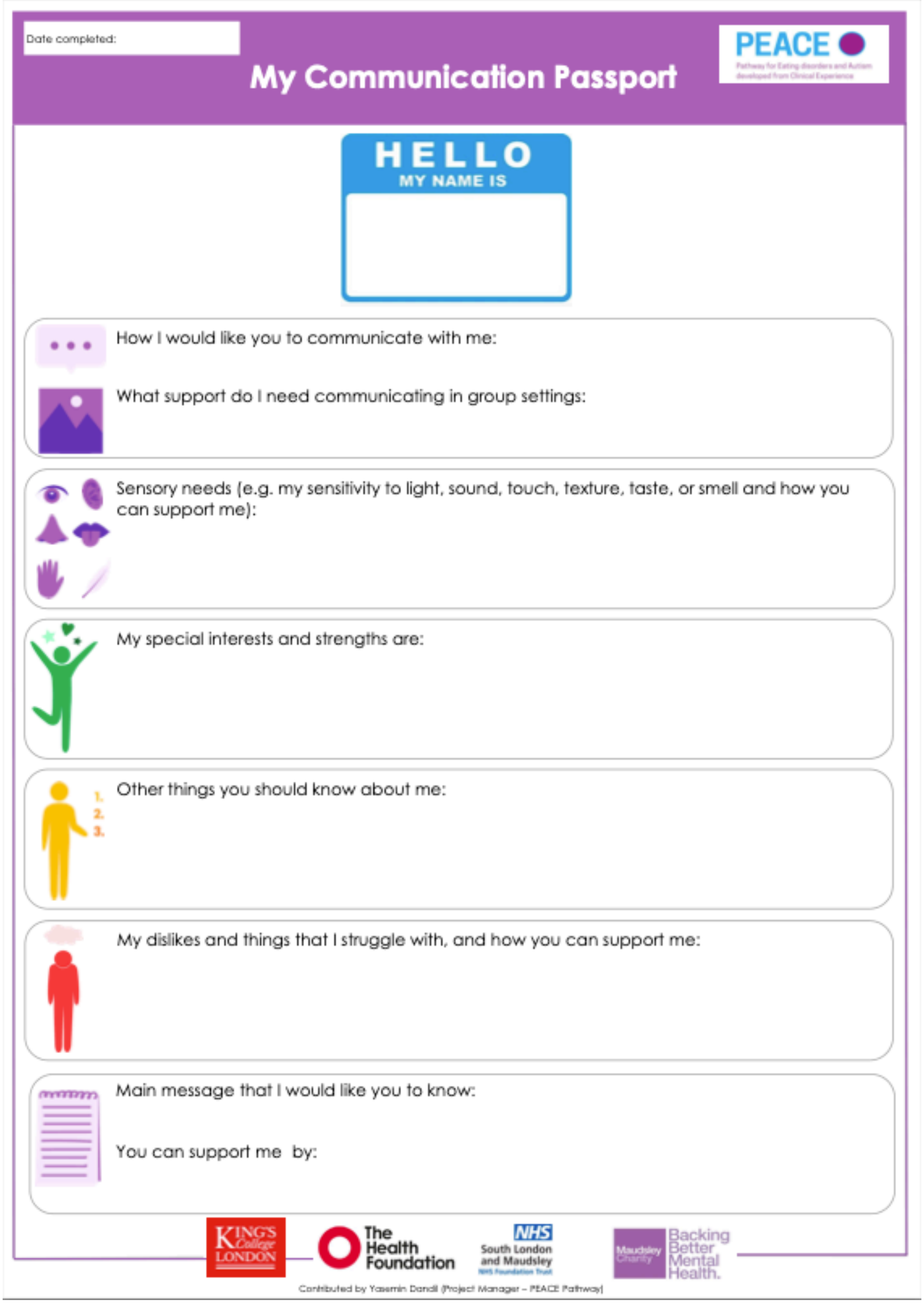
This dissertation presents a mixed methods evaluation of the PEACE Pathway, which was identified by a systematic review to be the only treatment adaptation pathway for people with co-occurring autism and ED. It provides evidence for the link between co-occurring autism and worse ED outcomes such as more severe comorbid depression and anxiety symptoms, increased use of intensive treatment, and generally more severe clinical presentation, which highlights the need for systematic adaptations to standard ED treatment programmes, such as the PEACE Pathway.

PEACE case studies and clinical notes reflect common clinical challenges associated with supporting the comorbidity, such as patients' communication difficulties, sensory sensitivities, emotion and eating difficulties, cognitive rigidity, other comorbid complications, and issues with autism screening and maintaining proper treatment boundaries. This dissertation further explores the PEACE Pathway clinicians' approach in addressing these challenges using a number of resources developed by the PEACE Pathway. Several benefits of PEACE are highlighted, such as increased awareness and knowledge about autism across the service, increased flexibility and individualisation in clinicians' approach, improved treatment engagement in autistic patients, increased clinicians' confidence in working with patients, and improved availability of resources and tools to support autism comorbidity. However, the results also highlight a need for better clinical guidelines for distinguishing between autism and ED, improvement in autism screening tools for clinical use, continuous support for clinicians, further testing of outcomes at different levels of care, and a national need for improvement in the diagnostic pathway and community support for autism.

An examination of clinical audit data at the SLaM ED service concluded that PEACE led to substantial and significant improvement in all clinical measures in patients upon finishing treatment, although there was no significant difference in patients' improvement in these outcomes before and after PEACE was implemented. However, PEACE implementation did lead to reduced use of intensive treatment in autistic patients, which brought cost-savings to the service. In addition, this dissertation evaluated a component of the PEACE Pathway, the sensory wellbeing workshop, and found that the workshop produced significant improvement in patients' sensory wellbeing. Evaluation of other components of the PEACE Pathway, such as the communication passport, is warranted. Overall, this dissertation shows that the PEACE Pathway has increased autism awareness at the SLaM ED service and improved clinicians’ ability to meet patients’ needs without compromising ED treatment outcomes, while reducing the length of hospitalisation for autistic patients to bring cost-savings to the service.

Appendices

Appendix 1.1 PEACE communication passport



Date completed:

My Communication Passport

How I would like you to communicate with me:

What support do I need communicating in group settings:

Sensory needs (e.g. my sensitivity to light, sound, touch, texture, taste, or smell and how you can support me):

My special interests and strengths are:

Other things you should know about me:

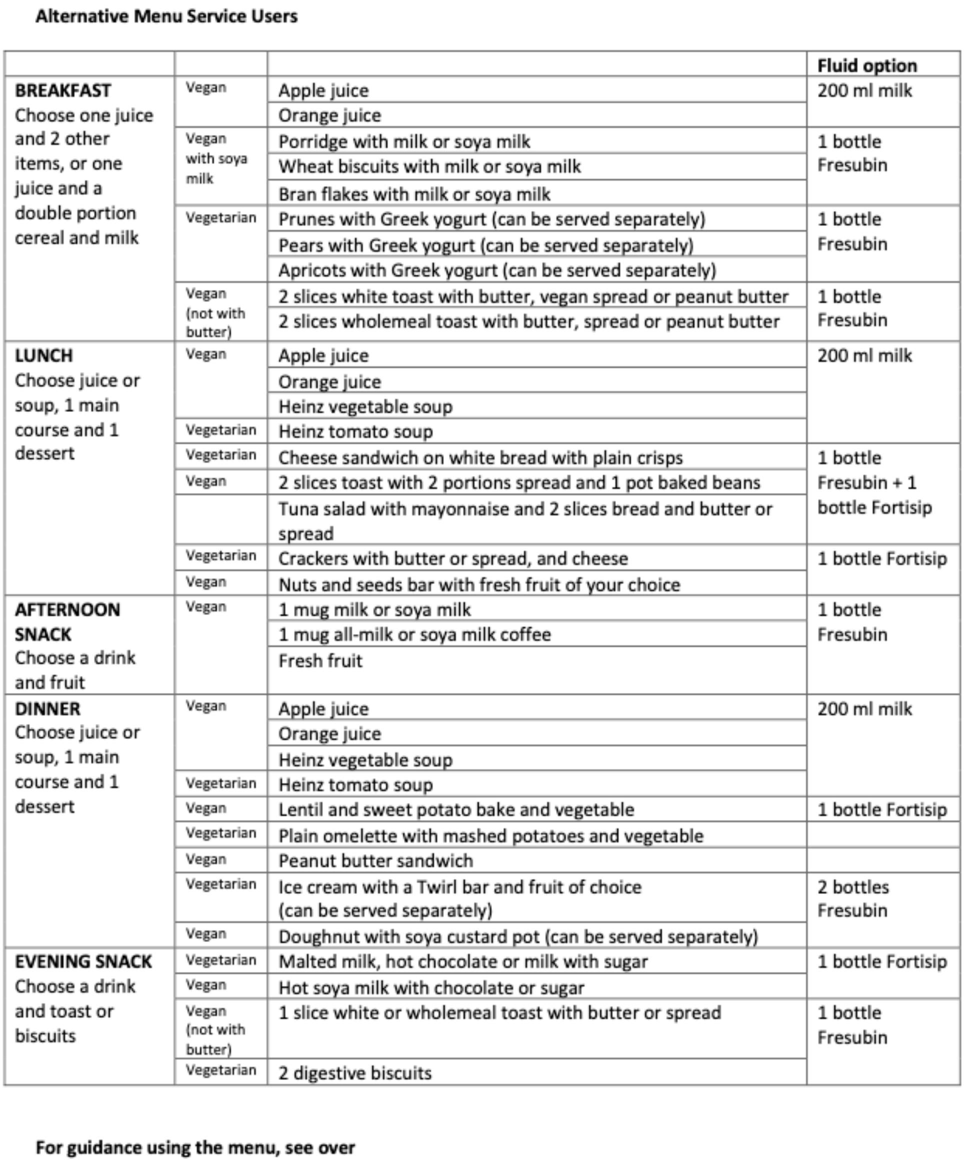
My dislikes and things that I struggle with, and how you can support me:

Main message that I would like you to know:

You can support me by:

Contributed by Yasemin Dandil (Project Manager – PEACE Pathway)

Appendix 1.2 Example of the PEACE alternative menu



Alternative Menu Service Users

			Fluid option
BREAKFAST Choose one juice and 2 other items, or one juice and a double portion cereal and milk	Vegan	Apple juice	200 ml milk
		Orange juice	
	Vegan with soya milk	Porridge with milk or soya milk	1 bottle Fresubin
		Wheat biscuits with milk or soya milk	
		Bran flakes with milk or soya milk	
	Vegetarian	Prunes with Greek yogurt (can be served separately)	1 bottle Fresubin
		Pears with Greek yogurt (can be served separately)	
		Apricots with Greek yogurt (can be served separately)	
	Vegan (not with butter)	2 slices white toast with butter, vegan spread or peanut butter	1 bottle Fresubin
		2 slices wholemeal toast with butter, spread or peanut butter	
LUNCH Choose juice or soup, 1 main course and 1 dessert	Vegan	Apple juice	200 ml milk
		Orange juice	
		Heinz vegetable soup	
	Vegetarian	Heinz tomato soup	
	Vegetarian	Cheese sandwich on white bread with plain crisps	1 bottle Fresubin + 1 bottle Fortisip
	Vegan	2 slices toast with 2 portions spread and 1 pot baked beans	
		Tuna salad with mayonnaise and 2 slices bread and butter or spread	
	Vegetarian	Crackers with butter or spread, and cheese	1 bottle Fortisip
	Vegan	Nuts and seeds bar with fresh fruit of your choice	
AFTERNOON SNACK Choose a drink and fruit	Vegan	1 mug milk or soya milk	1 bottle Fresubin
		1 mug all-milk or soya milk coffee	
		Fresh fruit	
DINNER Choose juice or soup, 1 main course and 1 dessert	Vegan	Apple juice	200 ml milk
		Orange juice	
		Heinz vegetable soup	
	Vegetarian	Heinz tomato soup	
	Vegan	Lentil and sweet potato bake and vegetable	1 bottle Fortisip
	Vegetarian	Plain omelette with mashed potatoes and vegetable	
	Vegan	Peanut butter sandwich	
	Vegetarian	Ice cream with a Twirl bar and fruit of choice (can be served separately)	2 bottles Fresubin
	Vegan	Doughnut with soya custard pot (can be served separately)	
EVENING SNACK Choose a drink and toast or biscuits	Vegetarian	Malted milk, hot chocolate or milk with sugar	1 bottle Fortisip
	Vegan	Hot soya milk with chocolate or sugar	
	Vegan (not with butter)	1 slice white or wholemeal toast with butter or spread	1 bottle Fresubin
	Vegetarian	2 digestive biscuits	

For guidance using the menu, see over

Early Stages - Getting Used to Regular Eating

You will probably begin your stay on the ward by choosing food from a menu which offers quite limited choices, and gradually increase the amount and variety of food you have, over a couple of weeks.

You will then be able to choose your food from the ward main menu. This menu offers a wide range of choices, and is different every day for 28 days, then begins again (the "four-week menu cycle"). The menu is developed from the main hospital menu, and offers dishes from a variety of cultures, with a wide range of cooking styles. It includes vegetarian and vegan options. It is carefully planned to ensure that whatever choices you make, the calories are about the same.

If the Main Menu is Not Always Right for You

We know that no menu can please everyone all the time, and there may be meals when you can't find any option that you like, or feel able to eat. You may feel a bit overwhelmed by the amount of choices, or find the food is too unfamiliar. To help, we also provide an alternative menu for lunch and dinner, with limited options of quite plain food. It is the same every day, though the choices at lunch and dinner are different. The calories match the main menu.

If you know you will find it difficult to choose from the main menu, arrange to see the dietitian as soon as possible, to make a care plan to meet your needs.

Times When You Can Use the Alternative Menu

1. You might find that you can't manage to eat the meal you selected from the main menu. Most people find this happens sometimes, for many reasons. Perhaps you were trying to challenge yourself with a new food, or an old favourite you have been avoiding, or maybe you are having a difficult day. Staff can provide a replacement drink, or a meal from the alternative menu to replace the one you chose, though not all choices are available at short notice. If this happens, you should talk to a member of staff afterwards, to care plan how you will manage if this happens again. You can see the dietitian to do this if you wish.

2. When you are looking at the main menu to make your choices, you may find there is a meal that doesn't provide any choice that you could eat. If this happens, talk to one of the staff. You can make a care plan for you to use the alternative menu at up to three meals a week. You can choose one course from the alternative menu, say just the dessert, and take the rest of the meal from the main menu, or you can choose the whole meal.

3. You may want to use the alternative menu more than three times a week. Perhaps you have been sticking to a very rigid eating routine, and don't feel ready yet to be more flexible. There may be a lot of foods that you dislike, or you may find it hard to make choices from a wide range of options. Whatever the reasons, you can make a care plan with the dietitian to use the alternative menu as often as you need. You can also plan to move on to choose more from the main menu if you want to work on expanding the variety of foods you eat.

How to use the Alternative Menu

Once you have a care plan to use it, cross out any items you don't want when you are making your menu choices, and clearly write in your choices from the alternative menu when you want to. Make sure you use it as you have agreed in your care plan – if this is difficult, see the dietitian to adjust your plan. If you have agreed a care plan to use only the alternative menu for a while, the dietitian can give you copies to order your choices. She can adjust it to show only the options you want.

Appendix 2.1 Autistic characteristics in eating disorders: Treatment adaptations and impact on clinical outcomes

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WILEY

REVIEW

Autistic characteristics in eating disorders: Treatment adaptations and impact on clinical outcomes

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Abstract

Objective: Autistic people with eating disorders (EDs) may have special needs that are not met in standard ED treatment, raising the need for treatment adaptations to accommodate co-existing autism spectrum condition (ASC). Little is currently known about the nature of existing treatment options or adaptations for this population. We conducted a pre-registered systematic review to: (1) identify research articles describing existing interventions for patients with ED and comorbid ASC, and to critically review evidence of their clinical effectiveness and cost-effectiveness (Review 1); (2) review the impact of ASC comorbidity on ED clinical outcomes (Review 2).

Method: Peer-reviewed studies published until the end of December 2020 were identified through a systematic search of the electronic databases: Medline, Embase, PsycINFO, Web of Science, CINAHL, Scopus and Cochrane Library.

Results: Only one clinical pathway of treatment adaptations (the 'PEACE' pathway) was identified in Review 1 with early evidence of cost-savings and favourable treatment outcomes. ASC characteristics were shown in Review 2 to have no direct impact on physical outcomes or ED symptoms, but could be associated with higher rates of comorbidities and greater use of intensive ED treatment. Additionally, patients with ASC characteristics may benefit more from individual sessions, rather than group sessions.

Conclusions: Any new treatments or treatment adaptations may not directly impact on ED symptoms, but may be better able to support the complex needs of the ASC population, thus reducing subsequent need for intensive treatment. Future research is warranted to explore evidence of clinical and cost-effectiveness of interventions for this population.

Abbreviations: ADI-R, Autism Diagnostic Interview-Revised; ADOS-2, Autism Diagnostic Observation Schedule, Second Edition; AN, anorexia nervosa; AQ, Autism Spectrum Quotient; AQ-10, Autism Spectrum Quotient 10-item version; ASC, autism spectrum condition; ASDI, Asperger Syndrome Diagnostic Interview; BED, binge eating disorder; BMI, body mass index; BN, bulimia nervosa; CBT, cognitive behavioural therapy; CRT, Cognitive Remediation Therapy; DFlex, Detail and Flexibility questionnaire; ED, eating disorder; EDE-Q, Eating Disorders Evaluation Questionnaire; HADS, Hospital Anxiety and Depression Scale; MeSH terms, Medical Subject Headings; MROAS, Morgan–Russell outcome assessment schedule; PEACE, Pathway for Eating disorders and Autism developed from Clinical Experience; RCT, randomised controlled trial; ROCF, Rey–Osterrieth Complex Figure test; SAS, Social Aptitude Scale; SDQ, Strengths and Difficulties Questionnaire; SEED, Short Evaluation of Eating Disorders; WSAS, Work and Social Adjustment Scale; YCED, Yorkshire Centre for Eating Disorders.

KEYWORDS
autism, comorbidity, eating disorder, systematic review, treatment

Highlights

- PEACE pathway was identified as the only clinical pathway of treatment adaptations for patients with anorexia nervosa and autism.
- Autistic characteristics have no direct impact on eating disorder symptoms and physical outcomes of treatment.
- However, autistic characteristics could be associated with higher rates of comorbidities and greater use of intensive treatment.

1 | INTRODUCTION

The potential link between eating disorders (EDs) and autism spectrum condition (ASC) was first conceptualised in the 1980s (Gillberg, 1983). Since then, growing research has attempted to explore the overlapping cognitive inefficiencies between the two conditions, including: set-shifting (Tchanturia et al., 2012; Westwood, Stahl, et al., 2016), theory of mind (Leppanen et al., 2018), central coherence (Lopez et al., 2008; Oldershaw et al., 2011) and socio-emotional aspects, such as alexithymia (Hobson et al., 2020; Poquérusse et al., 2018; Råstam et al., 1997), social anhedonia (Chevallier et al., 2012; Harrison et al., 2014) and social functioning (Tchanturia et al., 2013).

Multiple reviews have examined the overlap between EDs and ASC (Huke et al., 2013; Kinnaird & Tchanturia, 2021; Saure et al., 2020; Westwood, Eisler, et al., 2016, 2017). Huke et al. (2013) published the first systematic review to synthesise studies on the prevalence of ASC in ED populations. The mean estimated prevalence of ASC from this review was 23%, although six of the eight included studies in the review were from the same Swedish longitudinal cohort (Råstam et al., 1989) which could have contributed to potential bias. Another issue that was reported in the review was the lack of consistency in ASC screening measures in the included studies, which made comparison across studies difficult.

Westwood, Eisler, et al. (2016) conducted a systematic review of studies using the Autism Spectrum Quotient (AQ), a 50-item questionnaire investigating symptoms of ASCs in adults (Baron-Cohen et al., 2001) or the shorter 10-item version AQ-10 (Allison et al., 2012) to assess autistic features in patients with anorexia nervosa (AN). The review concluded that individuals with AN had significantly more autistic features compared to healthy controls. An updated literature review by the same group later reported consistency in literature on the overrepresentation of symptoms of ASC in AN (Westwood et al., 2017).

The most recent systematic review examined the association between characteristics of ASC and duration of illness of AN (Saure et al., 2020), and suggested that a prolonged course of AN appears to be associated with problems in central coherence, cognitive flexibility and emotion recognition, which are also underlying neuropsychological characteristics distinctive to ASC. This finding indicates similar characteristics between ASC and severe and enduring EDs based on self-report.

A recent overview study (Kinnaird & Tchanturia, 2021) presented a framework of clinical features associated with autism in AN, including obsessional interests, emotional insight, social difficulties, attentional biases, preference for routines and cognitive rigidity. These features, whilst common in autism, are more likely to be centred on food and weight in AN. For example, specific interests in autism could relate to any topic, for example, animals, music, numbers, whereas in AN it is more likely to be centred on dieting. When these two conditions are combined, the article pointed out, this could create an additive effect, with people with AN and autistic characteristics exhibiting additional difficulties not seen in AN only.

It is worth noting that only the first review (Huke et al., 2013) included studies on bulimia nervosa (BN) and ASC, whereas the other reviews all focused on ASC and AN only. Indeed, only a limited amount of studies to date have discussed links between ASC and ED subtypes other than AN, such as BN or binge eating disorders (BEDs). A pilot study in 2017 reported for the first time that not only AN but also BN and BED patients show greater autistic characteristics compared to healthy controls (Gesi et al., 2017). More recently, studies have reported a high prevalence of AN and BED in individuals with childhood onset ASC and/or attention-deficit/hyperactivity disorder (Karjalainen et al., 2016), also that patients with BED show higher autistic characteristics compared to other subtypes (Numata et al., 2021).

These links between ED and ASC could have substantial implications for current treatment strategies for ED. Indeed, studies have found that having autistic characteristics is a negative predictor of treatment outcome for EDs (Nielsen et al., 2015; Speranza et al., 2007), raising the need for treatment programmes to be modified to accommodate co-existing ASC. Patients with AN and autistic characteristics may have more difficulties in expressing their needs and communicating during treatment sessions, and clinicians have also expressed their lack of confidence in treating patients with this comorbidity (Kinnaird et al., 2017). Furthermore, research has shown that over 90% of children and adults with autism have sensory abnormalities in specific domains of vision and smell/taste (Leekam et al., 2007), which may contribute to active avoidance of certain foods in AN patients with autistic characteristics. These sensory difficulties may be hard to address without identifying and understanding the role of autism in the EDs, which again suggests the need for ED treatment options or treatment adaptations for patients with comorbid ASC.

New or adapted treatment options, however, should be evidence-based to ensure they are of clinical benefit for patients with both conditions. Little is currently known about the nature of existing ED treatment options or treatment adaptations for patients with comorbid ASC. In addition, any new treatment options or adaptations are likely to require additional resources to implement. In a health system with constrained resources, such additional costs must be justified through demonstration of value for money. Therefore, evidence of effectiveness and cost-effectiveness of existing options for patients with ED and ASC is required to justify the required resource allocation.

2 | METHODS

2.1 | Aims and objectives

The primary aim of this systematic review was to identify research articles describing existing interventions for patients with ED and comorbid ASC, and to critically review evidence of their clinical effectiveness and cost-effectiveness (Review 1). We hypothesised that such interventions would be rare, therefore a secondary aim was included to systematically review the impact of ASC comorbidity on clinical outcomes in patients with ED (Review 2), in order to provide insight into whether patients with autism have different ED outcomes or trajectory compared to patients without comorbid ASC, and thus to provide evidence to support the need for new treatments or treatment adaptations.

It was hypothesised that the number of studies describing or evaluating the effectiveness or cost-effectiveness of adapted interventions for the comorbidity would be low, and that ASC comorbidity would result in poorer outcomes in patients with ED, such as slower weight improvement, longer hospital admissions and poorer ED psychopathology outcome.

This review was registered in the International Prospective Register of Systematic Reviews (PROSPERO; ID: CRD42021232322) after the search strategy was finalised.

2.2 | Eligibility criteria

Eligibility criteria were determined following the Population, Intervention, Comparison, Outcome and Study design (PICOS) Framework for both Review 1 (identification and evaluation of interventions for ED and ASC comorbidity) and Review 2 (impact of ASC comorbidity on clinical outcome in patients with ED).

2.2.1 | Inclusion and exclusion criteria for Review 1

Adults and young people over the age of 12 years, with an ED diagnosis and either autistic characteristics screened using a validated screening tool or a formal ASC diagnosis were included. ED diagnoses of AN (all subtypes), BN, BED or avoidant restrictive food intake disorder from the Diagnostic and Statistical Manual of Mental Disorders IV or 5 (DSM IV/5; American Psychiatric Association [APA], 1994, 2013) or the International Classification of Diseases 10 or 11 (ICD 10/11; World Health Organization, 1993, 2018) were included.

Both service-level or treatment-level adaptations and new treatments for patients with comorbid ED and ASC were included. Service-level adaptations were defined as those applied to primary and secondary care ED services with the aim of changing the treatment environment, staff training, case management and referral process to make them more acceptable to individuals with autism. Examples include clinician training in the assessment and understanding of ASCs, and adjusting treatment environment (noise reduction, decluttered walls, etc.) in acknowledgement of atypical sensory profiles.

Treatment-level adaptations were defined as those applied to individual and group treatment processes and manuals to make them more effective for individuals with autism, such as individualised strategies modifying the length, pace and focus of sessions, enhanced interviewing techniques or adapted psychoeducation materials for patients and carers.

In this review, the term 'intervention' will be used when referring to new treatments or adaptations to existing treatments for patients with the comorbidity, including both treatment-level and service-level adaptations.

For studies describing interventions for patients with ED and ASC, without any assessment or effectiveness or cost-effectiveness, no comparison group was necessary and thus no inclusion criteria were applied. For studies evaluating the clinical effectiveness or cost-effectiveness of interventions for patients with ED and ASC, a comparison group was required. This could be a separate, concurrent control or comparison group or the cases could be acting as their own controls in a before-and-after design.

Any outcome and all study designs was included for studies that either described or evaluated the effectiveness or cost-effectiveness of interventions.

Non-English language publications, conference abstracts, letters and articles with no full-text available were excluded. Diagnosis of pica, rumination disorder or feeding difficulties in children were excluded as they are not commonly treated at ED services.

2.2.2 | Inclusion and exclusion criteria for Review 2

The population of interest were the same as for Review 1. All types of interventions targeting people with EDs were included to consider outcomes in any setting, including hospital, community, school, care institution or outpatient-based interventions.

To investigate the impact of ASC comorbidity on ED outcomes, studies comparing between individuals with and without ASC characteristics on outcomes commonly used in ED research (physical outcomes, such as Body mass index [BMI] or weight change), psychopathological outcomes (ED symptoms or comorbid symptoms) or service use (such as premature discharge, treatment completion or augmentation)) were included.

Clinical and community studies that investigated ED outcomes were included, including randomised controlled trials, cohort studies, case–control studies, cross-sectional studies, case series and before-and-after observational studies.

Non-English language publications, conference abstracts, letters and articles with no full-text available were excluded. In terms of study designs, reviews and case reports of individual patients were excluded due to lack of statistical validity. Diagnosis of pica, rumination disorder or feeding difficulties in children were excluded as they are not commonly treated at ED services.

2.3 | Search strategy

The same search strategies were used for Review 1 (interventions for patients with ED and comorbid ASC) and Review 2 (impact of ASC on clinical outcomes in patients with ED). This was accomplished by conducting a single, broad search with minimal limits, but applying different inclusion and exclusion criteria for the two reviews at the abstract screening stage. In accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) guidelines (Moher et al., 2009), the following electronic databases were searched for relevant literature from inception to the end of December 2020: Medline, Embase, PsycINFO, Web of Science, CINAHL, Scopus and Cochrane Library. Each search strategy followed a similar structure and included relevant Medical Subject Headings (MESH terms) and keywords limited to the title, abstract and keywords of publications. In addition, the NHS Economic Evaluation Database was searched for relevant economic evaluation studies.

Search terms were a combination of Medical Subject Headings (MeSH terms) and keywords in all possible permutations: (Anorexia Nervosa, Bulimia Nervosa, Eating Disorders, Eating Disorder Not Otherwise Specified, Avoidant Restrictive Food Intake Disorder, Purging Disorder, Binge Eating Disorder) AND (Autism Spectrum Disorder, Autism, Autistic Disorder, Asperger's Syndrome, Pervasive Developmental Disorder). No search term for intervention type was used to ensure comprehensiveness of the search. In addition, using only ED terms and ASC terms allowed the same search strategy to be used by both Review 1 and Review 2. The search strategy is provided in full in Supporting Information S1.

Citations of all search results were first imported into the EndNote citation management software. Duplicates were removed. All abstracts were first screened by ZL for relevance and shortlisted for the two review questions, one shortlist for each. Where there was any uncertainty, abstracts were retained. Overlap was allowed and some studies were included in both shortlists. All shortlisted articles were then read in entirety by two reviewers (ZL and DH) independently to ascertain whether they met the corresponding inclusion criteria. Disagreements were discussed with supervisors SB and KT until a consensus was reached. References of included studies and relevant reviews identified by the search strategies were also checked by hand for additional eligible studies.

2.4 | Analysis

For Review 1, it was hypothesised that the number of studies describing or evaluating such interventions would be very low, and any studies that evaluated the clinical effectiveness or cost-effectiveness of such interventions would be subject to significant heterogeneity in sample characteristics and outcome measures. Thus, a narrative synthesis of the results would be most appropriate. For Review 2 on the impact of ASC on clinical outcomes in patients with ED, a narrative review was appropriate given the nature of the question. Overall, the main output of this systematic review was descriptive.

3 | RESULTS

Initial search of the seven databases yielded 3527 publications. The search located two relevant literature reviews that included studies of the impact of ASC on clinical outcomes in ED (Brown & Stokes, 2020; Westwood et al., 2017). The reference lists for the reviews were checked and no additional studies were located. A search of the NHS Economic Evaluation Database also located no additional studies.

All 3,527 records were downloaded into Endnote and duplicates were removed, leaving 2037 abstracts to be checked and shortlisted. At the full review stage, the two reviewers agreed on 100% of the abstracts for Review 1 and 93% of abstracts for Review 2. Disagreements in Review 2 were discussed with the supervisors until agreement was reached.

3.1 | Screening of abstracts for Review 1

Figure 1 provides the PRISMA flow diagram of the records retrieved for Review 1: description and evaluation of interventions for patients with ED and comorbid ASC. Out of the 2,037 records screened, 20 articles were identified as potentially meeting inclusion criteria for Review 1 and subject to full text review. Of these, three articles met the inclusion criteria (Smith & Tchanturia, 2020; Tchanturia, Smith, Glennon, & Burhouse, 2020; Tchanturia et al., 2021), all published by the same research group and either described or evaluated the

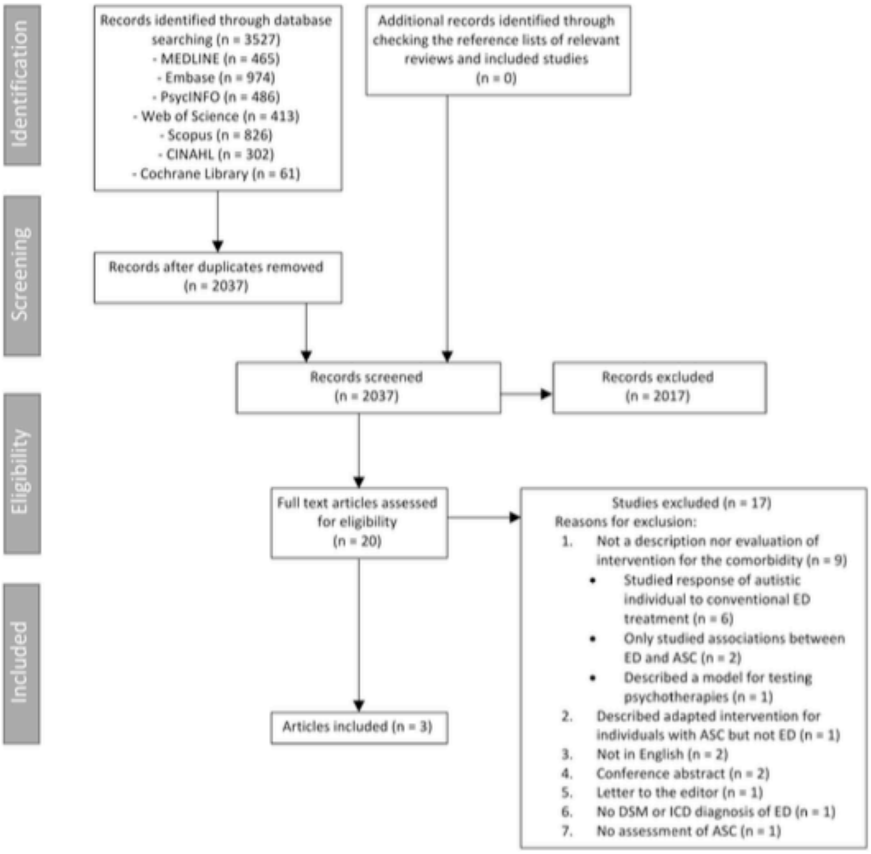

FIGURE 1 PRISMA diagram of the records retrieved for Review 1

Pathway for Eating disorders and Autism developed from Clinical Experience (PEACE pathway).

The two articles describing the PEACE pathway intervention are summarised in Table 1. The first article (Tchanturia, Smith, Glennon, & Burhouse, 2020) describes the design and implementation of the PEACE pathway. The pathway was co-developed by the clinical team and service users following a needs assessment, and piloted at an ED service in South London and Maudsley NHS Foundation Trust, London. All patients at the ED service received a DSM-5 diagnosis of ED. The implementation involved a series of treatment adaptations, including: adaptations to various therapeutic modalities, such as cognitive behavioural therapy (CBT) and formulation-based approach, introduction of workshops and psychoeducation materials on sensory well-being and communication and reinforcing carers' support. Service-level adaptations were also described in this article: the ward environment was redecorated, and clinician training on autism assessment (AQ-10, ADOS-2 and ADI-R) and autism awareness was introduced.

The second article (Smith & Tchanturia, 2020) focussed on one part of the implementation of the PEACE pathway: the PEACE huddles, which are brief, weekly meetings of the clinical teams to share feedback on PEACE patients and updates on the pathway implementation. The article included a study which aimed to evaluate clinicians' opinions on the benefits of the huddles in ED treatment settings in providing a higher level of care for patients with comorbid ASC. Because no patient-level measure of clinical effectiveness was evaluated and only clinician feedback was collected, the article was included in this review as a description of an intervention for ED and comorbid ASC, rather than as an evaluation of the effectiveness of an intervention for ED and comorbid ASC. A total of 283 responses evaluating huddles were collected from participating clinicians over a 12-months period, and the usefulness of the PEACE huddles were rated 84 of the 100 on average. Overall, the huddles were reported to be well-structured, focussed and well-received. Data extracted from this study are summarised in Table 1.

The third article (Tchanturia et al., 2021, early version published in 2020 and therefore picked up by the search), summarised in Table 2, was a preliminary economic evaluation exploring the cost-savings generated by the PEACE pathway and was the only manuscript identified which contained an evaluation. Whilst not a formal assessment of cost-effectiveness, which requires the comparative analysis of both costs and effects, this was an early, hypothesis generating study to explore potential for

TABLE 1 Data extracted from included articles describing interventions for ASC co-morbidity

References	Country	Study design	Aims	Intervention
Tchanturia, Smith, Glennon, & Burhouse (2020)	UK	Implementation paper	To describe the design and implementation of the PEACE pathway	Treatment-level adaptations • Adaptations to therapeutic modalities (CBT, DBT, formulation-based approach, CRT and CREST) • Introduction of workshops and psychoeducation materials • Reinforcing carers' support Service-level adaptations • Redecoration of ward environment • Clinician training on autism assessment and awareness
Smith and Tchanturia (2020)	UK	Survey	To evaluate the clinicians' opinions on the benefits of PEACE huddles in ED treatment settings	PEACE huddles, which are weekly meetings of the clinical team to • Share feedback on PEACE patients who have comorbid ED and ASC • Share updates and gather feedback on the pathway implementation • Improve team communication • Update on any other PEACE-related business

Abbreviations: ASC, autism spectrum condition; CBT, cognitive behavioural therapy; CRT, cognitive remediation therapy; CREST, cognitive remediation and emotion skills training; DBT, dialectical behaviour therapy; ED, eating disorder; PEACE, pathway for eating disorders and autism developed from clinical experience.

TABLE 2 Data extracted from included evaluations of interventions for ASC comorbidity

Reference	Country	Study design	Aim	Sample	ED diagnosis	ASC assessment	Outcome	Result
Tchanturia et al. (2021)	UK	Cohort study	To explore the impact of the development of the PEACE pathway on the length and cost of hospital admissions	Not reported in the text but known to the author who was a co-author of the article: $N = 333$ Female = 331 (99%) Age range = 18–65 (mean = 28.3)	AN (DSM-V)	ADOS-2	Length of admission; cost of admission	Implementation of the pathway is associated with a reduction in length of admission of patients with autistic characteristics, leading to estimated cost-savings of £22,837 per patient and approximately £275,000 per year for the service

Abbreviations: ASC, autism spectrum condition; ED, eating disorder.

cost-effectiveness and can be described as a partial economic evaluation, which are not themselves sufficient to inform decisions but often provide the key evidence required for decision-making (Drummond et al., 2015). The article was therefore included in the review.

The study was a service-level retrospective before and after evaluation comparing length of admission and cost of admission in patients with a DSM-5 diagnosis of ED with and without autistic characteristics. Data were collected from clinical records for 6 years before the PEACE pathway was introduced and 2 years after the pathway was introduced. Autistic characteristics were screened by ADOS-2 (Lord et al., 2012). Before the pathway was implemented, the average length of admission for autistic patients was longer (mean 19 weeks) than non-autistic patients (mean 16 weeks). This finding was reversed after the pathway was implemented, with autistic patients spending less time in hospital (mean 13 weeks) than non-autistic patients (mean 17 weeks) on average. Cost-savings associated with the reduction in length of admission of patients with autistic characteristics were estimated to be £22,837 per patient and approximately £275,000 per year for the service as a whole.

3.2 | Screening of records for Review 2

Figure 2 shows the PRISMA diagram for Review 2: impact of ASC comorbidity on clinical outcome in patients with ED. Of the 2037 records, 28 articles were initially identified as potentially meeting inclusion criteria for Review 2 and were subject to full text review. Of these 28 articles, 9 met the inclusion criteria.

The economic evaluation (Tchanturia et al., 2021) included in Review 1 was also eligible for inclusion in Review 2, since it explored the impact of ASC comorbidity on the length of hospital admission, which is a treatment outcome. Of the eight remaining studies eligible for this research question, the majority ($n = 6$) were carried out in the United Kingdom. The remaining two studies were carried out in Sweden. All were published between 2012 and 2021. Characteristics of the included articles are summarised in Table 3.

3.2.1 | Swedish studies

Two of the included studies (Anckarsäter et al., 2012; Nielsen et al., 2015) were based on a Swedish longitudinal cohort initiated in the mid-1980s (Råstam et al., 1989). The longitudinal cohort sample contained 51 participants with AN and 51 gender-matched controls in Gothenburg, Sweden who were examined with

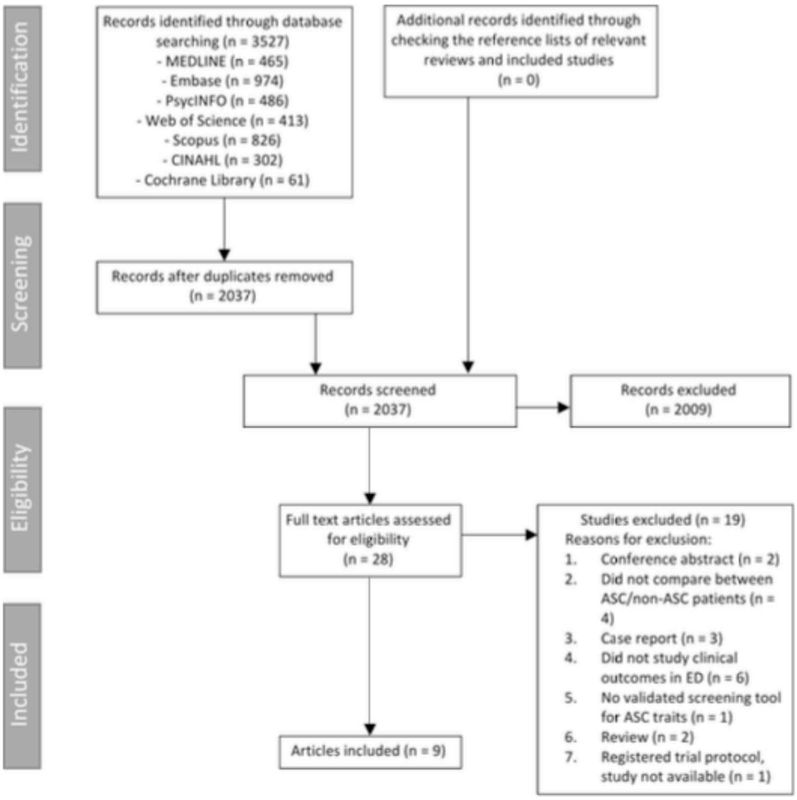

FIGURE 2 PRISMA diagram of the records retrieved for Review 2

assessments of psychiatric disorders, health-related quality of life and general outcomes on different occasions: at the ages of 16 (baseline, Study 1), 21 (Study 2), 24 (Study 3) and 32 (Study 4). All AN cases fulfilled DSM-III-R (APA, 1987) and subsequently DSM-IV (APA, 1994) criteria for AN within a year of the assessment of Study 1 (Råstam, 1992; Råstam et al., 1989). At all four occasions, an investigator blinded to group status assigned ASC diagnoses using instruments that were most up-to-date and comprehensive at each time point: a structured interview with the mother was used at baseline; the Dewey social awareness test (Dewey, 1991), DSM-III-R and a checklist for Asperger's syndrome outlined by Gillberg and Gillberg (1989) were used at Study 2; the ASDI (Gillberg et al., 2001), DSM-IV and the checklist for Asperger's syndrome were used at Study 3; and the ASDI, DSM-IV, the checklist for Asperger's syndrome and the Autism-Spectrum Quotient (AQ; Baron-Cohen et al., 2001) were used at Study 4.

Anckarsäter et al. (2012) used cross-sectional data from Study 4 (at mean age 32 years) of the Swedish longitudinal cohort to investigate the ASC symptoms, personality profiles, neurocognition and outcomes in the sample. A lifetime prevalence of ASC of 33.3% was noted in the AN sample at this time point, compared with 2% prevalence in the matched controls (Anckarsäter et al., 2012). Outcomes were measured with the Morgan–Russell outcome assessment schedule (MROAS; Morgan & Hayward, 1988), a clinical assessment of AN which summarises outcome data on five dimensions: food intake and weight concern, menstrual pattern, mental state, psychosexual state and social relationships and employment activity. The results indicate that participants with AN and comorbid ASC had higher prevalence of personality disorders (20%) and poorer overall outcomes as measured by the MROAS ($p < 0.01$) compared to participants without ASC.

TABLE 3 Data extracted from studies included in Review 2

References	Country	Study type	Aims	Sample	ED diagnosis	ASC assessment	Outcomes measured	Results
Anckarsäter et al. (2012)	Sweden	Cross-sectional, with control	To compare clinical outcomes and cognitive test results between patients with AN with and without an ASC diagnosis	$N = 51$ Female = 48 (94%) Age range not reported (mean = 32)	AN (DSM-IV)	ASDI; DSM-IV diagnosis	Overall clinical outcome based on five scales (Morgan–Russell outcome assessment schedule; MROAS): • Food intake and weight concern • Menstrual pattern • Disturbance of mental state • Psychosexual state • Social relationships and employment activity	• Individuals with AN and comorbid ASC had worse overall outcome (body weight, diet restriction, menstruation, attitude to sex and menstruation, social relationships, relationship with family and mental state) compared to individuals with AN without ASC and healthy controls
Huke et al. (2014)	UK	Cross-sectional	To examine ASC features in relation to treatment completion and ED psychopathology in patients with AN	$N = 32$ Female = 32 (100%) Age range not reported (mean = 28.7)	AN (DSM-IV)	AQ	ED symptoms (EDE-Q); Treatment completion	• There was no significant relationship between ED symptoms and ASC characteristics • Patients with ASC were more likely to complete ED treatment as planned compared to patients without ASC, although this result was not statistically significant
Nielsen et al. (2015)	Sweden	Cohort study	To analyse the influence of diagnostic stability of ASC on clinical outcome in patients with teenage onset AN.	$N = 51$ Female = 48 (94%) Mean age = 32	AN (DSM-IV)	ASDI; AQ	Overall clinical outcome based on five scales (Morgan–Russell outcome assessment schedule; MROAS): • Food intake and weight concern • Menstrual pattern • Mental state • Psychosexual state • Social relationships and employment activity	• Presence of ASC in individuals with AN was negatively associated with mental state, psychosexual state and social relationships and employment activities

(Continues)

TABLE 3 (Continued)

References	Country	Study type	Aims	Sample	ED diagnosis	ASC assessment	Outcomes measured	Results
Tchanturia et al. (2016)	UK	Case series	To investigate the effects of group cognitive remediation therapy (group CRT) for AN patients with and without ASC characteristics	$N = 35$ Female = 35 (100%) Age range not reported (mean age = 26.2)	AN (DSM-V)	AQ-10; ADOS	Cognitive flexibility (DFlex); self-reported ability to change (motivational ruler)	• Patients with low ASC characteristics showed significantly more increase in self-reported ability to change and improvement in cognitive flexibility after the intervention, compared to the high ASC group • In patients with high ASC characteristics, brief group cognitive remediation therapy (group CRT) showed no influence on cognitive flexibility or motivation to change
Stewart et al. (2017)	UK	Cross-sectional	To report the impact of ASC characteristics on treatment outcomes of girls with AN, EDNOS-restrictive subtype or atypical anorexia.	$N = 409$ Female = 409 (100%) Age range = 9–18 (mean = 14.6)	AN (DSM-IV and V), EDNOS-Restrictive (DSM-IV), atypical anorexia (DSM-V)	AQ; SAS	Composite outcome on BMI, bulimic symptoms and menstrual pattern (Morgan–Russell Criteria); ED symptoms (EDE-Q); Depression symptoms (Moods and Feelings Questionnaire); Anxiety symptoms (screen for Child anxiety related disorders); Obsessive and compulsive disorder symptoms (Child Obsessional Compulsive Inventory); Treatment augmentation (through admission to inpatient or intensive day patient programme)	• There was no significant difference in BMI, bulimic symptoms or menstrual pattern between patients with high and low ASC characteristics • ASC characteristics were not correlated with ED symptoms • ASC characteristics were significantly correlated with depression, anxiety and obsessive compulsive symptoms • Patients with ASC characteristics showed a greater need for treatment augmentation compared to patients without ASC

TABLE 3 (Continued)

References	Country	Study type	Aims	Sample	ED diagnosis	ASC assessment	Outcomes measured	Results
Nazar et al. (2018)	UK	Cross-sectional study	To examine the clinical outcomes of adolescents and young adults with anorexia nervosa (AN) comorbid with broad autism spectrum disorder (ASC) or ASC characteristics	$N = 149$ Female = 137 (92%) Age range = 13–21 (mean = 16.9)	AN, EDNOS, atypical AN (DSM-IV)	ASC diagnosis (DSM-IV and ICD 10); SAS	BMI increase; ED symptoms (SEED); Socioemotional difficulties (SDQ); Treatment augmentation (through admission to inpatient or intensive day patient programme)	• There was no significant difference in change in BMI or ED symptoms between patients with or without ASC • The ASC group appeared to have more socioemotional difficulties compared to those without ASC • The ASC group showed a greater need for treatment augmentation compared to patients without ASC
Tchanturia et al. (2021)	UK	Cohort study	To explore the impact of the development of the PEACE pathway on the length and cost of hospital admissions	Not reported in the text but known to the author who was a co-author of the article: $N = 333$ Female = 331 (99%) Age range = 18–65 (mean = 28.3)	AN (DSM-V)	ADOS	Length of admission; cost of admission	• Prior to implementation of adapted interventions, patients with ASC had longer admissions compared to patients without ASC • Implementation of the pathway is associated with a reduction in length and therefore costs of admission of patients with ASC characteristics
Dandil et al. (2020)	UK	Case series	Examine the effects of individual cognitive remediation therapy (individual CRT) treatment for adult women with AN with or without ASC characteristics	$N = 99$ Female = 99 (100%) Age range not reported (mean = 23.9)	AN (DSM-V)	AQ-10	Bigger picture thinking (ROCF); set shifting (Brixton Spatial Anticipation Test)	• High ASC characteristics did not impact the effects of individual cognitive remediation therapy (CRT); both groups with or without ASC characteristics showed improvement in set shifting after individual CRT treatment

(Continues)

TABLE 3 (Continued)

References	Country	Study type	Aims	Sample	ED diagnosis	ASC assessment	Outcomes measured	Results
Li et al. (2020)	UK	Cross-sectional	To examine the outcomes in patients with AN with and without ASC characteristics in three different treatment settings: inpatient, day treatment and step-up treatment	$N = 476$ Female = 466 (98%) Age range = 18–65 (mean = 26.9)	AN (DSM-V)	AQ-10	BMI; ED symptoms (EDE-Q); Anxiety and depression symptoms (HADS); Work and social functioning (WSAS)	• There was no difference in discharge BMI and ED symptoms between patients with and without ASC characteristics • Patients with ASC characteristics showed more severe depression and anxiety symptoms as well as more severe social impairment compared to patients without ASC characteristics

Abbreviations: ADOS, Autism Diagnostic Observation Schedule; AQ, Autism-Spectrum Quotient; AQ-10, Autism-Spectrum Quotient 10-item version; ASC, autism spectrum condition; ASDI, Asperger Syndrome Diagnostic Interview; DFlex, Detail and Flexibility questionnaire; EDE-Q, Eating Disorders Evaluation Questionnaire; HADS, Hospital Anxiety and Depression Scale; MROAS, Morgan–Russell outcome assessment schedule; ROCF, Rey–Osterrieth Complex Figure test; SAS, Social Aptitude Scale; SDQ, Strengths and Difficulties Questionnaire; SEED, Short Evaluation of Eating Disorders; WSAS, Work and Social Adjustment Scale.

Nielsen et al. (2015) used data from Study 1 to Study 4 of the Swedish longitudinal cohort to investigate the impact of ASC diagnostic stability on outcomes in AN. Outcomes were measured with the MROAS (Morgan & Hayward, 1988) at each follow-up. Additionally, the Morgan–Russell criteria of good/intermediate/poor, based on the combined status of BMI, bulimic symptoms and menstrual pattern, were reported. The results indicated that positive development in body weight, dietary restriction, menstrual pattern, sexual behaviour and social relationship was limited to those individuals who had never been assigned an ASC diagnosis. Additionally, the diagnostic stability of ASC, particularly when ASC was present at all examinations, contributed to poorer outcomes in mental state, psychosexual state, social relationships and employment activity compared with individuals with no ASC diagnosis.

3.2.2 | UK studies

The remainder of the included studies were from the United Kingdom. Huke et al. (2014) investigated the relationship between ASC features and treatment completion and ED psychopathology in patients with AN. Atotal of 32 participants with AN were recruited from the Yorkshire Centre for Eating Disorders (YCED, Leeds, UK), all were female and the mean age was 28.7 years. Healthy controls ($n = 32$) were matched for age and gender. Supervisor KT was familiar with the YCED and was able to confirm that all patients received a DSM diagnosis of ED in the service. ASC characteristics were measured with the AQ (Baron-Cohen et al., 2001). Outcomes measures included ED symptoms assessed with the Eating Disorders Evaluation Questionnaire (EDE-Q; Fairburn et al., 1993) and treatment completion ('premature termination of treatment' vs. 'treatment completed as planned'). Obsessive-compulsive characteristics and anxiety and depression symptoms were also assessed, although not compared between those with and without ASC. The results indicate that there was no significant relationship between ASC characteristics and ED symptoms, nor between ASC characteristics and premature termination of treatment. One non-significant but interesting finding was that 87.5% ($n = 7/8$) of participants with ASC completed treatment as planned compared with 50% ($n = 12/24$) of those without ASC. This may suggest enhanced treatment adherence in ASC patients, who may respond well to the rules and routines in an inpatient ward since these may ease anxieties in a novel environment.

Tchanturia et al. (2016) examined the treatment response of group format Cognitive Remediation Therapy (CRT) for AN patients with and without ASC characteristics. The study recruited 35 participants from an inpatient ED unit in London. All were female with a mean age of 26.2 years. All had a DSM-5 (APA, 2013) diagnosis of AN. ASC characteristics were assessed with either the AQ-10 (Allison et al., 2012) or the Autism Diagnostic Observation Schedule (ADOS; Gotham et al., 2007). Motivation and cognitive styles (rigidity and attention to detail) were assessed with motivational ruler (Miller & Rollnick, 2012) and DFlex (Roberts et al., 2011) before and after the groups received the CRT intervention, and compared between patients with and without ASC characteristics. The results indicate that patients without ASC showed significant improvement in cognitive rigidity ($p = 0.007$) and self-reported ability to change ($p = 0.004$). However, patients with ASC characteristics showed no significant improvement in self-reported cognitive flexibility or in motivation; and the effect sizes were negligible.

Dandil et al. (2020) carried out an evaluation in the same London ED unit which aimed to examine the treatment response to individual format (rather than group format) CRT for AN patients with and without ASC characteristics. A total of 99 inpatients were recruited. All were female with a mean age of 23.9 years, and all had a DSM-5 diagnosis of AN. ASC characteristics were screened using the AQ-10. Treatment outcome was measured in change in cognitive styles (bigger picture thinking assessed with Rey–Osterrieth Complex Figure (ROCF) test (Rey, 1941) and set shifting assessed with Brixton Spatial Anticipation Test [Burgess & Shallice, 1996]) and compared between patients with and without ASC characteristics. The results showed that although neither group saw improvement in central coherence after CRT, there was positive improvement in set shifting in both groups with and without ASC characteristics ($p < 0.001$ for both groups) and high ASC characteristics did not impact the effects of individual CRT.

Stewart et al. (2017) investigated through clinical audit the impact of ASC characteristics on treatment outcomes of patients at a specialist outpatient child and adolescent ED service in London. A total of 409 female patients were recruited, with a mean age of 14.6 years. All patients had a DSM-IV or DSM-V diagnosis of AN, restrictive subtype ED Not Otherwise Specified or Atypical Anorexia. ASC characteristics were measured using the Social Aptitude Scale (SAS; Liddle et al., 2009) and the AQ (Baron-Cohen et al., 2001). Morgan–Russell criteria of good/intermediate/poor (based on the combined status of BMI, bulimic symptoms and menstrual pattern) were used to classify physical treatment outcomes. ED psychopathology was also measured using the EDE-Q. The results showed no differences in physical outcomes and ED psychopathology between patients with and without ASC characteristics. However, ASC characteristics were associated with symptoms of depression ($p < 0.001$), anxiety ($p < 0.001$), OCD ($p < 0.001$) and treatment augmentation reflected by greater use of the intensive day patient or inpatient treatment ($p < 0.01$).

Nazar et al. (2018) also examined the impact of ASC characteristics on clinical outcomes of patients with AN. This study was a secondary data analysis from a multi-centre randomised controlled trial in the United Kingdom. A total of 149 patients were recruited, 137 were female and the mean age was 16.9 years. All patients received a DSM-IV or ICD-10 diagnosis of AN or atypical AN. Formal diagnosis of ASC was based on DSM-IV and ICD 10, and ASC characteristics were additionally assessed with the SAS (Liddle et al., 2009). Patients with and without ASC showed similar reductions in ED symptoms and BMI change at 12 months follow-up. However, social difficulties and global dysfunctioning remained higher in the ASC group at follow-up compared to those without ASC ($p = 0.002$). In addition, the ASC group showed treatment augmentation marked by a greater use of intensive inpatient or day-patient treatment ($p = 0.015$) and medication use prior to admission to hospital ($p < 0.001$).

Lastly, Li et al. (2020) investigated the treatment outcomes in inpatient and day-patient treatment settings through clinical audit data. Impact of ASC characteristics on the clinical outcomes was evaluated as part of the study objectives. Data from 476 patients were collected, 466 of whom were female, and the mean age was 26.9 years. All patients had a DSM-V diagnosis of AN. ASC characteristics were assessed with the AQ-10. Outcomes were measured by BMI, ED symptoms represented by the EDE-Q, comorbid depression and anxiety symptoms and social impairment and all outcomes were compared between patients with and without ASC characteristics. The results indicate no difference in discharge BMI and ED symptoms between patients with and without ASC characteristics. However, patients with ASC characteristics exhibited more severe depression symptoms ($p = 0.009$), anxiety symptoms ($p = 0.013$) and social impairment ($p = 0.008$) compared to patients with no ASC characteristics.

4 | DISCUSSION

Overall, the number of studies identified in Review 1 (description or evaluation of treatments or adaptations for comorbid ASC) was low and all related to the same intervention – the PEACE pathway. The PEACE Pathway was the only intervention for patients with ED and comorbid ASC that has been described and evaluated in published manuscripts (Smith & Tchanturia, 2020; Tchanturia et al., 2021; Tchanturia, Smith, Glennon, & Burhouse, 2020), despite the broad search strategy, indicating that few such treatments have been developed and few adaptations have been carried out. No RCTs of treatments or adaptations were identified, and the partial economic evaluation of the PEACE pathway (Tchanturia et al., 2021) explored cost-savings only and so does not provide any evidence of either effectiveness or cost-effectiveness. This means there is currently no evidence base to support the development of interventions to improve the effectiveness of ED services for patients with comorbid ASC and no evidence of cost-effectiveness.

Nine studies were identified for Review 2 (impact of ASC on treatment outcomes in AN), including the partial economic evaluation identified in Review 1. These studies were predominantly cross-sectional or case series and all were published in the past decade. The main findings from the studies included in Review 2 are clustered and visualised in a diagram (Figure 3). ASC characteristics were shown to have no impact on physical outcomes or ED symptoms in studies using the EDE-Q, SEED or BMI change to assess ED symptomatology (Huke et al., 2014; Nazar et al., 2018; Stewart et al., 2017). However, when an overall clinical outcome was measured with the Morgan–Russell assessment schedule (Anckarsäter et al., 2012; Nielsen et al., 2015), ASC characteristics came to have a negative impact on the outcomes. It is worth noting that the Morgan–Russell outcome is a composite score summarizing an individual's food intake, weight concern, mental state, psychosexual state and social relationships, whereas the EDE-Q and the SEED target food intake and weight concerns only. Subsequently, social-emotional processing difficulties and cognitive rigidity which are common features of an autistic individual (Davies et al., 2016; South et al., 2007) might be reflected negatively on the Morgan–Russell assessment, but would not have an impact on the EDE-Q or SEED outcome. Hence, when evaluating treatment outcomes in patients with ASC features, the outcome measure should be chosen and interpreted with caution. The majority of the included studies also found a positive association between ASC characteristics and other comorbidities such as personality disorders (Anckarsäter et al., 2012), depression and anxiety symptoms (Li et al., 2020; Stewart et al., 2017), obsessive compulsive symptoms (Stewart et al., 2017) and social and psychosexual impairment (Li et al., 2020; Nazar et al., 2018; Nielsen et al., 2015).

High ASC characteristics were also shown by a number of studies to lead to treatment augmentation either through greater use of intensive day-patient or inpatient treatment (Nazar et al., 2018; Stewart et al., 2017) or longer hospital admissions (Tchanturia et al., 2021) compared to patients without ASC characteristics (Figure 3). Since patients with ASC characteristics showed no difference in ED

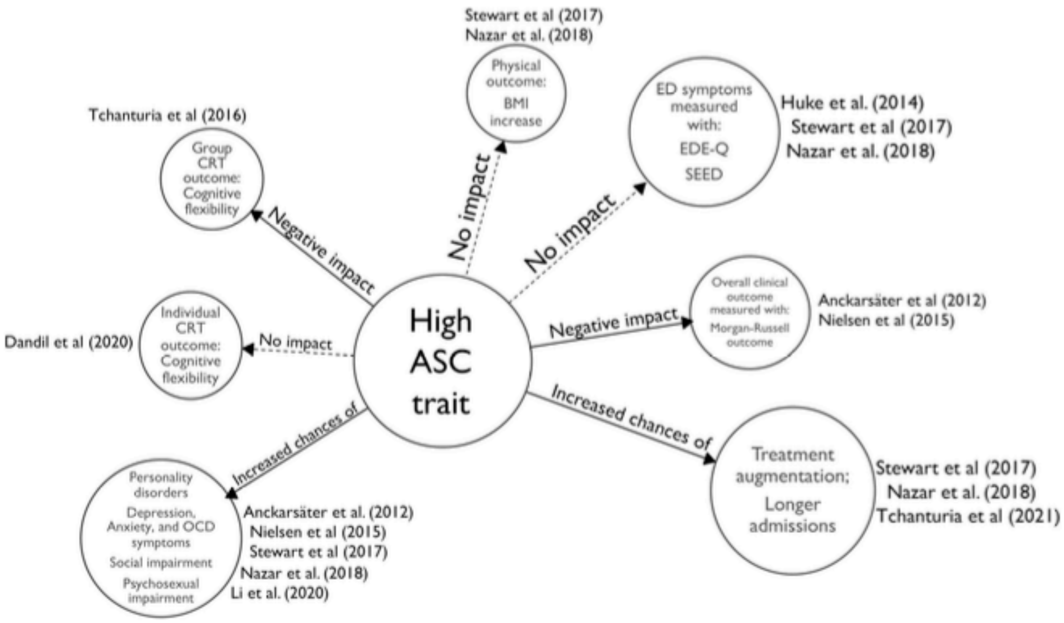

FIGURE 3 Visual synthesis of the findings of the included studies. Items in bigger circles appeared in the findings of more studies; their related studies are listed next to the circles

symptoms or rate of BMI change compared to others without ASC, this treatment augmentation could potentially be explained by the high rate of other comorbidities that could have an impact on treatment effectiveness. Indeed, in one of the included studies, ASC characteristics did not predict treatment augmentation once levels of depression had been accounted for (Stewart et al., 2017). Thus, the need for treatment augmentation in high ASC patients may be a result of untreated comorbidities or unfulfilled emotional needs.

4.1 | Clinical implications of ASC comorbidity in ED treatment

Patients with high ASC showed a need for treatment augmentation and prolonged hospitalisation in ED units (Nazar et al., 2018; Stewart et al., 2017; Tchanturia et al., 2021), indicating that they were not responding well to conventional treatment which primarily targets ED cognitive symptoms. Moreover, the high rate of comorbidities associated with autistic characteristics might be a risk factor for future relapse. Therefore, these patients with ASC characteristics may be in need of alternative treatment strategies in order to recover fully and prevent relapse.

Two case series included in this review examined treatment response to group and individual format of CRT respectively (Dandil et al., 2020; Tchanturia et al., 2016). Patients with high ASC did not respond to group CRT and did not report any significant improvement in cognitive flexibility, and the negligible effect sizes suggest that it is unlikely due to the power of the study. The individual CRT study, on the other hand, reported favourable outcomes in autistic patients. This indicates that the group environment may have presented difficulties for patients on the autism spectrum. Future treatment adaptations could take into account social difficulties, and it is possible that the group setting, dosage or style of delivery of CRT sessions could be modified for people with both AN and ASC.

It was also suggested in a study that common autistic features, such as preference for routines and difficulties in set shifting, may enhance treatment completion and adherence (Huke et al., 2014). Thus, modifying psychological therapies for ASC processing styles could in turn enhance treatment effectiveness. Indeed, as was demonstrated in the partial economic evaluation of a novel pathway for patients with the comorbidity (Tchanturia et al., 2021), once appropriate adaptations had been made in treatment settings, patients with autistic characteristics showed reduced lengths of hospital admission compared to ASC patients prior to the introduction of the pathway and compared to non ASC patients, which may suggest the pathway generated comparatively more favourable treatment outcomes, although further research is needed to confirm this.

4.2 | Screening tools

One main issue arising from this review is the lack of a consistent screening system for ASC in ED, similar to previous reviews on the ASC and ED population (Huke et al., 2013). A variety of screening measures were used in the included studies, such as the AQ, AQ-10, ADOS, ASDI, SAS, Dewey social awareness test and more. This lack of consistency in screening measures makes comparison across studies difficult. Some of the earlier studies also used screening tool that had not been specifically tested for reliability or validity (Nielsen et al., 2015). More recently, there has been an increase in studies using the AQ or the shorter version AQ-10 to examine ASC characteristics in clinical groups (Allison et al., 2012; Baron-Cohen et al., 2001; Kinnaird et al., 2020; Li et al., 2020; Mealey et al., 2014; Mito et al., 2014). Although self-report measures such as the AQ or AQ-10 have the benefit of being brief and low cost, it is worth noting that they only focus on the present time-frame and the information provided by the patients themselves, missing early developmental history and input from carers which are two crucial elements in a formal ASC assessment. Specific to assessing ASC in patients with AN, there is the possibility that social withdrawal and social anhedonia exacerbated by ongoing starvation (Keys et al., 1950) could also confound the results of ASC screening, if only current presentation is considered and developmental aspects are not screened. Moreover, it has been suggested that the common tools for screening ASC do not adequately identify difficulties in girls who may have a qualitatively different presentation than boys (Halladay et al., 2015). Indeed, females often show fewer repetitive and restricted behaviours than males and are more prone to 'camouflage' their social difficulties (Hull et al., 2020; Westwood et al., 2017) leading to increased obstacle to assessing ASC using the available tools. Hence, there is an urgent need for a pragmatic and universal screening tool for ASC in a predominantly female population with ED.

4.3 | ED diagnoses

Although we used a broad search strategy that covered all ED subtypes, almost all identified studies focussed on AN only. A possible explanation could be that compared to other subtypes, AN is associated with more intensive service use given the need for medical stabilisation and therefore generates more data available for publication. Patients with BN, on the other hand, are less likely to be hospitalised despite the often serious physical complications brought by purging, because they tend to be at a healthier weight, more active sexually and more likely to menstruate regularly in contrast with patients with AN (Russell, 1979). BED, despite being the most prevalent ED (Kornstein et al., 2016), is often underdiagnosed and undertreated (with <40% of individuals with BED having ever been treated for an ED), partly because BED was only widely recognised as a diagnostic entity in the early 1990s (Stice, 1999), and partly because individuals with BED may be reluctant to seek treatment because of shame and lack of awareness of the disorder (Kornstein et al., 2016).

There has been a wealth of work showing that children, young people and adults on the spectrum are more likely to be overweight or obese than their non-autistic peers (Broder-Fingert et al., 2014; Hill et al., 2015; Sedgewick et al., 2019). This finding has implications for association between autistic characteristics and BED, a disorder frequently observed amongst overweight or obese individuals. Indeed, recent pilot data showed that not only AN but also BN and BED patients exhibited greater autistic characteristics compared to controls (Gesi et al., 2017). In this study, patients with BN also scored higher than patients with AN on sensory difficulties, and the BED group showed the most mentalising deficits. In a more recent study investigating ASC characteristics in patients with binge-purge AN, restrictive AN, BN and BED, an association was found between high autistic characteristics and non-vomiting behaviour (Numata et al., 2021). Of the four ED subtypes, the BED group had the highest ASC characteristics.

Given that the consequences of other subtypes could be just as debilitating as AN, and 'crossovers' between ED subtypes are not uncommon, it is worth expanding the scope of research on autism comorbidity to BN and BED as well. Further research on how treatments can be adapted for autistic individuals with BN or BED is warranted.

4.4 | Strengths and limitations of the reviews

To our knowledge, this is the first review of new or adapted treatments for ED and comorbid ASC, and of the impact of ASC comorbidity on clinical outcomes in patients with ED, that has used a broad range of databases and a systematic search strategy. An earlier literature review which focussed on ASC in AN briefly explored the potential impact of ASC symptoms on treatment outcome in ED groups as a sub-topic (Westwood et al., 2017) and included three publications (Nielsen et al., 2015; Stewart et al., 2017; Tchanturia et al., 2016), all of which are included in the current review.

This review has some limitations. Only including manuscripts in English language could potentially lead to loss of data when studies are excluded. Search strategies were therefore carefully tested and bibliographies of included studies and relevant reviews hand checked to minimise data loss. Furthermore, a number of the included studies suffered from small sample sizes, with 5 (55%) having fewer than 100 and 2 (22%) having fewer than 50 participants, which may have led to a lack of power to identify true differences between patients with and without ASC. Missing data was another pervasive problem in the clinical studies included in this review, with one case series reporting only 41% complete data for patients with high autistic features (Dandil et al., 2020), and another cross-sectional study using audit data also reporting high attrition rates at follow-up (Li et al., 2020). Nevertheless, the results synthesised from these early studies are hypothesis generating and warrant future research on ASC and EDs with more robust study designs.

5 | CONCLUSION AND FUTURE DIRECTIONS

There has been only one identifiable clinical pathway of treatment adaptations for patients with AN and comorbid ASC – the PEACE pathway. Early studies, one focussing on the value of a single component of the pathway (PEACE huddles), as perceived by clinicians, and one focussing on the impact of the pathway on length of hospital stay and associated costs, have produced positive indications to hypothesise that the PEACE pathway may generate benefits for ASC comorbid patients. Results from the cost-savings analysis, in particular, may suggest that the PEACE pathway is better able to support patients with comorbid ASC, leading to reduced lengths of hospital stay, however further research is needed to confirm this. Evidence of clinical and cost-effectiveness is therefore needed to determine whether similar adaptations should be implemented in more ED services.

Studies exploring the impact of ASC comorbidity on treatment outcomes in patients with ED suggest that ASC characteristics have no impact on ED symptoms and physical outcomes of treatment, but could be associated with higher rates of comorbidities and greater use of, and thus perhaps need for, intensive treatment. This may suggest that any new treatments or adaptations to existing treatments may not directly impact on ED symptoms, but may be better able to support the complex needs of the ASC population, thus reducing subsequent need for intensive support. Initial evidence from the PEACE pathway supports this hypothesis that treatment and service level adaptations may help to reduce this greater use of intensive treatment. Nevertheless, controlled studies utilising a robust longitudinal design and following stringent diagnostic criteria are clearly needed to further elucidate the relationship between ASC characteristics and treatment outcomes in ED. A universal screening tool for ASC in ED is also needed to establish consistency across studies.

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CONFLICT OF INTEREST

Zhuo Li, Kate Tchanturia and Sarah Byford took part in the development and/or evaluation of the PEACE pathway in some of the included studies.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon a reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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Appendix 2.2 Search Strategies

MEDLINE

#	Searches	Results
1	exp Anorexia Nervosa/	13083
2	exp Bulimia Nervosa/	2397
3	exp Avoidant Restrictive Food Intake Disorder/	38
4	exp Binge-Eating Disorder/	1549
5	eating dis*.ti,ab,kw.	21235
6	anorex*.ti,ab,kw.	34227
7	bulimi*.ti,ab,kw.	8762
8	(EDNOS or ED-NOS or "Eating Disorder not Otherwise Specified").ti,ab,kw.	620
9	(ARFID or Avoidant Restrictive Food Intake Disorder).ti,ab,kw.	217
10	Purg* disorder.ti,ab,kw.	99
11	("Binge eating disorder" or "binge-eating disorder").ti,ab,kw.	2711
12	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11	53101
13	exp Child Development Disorders, Pervasive/	36820
14	exp Autism Spectrum Disorder/	31411
15	exp Asperger Syndrome/	1761
16	exp Autistic Disorder/	20738
17	Autis*.ti,ab,kw.	51718
18	Asperger*.ti,ab,kw.	2261
19	(PDD-NOS or "pervasive developmental disorder" or PDDNOS).ti,ab,kw.	1369
20	13 or 14 or 15 or 16 or 17 or 18 or 19	56394
21	12 and 20	465

Embase

#	**Searches**	**Results**
1	exp Anorexia Nervosa/	20681
2	exp Bulimia Nervosa/	14381
3	exp Avoidant Restrictive Food Intake Disorder/	228
4	exp Binge-Eating Disorder/	7356
5	eating dis*.ti,ab,kw.	28953
6	anorex*.ti,ab,kw.	48454
7	bulimi*.ti,ab,kw.	11850
8	(EDNOS or ED-NOS or "Eating Disorder not Otherwise Specified").ti,ab,kw.	824
9	(ARFID or Avoidant Restrictive Food Intake Disorder).ti,ab,kw.	317
10	Purg* disorder.ti,ab,kw.	114
11	("Binge eating disorder" or "binge-eating disorder").ti,ab,kw.	3504
12	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11	77161
13	exp Child Development Disorders, Pervasive/	73460
14	exp Autism Spectrum Disorder/	73460
15	exp Asperger Syndrome/	4677
16	exp Autistic Disorder/	73460
17	Autis*.ti,ab,kw.	67622
18	Asperger*.ti,ab,kw.	3471
19	(PDD-NOS or "pervasive developmental disorder" or PDDNOS).ti,ab,kw.	2129
20	13 or 14 or 15 or 16 or 17 or 18 or 19	84722
21	12 and 20	974

PsycInfo

#	Searches	Results
1	exp Anorexia Nervosa/	11436
2	exp Bulimia/	7748
3	exp "purging (eating disorders)"/	505
4	exp Binge-Eating Disorder/	1809
5	eating dis*.ti,ab.	25035
6	anorex*.ti,ab.	16615
7	bulimi*.ti,ab.	11259
8	(EDNOS or ED-NOS or "Eating Disorder not Otherwise Specified").ti,ab.	701
9	(ARFID or Avoidant Restrictive Food Intake Disorder).ti,ab.	177
10	Purg* disorder.ti,ab.	111
11	("Binge eating disorder" or "binge-eating disorder").ti,ab.	2687
12	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11	37978
13	exp Autistic Traits/	235
14	exp Autism Spectrum Disorders/	45281
15	Autis*.ti,ab.	53216
16	Asperger*.ti,ab.	3573
17	(PDD-NOS or "pervasive developmental disorder" or PDDNOS).ti,ab.	1723
18	13 or 14 or 15 or 16 or 17	56346
19	12 and 18	486

Web of Science

#	Searches	Results

1	TS="eating dis*"	30799
2	TS= anorex*	41977
3	TS=bulimi*	15426
4	TS=(EDNOS OR ED-NOS OR "Eating Disorder not Otherwise Specified")	646
5	TS=(ARFID OR "Avoidant Restrictive Food Intake Disorder")	275
6	TS="Purg* disorder"	111
7	TS=("Binge eating disorder" OR "binge-eating disorder")	3819
8	#7 OR #6 OR #5 OR #4 OR #3 OR #2 OR #1	63404
9	TS=Autis*	81028
10	TS=Asperger*	7513
11	TS=(PDD-NOS OR "pervasive developmental disorder" OR PDDNOS)	2059
12	#11 OR #10 OR #9	82538
13	(#12 AND #8) *AND* **LANGUAGE:** (English) *AND* **DOCUMENT TYPES:** (Article)	413

Scopus

#	**Searches**	**Results**
1	TITLE-ABS-KEY ("eating dis*")	44640
2	TITLE-ABS-KEY (anorex*)	96359
3	TITLE-ABS-KEY (bulimi*)	18710

4	(TITLE-ABS-KEY (ednos) OR TITLE-ABS-KEY (ed-nos) OR TITLE-ABS-KEY ("Eating Disorder not Otherwise Specified"))	1099
5	(TITLE-ABS-KEY (arfid) OR TITLE-ABS-KEY ("Avoidant Restrictive Food Intake Disorder"))	337
6	TITLE-ABS-KEY ("Purg* disorder")	219
7	(TITLE-ABS-KEY ("Binge eating disorder") OR TITLE-ABS-KEY ("binge-eating disorder"))	7718
8	#7 OR #6 OR #5 OR #4 OR #3 OR #2 OR #1	131305
9	TITLE-ABS-KEY (autis*)	88062
10	TITLE-ABS-KEY (asperger*)	6260
11	(TITLE-ABS-KEY (pdd-nos) OR TITLE-ABS-KEY ("pervasive developmental disorder") OR TITLE-ABS-KEY (pddnos))	3938
12	#11 OR #10 OR #9	89903
13	#12 AND #8	1568
14	#13 AND (LIMIT-TO (DOCTYPE , "ar")) AND (LIMIT-TO (LANGUAGE , "English")	826

<u>CINAHL</u>

#	Searches	Results
1	(MH "Anorexia Nervosa") OR (MH "Eating Disorders+") OR (MH "Binge Eating Disorder") OR (MH "Bulimia Nervosa") OR (MH "Avoidant Restrictive Food Intake Disorder")	18385
2	"eating dis*"	15564
3	"anorex*"	9945
4	"bulimi*"	5425

5	"EDNOS" OR "ED-NOS" OR "Eating Disorder not Otherwise Specified"	319
6	"ARFID" OR "Avoidant Restrictive Food Intake Disorder"	162
7	"Purg* disorder"	69
8	"Binge eating disorder" OR "binge-eating disorder"	3627
9	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8	24042
10	(MH "Autistic Disorder") OR (MH "Asperger Syndrome") OR (MH "Pervasive Developmental Disorder-Not Otherwise Specified")	25704
11	"Autis*"	31290
12	"Asperger*"	2090
13	"PDD-NOS" OR "pervasive developmental disorder" OR "PDDNOS"	1859
14	OR/10-13	32448
15	9 AND 14	302

Cochrane Library

#	**Searches**	**Results**
1	[mh "anorexia nervosa"]	528
2	[mh "bulimia nervosa"]	269
3	[mh "binge-eating disorder"]	280
4	[mh "avoidant restrictive food intake disorder"]	0
5	(anorex*):ti,ab,kw	5728
6	(bulimi*):ti,ab,kw	1431
7	(eating dis*):ti,ab,kw	8446
8	(EDNOS or ED-NOS or "Eating Disorder not Otherwise Specified"):ti,ab,kw	76

9	(ARFID or Avoidant Restrictive Food Intake Disorder):ti,ab,kw	18
10	(Purg* disorder):ti,ab,kw	173
11	("Binge eating disorder" or "binge-eating disorder"):ti,ab,kw	785
12	OR/1-11	13992
13	[mh "Child Development Disorders, Pervasive"]	1672
14	[mh "Autism Spectrum Disorder"]	1495
15	[mh "Asperger Syndrome"]	71
16	[mh "Autistic Disorder"]	1017
17	(Autis*):ti,ab,kw	3777
18	(Asperger*):ti,ab,kw	247
19	(PDD-NOS or "pervasive developmental disorder" or PDDNOS):ti,ab,kw	153
20	(Child* disintegrat* disorder):ti,ab,kw	14
21	OR/13-20	3843
22	#12 AND #21	61

Appendix 3.1 Analysis of symptom clusters amongst adults with anorexia nervosa: Key severity indicators

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Analysis of symptom clusters amongst adults with anorexia nervosa: Key severity indicators

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ABSTRACT

This study used cluster analysis to explore clinically relevant subgroups of adult patients with anorexia nervosa (AN). Patients were clustered based on their body mass index (BMI), eating disorder symptomatology, anxiety and depression symptoms and autistic characteristics. The difference between clusters in work and social functioning, duration of illness, bingeing and purging behaviour, previous hospitalisations and number of comorbidities was also investigated. Two meaningful clusters emerged: a higher symptoms cluster with more severe eating pathology, anxiety, depression, and more autistic traits, and a second cluster with lower symptoms. BMI did not make major contributions to cluster formation. The higher symptoms cluster also reported lower self-efficacy to change, more previous hospitalisations, comorbid diagnoses, binge eating and purging behaviours and use of psychotropic medication. Our findings suggest that weight alone may not be a significant severity indicator amongst inpatients with AN, and targeted treatment of AN should consider a broader range of symptom severity indicators.

1. Introduction

Anorexia nervosa (AN) is a serious eating disorder (ED) with poor treatment outcome that can affect people of all ages, genders, and races (Schaumberg et al., 2017). Clinical decisions on the severity of AN are often guided by the patient's weight, as refusal to maintain healthy weight (given the patient's age and developmental stage) is a part of the diagnostic criteria for the illness. The 11th Edition of the International Classification of Diseases (ICD-11) (World Health Organization, 2019) has provided specific weight cut-offs and body mass index (BMI; kg/m^2)-based severity indicators for AN, and the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013) also outlines weight criteria for AN. The Morgan-Russell outcome assessment schedule (Morgan and Hayward, 1988), which is often used in the clinical assessment of AN, defines patient outcomes based on body weight and menstrual function. Additionally, it has been reported that those with severe or extremely severe AN defined by BMI < 16.0 scored higher on measures of perfectionism and clinical impairment, suggesting that BMI is a crucial severity indicator in AN (Dakanalis et al., 2018). However, some studies have raised questions about the clinical validity of weight-based severity specifiers (Machado et al., 2017; Engelhardt et al., 2021; Toppino et al., 2022). One study reported that individuals who have lost a significant amount of weight but are not as emaciated as other patients with AN can still experience similar levels of life-threatening medical complications (Whitelaw et al., 2014). Other studies have found no significant evidence in favour of grouping AN patients into the BMI-based severity categories in terms of ED psychopathology or treatment outcomes (Machado et al., 2017; Toppino et al., 2022). Although low BMI remains a significant factor in AN, exploration of illness severity may benefit from including a wider range of psychological features.

AN has been reported to be a highly comorbid illness with some estimates suggesting that up to 97% of adult patients have at least one comorbid psychiatric diagnosis (Blinder et al., 2006; Marucci et al.,

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2018). The most common comorbid psychiatric diagnoses include depression and anxiety (Guinhut et al., 2021), which have been reported to be key factors in the development and maintenance of the AN (Lulé et al., 2014). Indeed, a recent [illegible]s by Monteleone and colleagues (2019) reported that depression and anxiety symptoms were central to the psychopathology of adolescent inpatients with AN. Another network analysis further documented that depression and anxiety symptoms, specifically feelings of worthlessness and avoidance of social eating, were not only strongly linked to core ED symptoms amongst adult AN patients, but also predicted recovery status at post-treatment follow-up (Elliott et al., 2020). Although most recent work has reported that severe depressive symptoms are associated with more severe AN pathology (Sternheim et al., 2015), worse treatment outcomes (Vall and Wade, 2015), and elevated risk of suicide (Kostro et al., 2014), there is some suggestion that moderate depression may have a positive association with weight gain and recovery in AN (Eskild-Jensen et al., 2020 for review). A large-scale study found that inpatients with AN who showed clinically significant improvements upon discharge were more likely to report moderate depression at admission when compared to deteriorated/unchanged patients (Schlegl et al., 2014). A similar effect of depression was found by Zeeck and colleagues, where inpatients with depression stayed longer in psychotherapy and may have a higher chance for clinically significant changes (Zeeck et al., 2005). These findings suggest that comorbid depression and anxiety are likely key factors contributing to illness severity in AN, but individual differences may also be present.

In addition to psychiatric comorbidities, recent evidence suggests that there is an over-representation of autism (Westwood and Tchanturia, 2017) and autistic features in AN (Kinnaird and Tchanturia, 2021). The estimated prevalence of autism or autistic characteristics in ED populations varies across studies from 22.9% to 36.2% (Wentz et al., 2005; Huke et al., 2013; Anckarsäter et al., 2012; Kinnaird et al., 2020; Vagni et al., 2016). Autistic patients often struggle with sensitivities to the sensory aspects of food, for example its smell, temperature, colour or texture (Leekam et al., 2007; Kinnaird et al., 2020) which may contribute to avoidance of certain food types in AN. Furthermore, both AN and autism are associated with high levels of alexithymia (Kinnaird and Tchanturia, 2021), interpersonal problems and social anxiety (Kerr-Gaffney et al., 2020), and neurocognitive aspects such as weak central coherence (Lang et al., 2014) and difficulties in set-shifting (Westwood et al., 2016). These findings warrant attention, as being autistic is often associated with greater use of intensive day-patient and inpatient treatment (Stewart et al., 2017; Nazar et al., 2018) and worse clinical outcomes in AN (Nielsen et al., 2015; Tchanturia et al., 2016).

Using exploratory, data-driven methods, such as cluster analysis, to explore patterns in a broad range of AN symptoms and severity indicators could help to shed light on the complexities in patients' presentation and guide clinical decision making in treatment of AN. Cluster analysis explores patterns by grouping datapoints based on distance and thus can be used to identify subgroups in data without prior assumptions of the internal structure of the subgroups. Several previous studies have explored clustering of neuro- and social-cognitive measures, personality measures, and autistic features in adults with AN (Renwick et al., 2015; Rose et al., 2016; Bentz et al., 2020; Holliday et al., 2006). These studies have identified a variety of different clusters within the data used, but the clusters have not differed in ED symptoms, severity markers, or comorbidities, limiting the clinical implications of these findings. One study (Damiano et al., 2015) has examined clustering of behaviour and general psychopathology in adolescents with AN and identified two subgroups: one group that was underweight and scored lower on general and ED-specific psychopathology measures, and one group with higher general and ED psychopathology and higher BMI. This seems to be in contrast with previous finding that lower BMI predicts higher AN symptom severity (Löwe et al., 2001), but it is important to note that the sample size ($N = 39$) was small for cluster analysis. Interestingly, another study conducted a cluster analysis of a broad range of ED risk factors within a large community sample (Miles et al., 2022). Similar to the findings by Damiano and colleagues (2015), the authors identified low-, medium-, and high-risk groups, with the high-risk group reporting higher BMI and more depression and general ED symptoms than the medium- and low-risk groups. To our knowledge, no studies have yet used cluster analysis to explore subgroups in a broad range of illness severity indicators in a large sample of people with AN.

Based on the work outlined above, we explored patterns in a broad range of data, including information regarding BMI, ED psychopathology, common comorbid symptoms, and autistic features, which were collected from inpatients with AN upon admission. Given the exploratory nature of this approach, a number of research questions were posed in place of hypotheses:

(1) Can the analysis yield independent subgroups of patients that are not specific to the diagnostic criteria for AN, each with a different level of severity on the clustering variables?
(2) Are these subgroups different in other aspects of illness, such as duration of illness, bingeing and purging behaviour, number of hospital admissions, and number of comorbidities?

2. Methods

2.1. Participants

This study utilised clinical service audit data collected at the South London and Maudsley (SLaM) NHS inpatient ED service. As part of the clinical service audit, patients are asked to complete self-report questionnaires upon admission and their height and weight are recorded by a clinical team. Data from patients with a diagnosis of AN were included in the present study. Patients who did not complete the questionnaires that were used in the cluster analysis or for whom admission BMI was not available were excluded. If a given patient had multiple previous admissions, the admission with the most complete data was included to minimise missing data and other repeated admissions for the same person were excluded. A total of 107 patients had one or more readmissions, and 182 duplicate entries of admissions for these patients were therefore excluded. Out of the original 710 entries in the clinical service audit database, we ended up with a sample of 227 patients (Fig 1). The clinical service audit data collection and use were reviewed and approved by the Clinical Governance Committee Research and Development Office in South London and Maudsley (SLaM) NHS Trust in 2004.

2.2. Materials

2.2.1. Measures used in cluster analysis

In addition to admission BMI recorded by members of staff, participants' responses to self-report questionnaires assessing key aspects of AN and common comorbid symptoms were included in the cluster analysis. The self-report questionnaires included the Eating Disorder Examination Questionnaire (EDE-Q; Fairburn and Beglin, 1994), which is a self-report measure of behaviours and attitudes towards eating and body image and had excellent internal consistency (Cronbach's $\alpha = 0.96$). To reduce dimensionality, the total score, which is given to summarise overall ED symptom severity, was included in the analysis. Participants also completed the Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983), which measures the severity of anxiety and depression symptoms in the week prior to admission with excellent internal consistency (Cronbach's $\alpha = 0.9$). The short version of the Autism Spectrum Quotient (AQ-10; Allison et al., 2012) was used to screen for autistic features with acceptable internal consistency (Cronbach's $\alpha = 0.78$). On all self-reported measures, higher scores indicate more severe symptoms.

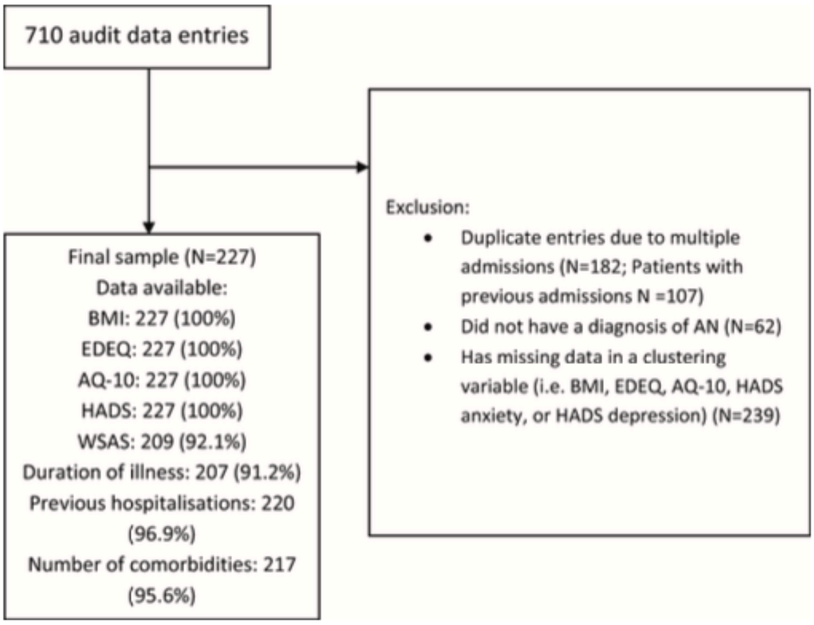

Fig. 1. Data processing flowchart
EDEQ: Eating Disorders Examination Questionnaire; AQ-10: Autism Spectrum Quotient, short version; HADS: Hospital Anxiety and Depression Scale; WSAS: Work and Social Adjustment Scale.

2.2.2. *Measures not used in cluster analysis*

The following measures were used to investigate differences between clusters that emerged from the current broad AN symptom profile. These included measures of general functioning, such as the Work and Social Adjustment Scale (WSAS; Mundt et al., 2002), which measures degree of everyday functional impairment with good internal consistency (Cronbach's α = 0.82). Items on the WSAS scale encompass different domains, including ability to work, home management, leisure activities, and ability to maintain close relationships. We also included data regarding participants' age, their living situation (alone or with others), and the number of years they had faced unemployment due to their illness.

We also examined other indicators of illness severity and complexity including duration of AN, number of previous hospital admissions due to AN, number of comorbid diagnoses, and self-reported importance and ability to change ED behaviour on the Motivational Ruler (Miller and Rollnick, 2012). In addition to information regarding AN subtype, the open-ended questions in the EDE-Q regarding binge eating and purging behaviour were also included as additional markers of severity and complexity.

2.3. *Data analysis*

All data were analysed with R 4.1.0 (R Core Team, 2013). Admission BMI, EDE-Q total, AQ-10, HADS anxiety and depression scores were centred and scaled, and then entered into robust sparse k-means cluster analysis conducted using the *RSKC* package (Kondo et al., 2016; for the distance matrix plot, see Supplementary figure S1). We used robust sparse clustering to handle any potential outliers and reduce the impact of noise arising from any variables that didn't make strong contributions to cluster formation (Kondo et al., 2016). The silhouette method, as implemented in the *factoextra* package, was used to first determine the number of clusters and the final *RSKC* analysis was then conducted (Kassambara and Mundt, 2020) (Supplementary figure S2). The number of clusters was then confirmed using another package, *NbClust*, which utilises multiple indices (Charrad et al., 2014) (Supplementary figure S2).

The clusters were compared using the clustering measures (BMI, EDE-Q total, HADS anxiety, HADS depression, AQ-10) to evaluate which variables made strong contributions. The resulting clusters were then also compared using measures that were not included in the cluster analysis to determine if the clusters differed in other meaningful ways. These measures included the demographic and general functioning measures, as well as the illness severity and complexity measures. The cluster comparisons were conducted within the Bayesian framework using the *rstanarm* package, and probability of direction (PD) and the region of practical equivalence (ROPE) was estimated (Goodrich et al., 2022). Using Bayesian approach instead of frequentist statistics allowed for quantification of evidence strength, which increases the interpretability of observational clinical data. Additionally, Bayesian approach enabled us to evaluate whether the evidence was in favour of the alternative or the null hypotheses, which is not possible using frequentist approaches as even very large p-values cannot be taken as evidence in favour of the null hypothesis (Quintana and Williams, 2018). Differences in continuous variables, including WSAS score and illness duration, were analysed by conducting a Bayesian generalised linear regression, while count variables, such as number of previous hospital admissions and number of comorbid diagnoses, were subject to Bayesian generalised Poisson regression. Due to the heavily skewed nature of the data, binge eating and purging variables in the EDE-Q ('How many such episodes have you had over the past four weeks') were turned into binary variables (i.e. one or more episodes vs. no episodes). These and other binary variables were entered into Bayesian logistic regressions. Information regarding AN subtype was analysed by conducting a Bayesian analysis of contingency tables. *Weakly informative* priors were used in all analyses because information about the clusters was not known prior to analysis. Variable weights were calculated to inspect the importance of each variable in cluster formation, where the higher the variable weight, the more important the variable was in the partition of data. Bayes factors (BF) were calculated comparing the alternative (clusters are different) and null hypothesis (clusters are not different) using the *bayestestR* package (Makowski et al., 2019) to estimate the strength of the evidence. The Bayes factors were interpreted in accordance with Jeffreys' (1961) proposed classification system (Table 1).

3. Results

3.1. Cluster characteristics

The silhouette method indicated that there were two clusters present in the data (Supplementary figure S2). The clinical and demographic characteristics of the clusters are presented in Table 2 and Fig. 3. The clusters were of almost equal sizes with 115 (51%) patients forming cluster 1 and 112 (49%) forming cluster 2. There was decisive evidence to indicate that the patients in cluster 2 reported more ED symptoms, anxiety, depression, and autistic features than those in cluster 1. Cluster 2 is subsequently labelled "higher symptoms cluster", and cluster 1 "lower symptoms cluster". The clusters did also significantly differ on BMI, such that patients in cluster 2 had higher admission BMI than those in cluster 1. However, the evidence was only moderate suggesting that compared to the other measures admission BMI did not make substantial contributions to the cluster formation. This is further supported by observing the relative contributing weights of each cluster analysis variable (Fig. 2). As can be shown on Fig 2, BMI as a variable had the lowest contributing weight (0.09) in clustering, therefore the least important variable in the grouping of the data.

3.2. General functioning and demographic characteristics

The clusters did not differ significantly in WSAS scores, the number of years the patients had been unemployed due to their illness, or in age. In fact, there was strong to very strong evidence in favour of the null hypothesis. The clusters also did not differ in the distribution of AN diagnostic subtypes (Table 3), with strong evidence in favour of the null hypothesis (BF = 1/22.26).

3.3. Illness severity and complexity

There was no significant difference between the clusters in duration of illness but there was decisive evidence that patients in cluster 2 had experienced significantly more previous hospitalisations due to AN than those in cluster 1. Additionally, patients in cluster 2 also reported lower self-efficacy in their ability to change, and more complex presentation including more comorbid diagnoses and a greater tendency to binge and purge than those in cluster 1 with very strong to decisive evidence. There was also a significant difference between the clusters in the self-reported use of psychotropic medication on admission, such that a higher proportion of patients in cluster 2 were taking medication on admission. However, there was only anecdotal evidence for this difference (BF = 1/1.52), suggesting no firm conclusions about medication use can be drawn based on the present data. Similarly, there was a significant difference between the clusters in motivation to change, but the evidence for this difference was only anecdotal (BF = 1.45), suggesting no firm conclusion about this variable can be drawn based on the observed data.

Table 1
Bayes factor interpretation table: classification of strength of evidence.

BF	Interpretation
> 100	Decisive evidence for the alternative hypothesis
$30 - 100$	Very strong evidence for the alternative hypothesis
$10 - 30$	Strong evidence for the alternative hypothesis
$3 - 10$	Moderate evidence for the alternative hypothesis
$1 - 3$	Anecdotal evidence for the alternative hypothesis
1	no evidence
$1 - \frac{1}{3}$	Anecdotal evidence for the null hypothesis
$\frac{1}{3} - \frac{1}{10}$	Moderate evidence for the null hypothesis
$\frac{1}{10} - \frac{1}{30}$	Strong evidence for the null hypothesis
$\frac{1}{30} - \frac{1}{100}$	Very strong evidence for the null hypothesis
$< \frac{1}{100}$	Decisive evidence for the null hypothesis

BF = Bayes factor.

4. Discussion

This study aimed to derive clinically distinct subgroups of adult patients with AN through a data-driven clustering approach. Patients were clustered based on their BMI, self-report eating pathology and general psychopathology. Amongst the two resulting clusters of similar sizes, cluster 2 ("higher symptoms cluster") reported higher scores on eating pathology, anxiety, depression, and autism screening than cluster 1 ("lower symptoms cluster"). The higher symptoms cluster also reported lower self-efficacy to change, more previous hospitalisations, comorbid diagnoses, binge eating and purging behaviours and use of psychotropic medication than the lower symptoms cluster. It should be highlighted that although the higher symptoms cluster also had slightly higher admission BMI, our inpatient sample overall had very low weight and BMI did not make major contributions to cluster formation.

4.1. The higher symptoms cluster

We found that the higher symptoms cluster scored high on all clustering variables, as well as on several illness severity and complexity indicators, such as binge and purge behaviours and number of comorbidities. Furthermore, the elevated autistic characteristics in this cluster are consistent with previous research suggesting an over-representation of autism in EDs (Westwood and Tchanturia, 2017). In particular, our results are in line with the literature highlighting emotional difficulties in autistic women with AN (Brede et al., 2020), which often relate to exacerbated anxiety and depression (Tchanturia et al., 2019). The maladaptive presentation and increased hospitalisations in this cluster also confirm previous research where individuals with co-occurring autism and EDs often present with worse treatment outcomes (Nielsen et al., 2015) and increased service use (Nazar et al., 2018). Similarly, a previous study clustering individuals with AN based on neuropsychological features (i.e. executive function, central coherence, and theory of mind) also identified an autism-like subset with difficulties in executive function and central coherence (Renwick et al., 2015). This link between autistic characteristics and illness severity warrants clinical attention, as autistic individuals' sensory and cognitive profile may make it more difficult for them to benefit from standard ED treatment designed for neurotypical patients, which calls for treatment adaptations and innovations for autistic patients or those with autistic traits.

Previous empirical work has also highlighted that purging behaviour is associated with negative outcomes, comorbidities, and life-threatening physical complications such as electrolyte disturbances (Keel et al., 2004; Solmi et al., 2015; Royal College of Psychiatrists, 2022). Indeed, the higher symptoms cluster in the current study presented with more binge and purge behaviours in combination with more negative affect. Notably, patients in this cluster also had more previous hospital admissions, despite having similar duration of illness as the lower symptoms cluster. This finding is in direct contrast with previous work which has argued that duration of illness is a key severity indicator (Maguire et al., 2012). On the other hand, this is in line with previous findings linking binge-purge behaviours and low affect with treatment

Table 2
Differences between clusters.

	Measure	Cluster 1 (*N* = 115)	Cluster 2 (*N* = 112)	Bayesian regression results			
				Median [95% CrI]	% in ROPE	PD	BF
Clustering variables	Admission BMI Mean (SD)	13.70 (1.13)	14.29 (1.41)	0.59 [0.26, 0.92]	0%	99.98%	4.35
	EDEQ total score Mean (SD)	3.07 (1.64)	4.95 (0.99)	1.88 [1.52, 2.23]	0%	>99.99%	4.39e+07
	AQ-10 score Mean (SD)	2.63 (1.71)	5.69 (2.07)	3.06 [2.56, 3.56]	0%	>99.99%	2.50e+13
	HADS anxiety score Mean (SD)	10.89 (4.21)	17.58 (2.61)	6.69 [5.77, 760]	0%	>99.99%	3.63e+14
	HADS depression score Mean (SD)	8.24 (4.54)	14.56 (3.59)	6.32 [5.24, 7.38]	0%	>99.99%	3.77e+09
General functioning and demographic variables	Age Mean (SD)	28.00 (12.01)	26.93 (9.01)	−1.08 [−3.84, 1.69]	45.26%	77.72%	1/46.07
	WSAS total Mean (SD)	24.89 (10.27)	26.88 (8.99)	1.99 [−0.65, 4.64]	21.37%	93.12%	1/16.79
	Years of unemployment due to AN Mean (SD)	12.21 (27.35)	10.46 (20.63)	−1.74 [−12.32, 8.80]	34.63%	62.89%	1/24.19
Illness severity and complexity variables	Duration of AN (years) Mean (SD)	8.98 (9.80)	10.20 (8.03)	1.23 [−1.25, 3.67]	36.67%	83.58%	1/33.08
	Medication use N (%)	54 (48.65%)	69 (64.49%)	0.65 [0.11, 1.21]	2.03%	99.05%	1/1.52
	Number of hospital admissions Mean (SD)	1.39 (2.39)	2.39 (3.86)	0.54 [0.34, 0.74]	0%	>99.99%	698.82
	Number of comorbidities Mean (SD)	0.66 (0.95)	1.25 (1.39)	0.64 [0.36, 0.93]	0%	>99.99%	113.18
	Binge eating N (%)	56 (48.70%)	82 (73.21%)	1.06 [0.51, 1.63]	0%	>99.99%	39.34
	Purging N (%)	35 (30.43%)	64 (57.14%)	1.12 [0.58, 1.67]	0%	>99.99%	69.92
	Motivational ruler: importance to change Mean (SD)	8.36 (2.34)	7.37 (2.47)	−0.98 [−1.64, −0.37]	0%	99.88%	1.45
	Motivational ruler: ability to change Mean (SD)	6.31 (2.99)	3.85 (2.69)	−2.46 [−3.19, −1.70]	0%	>99.99%	1.48e+04

BMI = body mass index; EDEQ = eating disorder examination questionnaire; AQ-10 = autism spectrum quotient, short version; HADS = hospital anxiety and depressions scale; WSAS = work and social adjustment scale; SD = standard deviation; CrI = credible interval; ROPE = region of practical equivalence; PD = probability of direction; BF = Bayes factor.

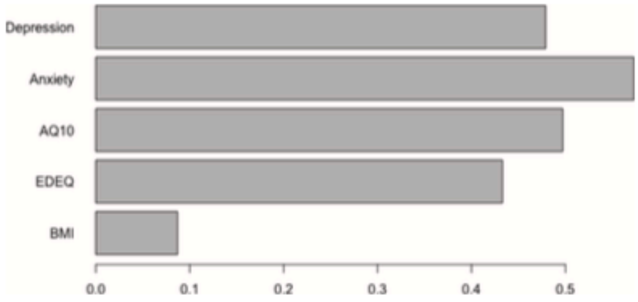

Fig. 2. Relative contributing weights of clustering variables.

resistance in severe AN (Smith and Woodside, 2021; Di Lodovico et al., 2021). Interestingly, despite one cluster reporting more binge-purge behaviours than the other, the two clusters did not differ in the proportion of individuals with AN binge-purge diagnosis. It is possible that for some patients, their frequency of binge and purge behaviours simply did not meet the clinical cut-off for receiving a diagnosis. Our results show that regardless of the level of engagement, binge-purge behaviour is linked to more complex and severe presentation and therefore needs clinical attention. Another possible explanation is that individuals reported binge-purge behaviours on the questionnaire but denied these behaviours when questioned in a diagnostic interview and therefore did not receive a binge-purge subtype diagnosis. This is in line with previous finding that approximately 40% of participants who reported purging behaviour on self-report measures subsequently denied this in a face-to-face interview (Mond et al., 2007), possibly due to a greater shame in disclosing purging behaviours when faced directly with an interviewer. This inconsistency between self-report and clinical assessment should be addressed with caution to prevent problematic behaviours like purging from being missed by the clinical team.

We also found that the higher symptoms cluster had significantly

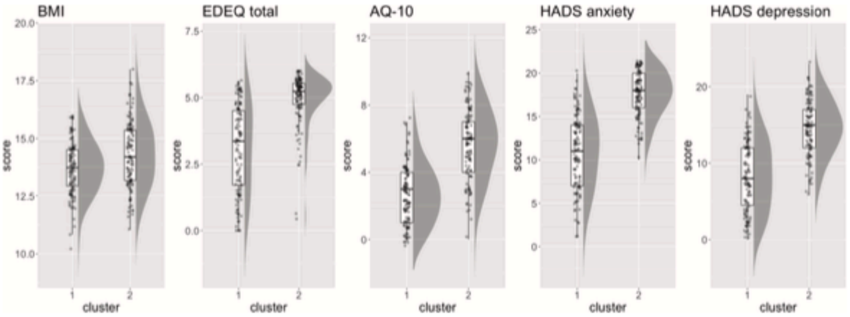

Fig. 3. Differences between clusters in clustering variables
BMI = body mass index; EDE-*Q* = eating disorder examination questionnaire; AQ-10 = autism spectrum quotient, short version; HADS = hospital anxiety and depressions scale.

Table 3
Distribution of AN diagnostic subtypes between the clusters.

	Cluster 1 ($N = 115$)	Cluster 2 ($N = 112$)
AN Restrictive, N (%)	84 (73.04%)	80 (71.43%)
AN Binge-purge, N (%)	26 (22.61%)	29 (25.89%)
AN Atypical, N (%)	5 (4.35%)	3 (2.68%)

higher, not lower, admission BMI (Mean=14.29, SD=1.41) than those in the lower symptoms cluster (Mean=13.70, SD=1.13). This is in line with previous clustering studies using larger (Miles et al., 2022) and smaller (Damiano et al., 2015) samples of patients with ED which identified high symptom groups reporting higher BMI. However, it is important to consider that this statistically significant difference may not be clinically meaningful. Indeed, the associated Bayes factor (BF=4.35) and cluster weight (0.09) of the BMI variable suggest that admission BMI did not make substantial contributions to the cluster formation. Together, the findings suggest that weight alone may not be a significant symptom severity indicator amongst inpatients with AN, most of whom have very low BMI. This is consistent with previous work showing that improvement in psychopathology in AN does not correlate with BMI improvement (Mattar et al., 2012), suggesting for a better indicator for illness severity such as purging behaviour and comorbid symptoms, rather than BMI alone. Furthermore, this finding brings attention to individuals who have lost a significant amount of weight but may still be at a higher weight than other patients. These patients are commonly diagnosed with atypical AN or Eating Disorder Not Otherwise Specified (EDNOS) (Moskowitz and Weiselberg, 2017). Despite not being as emaciated as patients who are more underweight, these patients can experience a similar profile of life-threatening complications (Whitelaw et al., 2014) and deserve just as much clinical attention.

4.2. *The lower symptoms cluster*

With lower scores on the self-report measures, individuals in the lower symptoms cluster appear to have better functioning and fewer difficulties with eating and general psychopathology. This is in line with previous findings that individuals reporting less fear of weight gain and ED symptoms also appeared to have less severe psychopathology (Ramacciotti et al., 2002). However, it is also possible that patients in this cluster are simply more used to suppressing their emotions, a problem that is most pronounced in the acute phase of the illness (Oldershaw et al., 2015), thereby leading to lower self-reported symptoms. It has been suggested that starvation may at least partly serve as a strategy to regulate unwanted emotions and feelings (Haynos and Fruzzetti, 2011). Starvation numbs both physiological and emotional responses thus provides escape or a safe place, but it also potentially makes it more difficult to describe or identify own internal states (Malova and Dunleavy, 2022; Lavis, 2018; Oldershaw et al., 2015; Rowsell et al., 2016). Therefore, the lower symptoms reported in this cluster might in fact be a warning sign of emotional avoidance. On the other hand, it is also possible that the lower scores on self-report measures were due to denial of symptoms, particularly on the EDE-Q where some patients reported next to no ED symptoms. Deliberate denial and distortion of symptoms are common in AN due to body image disturbance and resistance to change (Vitousek et al., 1991). This also reflects reduced insight and low self-awareness in this cluster, which may dangerously lead to a more difficult recovery path (Errichiello et al., 2016). Longitudinal research would be of interest to shed light on the underlying mechanisms and outcomes for under-reported symptoms amongst inpatients with AN.

4.3. *Limitations*

One limitation of this study is the use of self-report questionnaires alone. As previously discussed, it is possible for individuals to deny or minimise symptoms in self-report measures such as the EDE-Q. Moreover, the accuracy of self-report autism screening tools such as the AQ-10 in the ED population has been controversial. The internal consistency for AQ-10 in this study (Cronbach's α = 0.78) was acceptable but not excellent. Future studies should consider combining assessment interviews with self-report measures of ED symptoms, as well as more rigorous measures of autistic characteristics. Another limitation of the study was the number of patient entries excluded due to missing data; although patients who were included in the end had complete data in all of the clustering variables, there was missing data in other clinical and demographic variables not used in clustering. This was inevitable, given that the study used observational clinical audit data. However, this does not affect the robustness of the clustering, and Bayesian inference was used for its enhanced interpretability in observational data. Lastly, due to demographic constraint of the inpatient setting, the current study only examines inpatients mostly with severe AN. Any conclusions on the significance of weight, purging, autistic characteristics, or negative affect would need to be validated within a larger cohort of people with a broader range of ED severity and subtypes.

5. Conclusions

This study suggests that distinct groups of illness severity exist in adults with AN. More complex and severe presentation in AN is associated with more comorbidities (including autism, anxiety and depression), previous hospitalisations, binge eating and purging behaviours and use of psychotropic medication. BMI did not make major contributions to the clustering, suggesting that weight alone may not be a significant severity indicator. Our findings warrant future studies that investigate aetiological categorisation including other ED populations (e.g., bulimia nervosa) and promote the use of a broader range of validators to guide treatment tailoring in ED.

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CRediT authorship contribution statement

Zhuo Li: Data curation, Writing – original draft, Writing – review & editing. **Jenni Leppanen:** Formal analysis, Writing – original draft, Writing – review & editing. **Jessica Webb:** Data curation, Writing – review & editing. **Philippa Croft:** Data curation, Writing – review & editing. **Sarah Byford:** Supervision, Writing – review & editing. **Kate Tchanturia:** Supervision, Writing – review & editing.

Declaration of Competing Interest

The authors have no conflicts of interest to declare that are relevant to the content of this article.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.psychres.2023.115272.

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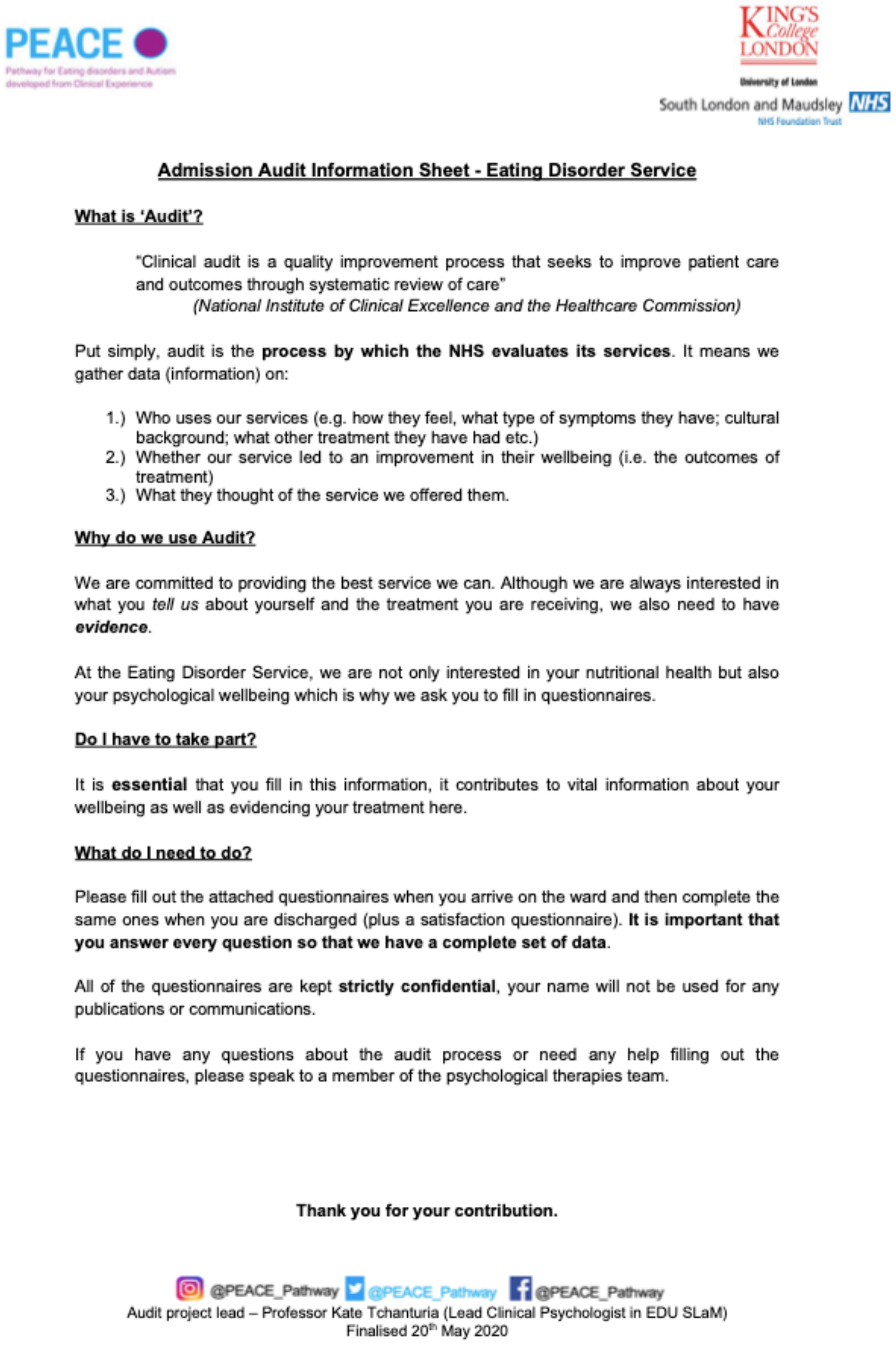
Appendix 3.2 SLaM ED service audit questionnaires



PEACE
Pathway for Eating disorders and Autism developed from Clinical Experience

KING'S College LONDON
University of London
South London and Maudsley NHS
NHS Foundation Trust

Admission Audit Information Sheet - Eating Disorder Service

What is 'Audit'?

> "Clinical audit is a quality improvement process that seeks to improve patient care and outcomes through systematic review of care"
> *(National Institute of Clinical Excellence and the Healthcare Commission)*

Put simply, audit is the **process by which the NHS evaluates its services**. It means we gather data (information) on:

1.) Who uses our services (e.g. how they feel, what type of symptoms they have; cultural background; what other treatment they have had etc.)
2.) Whether our service led to an improvement in their wellbeing (i.e. the outcomes of treatment)
3.) What they thought of the service we offered them.

Why do we use Audit?

We are committed to providing the best service we can. Although we are always interested in what you *tell us* about yourself and the treatment you are receiving, we also need to have ***evidence***.

At the Eating Disorder Service, we are not only interested in your nutritional health but also your psychological wellbeing which is why we ask you to fill in questionnaires.

Do I have to take part?

It is **essential** that you fill in this information, it contributes to vital information about your wellbeing as well as evidencing your treatment here.

What do I need to do?

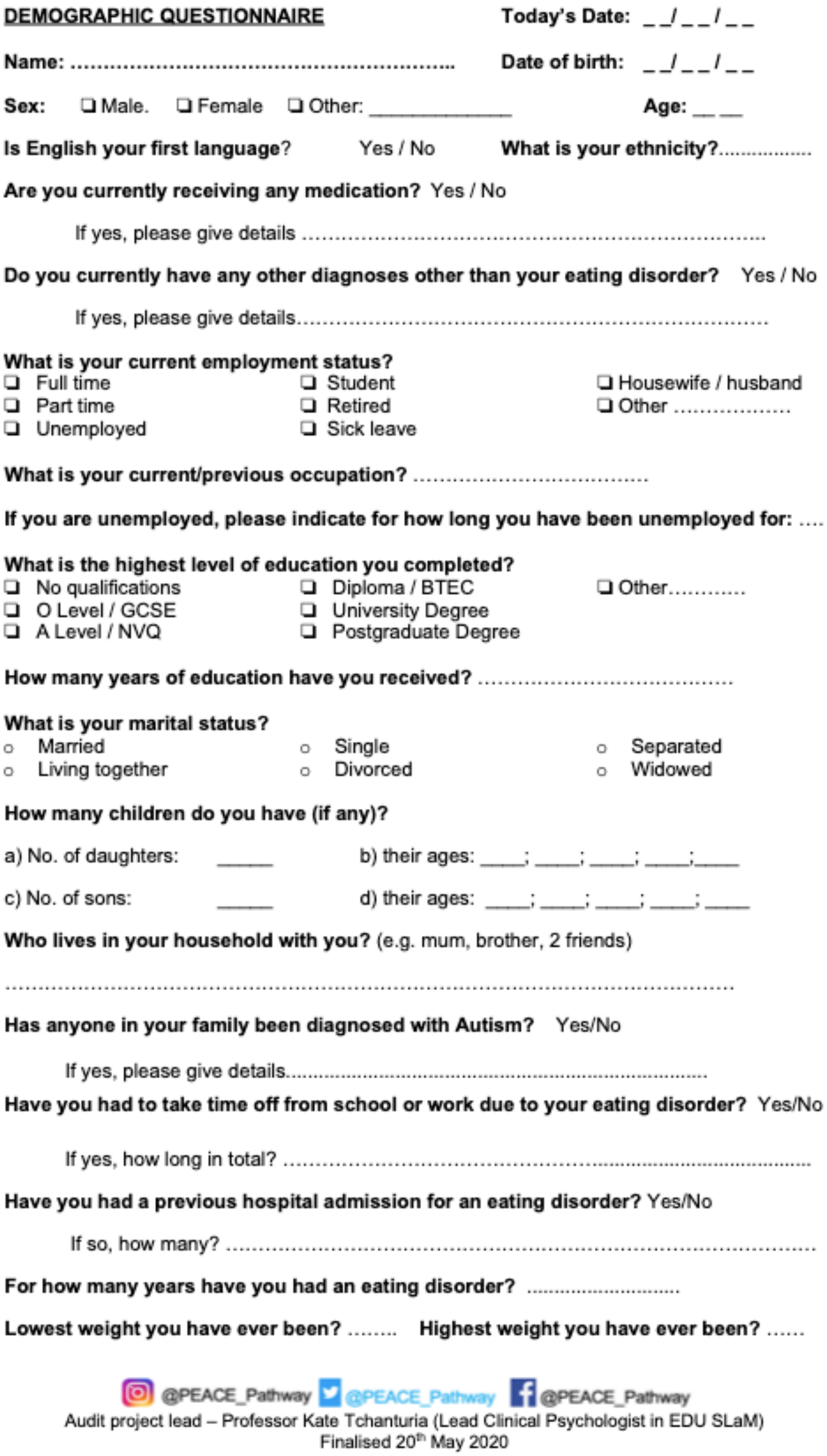
Please fill out the attached questionnaires when you arrive on the ward and then complete the same ones when you are discharged (plus a satisfaction questionnaire). **It is important that you answer every question so that we have a complete set of data**.

All of the questionnaires are kept **strictly confidential**, your name will not be used for any publications or communications.

If you have any questions about the audit process or need any help filling out the questionnaires, please speak to a member of the psychological therapies team.

Thank you for your contribution.

@PEACE_Pathway @PEACE_Pathway @PEACE_Pathway
Audit project lead – Professor Kate Tchanturia (Lead Clinical Psychologist in EDU SLaM)
Finalised 20th May 2020



DEMOGRAPHIC QUESTIONNAIRE **Today's Date:** _ _/ _ _ / _ _

Name: ………………………………………………….. **Date of birth:** _ _/ _ _ / _ _

Sex: ☐ Male. ☐ Female ☐ Other: ____________ **Age:** __ __

Is English your first language? Yes / No **What is your ethnicity?**................

Are you currently receiving any medication? Yes / No

If yes, please give details …………………………………………………………………..

Do you currently have any other diagnoses other than your eating disorder? Yes / No

If yes, please give details……………………………………………………………………

What is your current employment status?
- ☐ Full time
- ☐ Part time
- ☐ Unemployed
- ☐ Student
- ☐ Retired
- ☐ Sick leave
- ☐ Housewife / husband
- ☐ Other ………………

What is your current/previous occupation? ……………………………….

If you are unemployed, please indicate for how long you have been unemployed for: ….

What is the highest level of education you completed?
- ☐ No qualifications
- ☐ O Level / GCSE
- ☐ A Level / NVQ
- ☐ Diploma / BTEC
- ☐ University Degree
- ☐ Postgraduate Degree
- ☐ Other…………

How many years of education have you received? …………………………………

What is your marital status?
- ○ Married
- ○ Living together
- ○ Single
- ○ Divorced
- ○ Separated
- ○ Widowed

How many children do you have (if any)?

a) No. of daughters: _____ b) their ages: ____; ____; ____; ____;____

c) No. of sons: _____ d) their ages: ____; ____; ____; ____; ____

Who lives in your household with you? (e.g. mum, brother, 2 friends)

……………………………………………………………………………………………………

Has anyone in your family been diagnosed with Autism? Yes/No

If yes, please give details...

Have you had to take time off from school or work due to your eating disorder? Yes/No

If yes, how long in total? ……………………………………………...........................

Have you had a previous hospital admission for an eating disorder? Yes/No

If so, how many? ………………………………………………………………………………

For how many years have you had an eating disorder? ....

Lowest weight you have ever been? …….. **Highest weight you have ever been?** ……

@PEACE_Pathway @PEACE_Pathway @PEACE_Pathway

Audit project lead – Professor Kate Tchanturia (Lead Clinical Psychologist in EDU SLaM)
Finalised 20th May 2020

Eating Disorder Examination Questionnaire

The following questions are concerned with the past four weeks only (28 days). Please read each question carefully and tick the appropriate box.

Please answer all the questions.

On how many days out of the past 28 days…	**No days**	**1-5 days**	**6-12 days**	**13-15 days**	**16-22 days**	**23-27 days**	**Every day**
1. Have you been deliberately trying to limit the amount of food you eat to influence your shape or weight?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
2. Have you gone for long periods of time (8 hours or more) without eating anything in order to influence your shape or weight?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
3. Have you tried to avoid eating foods which you like in order to influence your shape or weight?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
4. Have you tried to follow definite rules regarding your eating in order to influence your shape or weight; for example, a calorie limit, a set amount of food, or rules about what or when you should eat?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
5. Have you wanted your stomach to be empty?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
6. Has thinking about food or its calorie content made it much more difficult to concentrate on things you're interested in; for example, read, watch TV or follow a conversation?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
7. Have you been afraid of losing control over eating?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
8. Have you had episodes of binge eating?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐

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9.	Have you eaten in secret? (Do not count binges)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐

	On how many days out of the past 28 days…	**No days**	**1-5 days**	**6-12 days**	**13-15 days**	**16-22 days**	**23-27 days**	**Every day**
10.	Have you definitely wanted your stomach to be flat?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
11.	Has thinking about shape or weight made it more difficult to concentrate on things you are interested in; e.g., read, watch TV or follow a conversation?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
12.	Have you had a definite fear that you might gain weight or become fat?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
13.	Have you felt fat?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
14.	Have you had a strong desire to lose weight?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐

	Over the past 4 weeks (28 days)	**None of the times**	**A few of the times**	**Less than ½ the time**	**Half the time**	**More than ½ the time**	**Most of the time**	**Every time**
15.	On what proportion of times that you have eaten have you felt guilty because of the effect on your shape or weight? (Do not count binges)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐

16.	Have there been any times when you have felt that you have eaten what other people would regard as an unusually large amount of food given the circumstances?	No ☐	Yes ☐
17.	How many such episodes have you had over the past four weeks?	☐	

18. During how many of these episodes of overeating did you have a sense of having lost control over your eating? ☐

19. Have you had other episodes of eating in which you have had a sense of having lost control and eaten too much, but have not eaten an unusually large amount of food given the circumstances? No ☐ Yes ☐

20. How many such episodes have you had over the past four weeks? ☐

21. Have you made yourself sick (vomit) as a means of controlling your shape or weight? No ☐ Yes ☐

22. How many times have you done this over the past four weeks? ☐

23. Have you taken laxatives as a means of controlling your shape or weight? No ☐ Yes ☐

24. How many times have you done this over the past four weeks? ☐

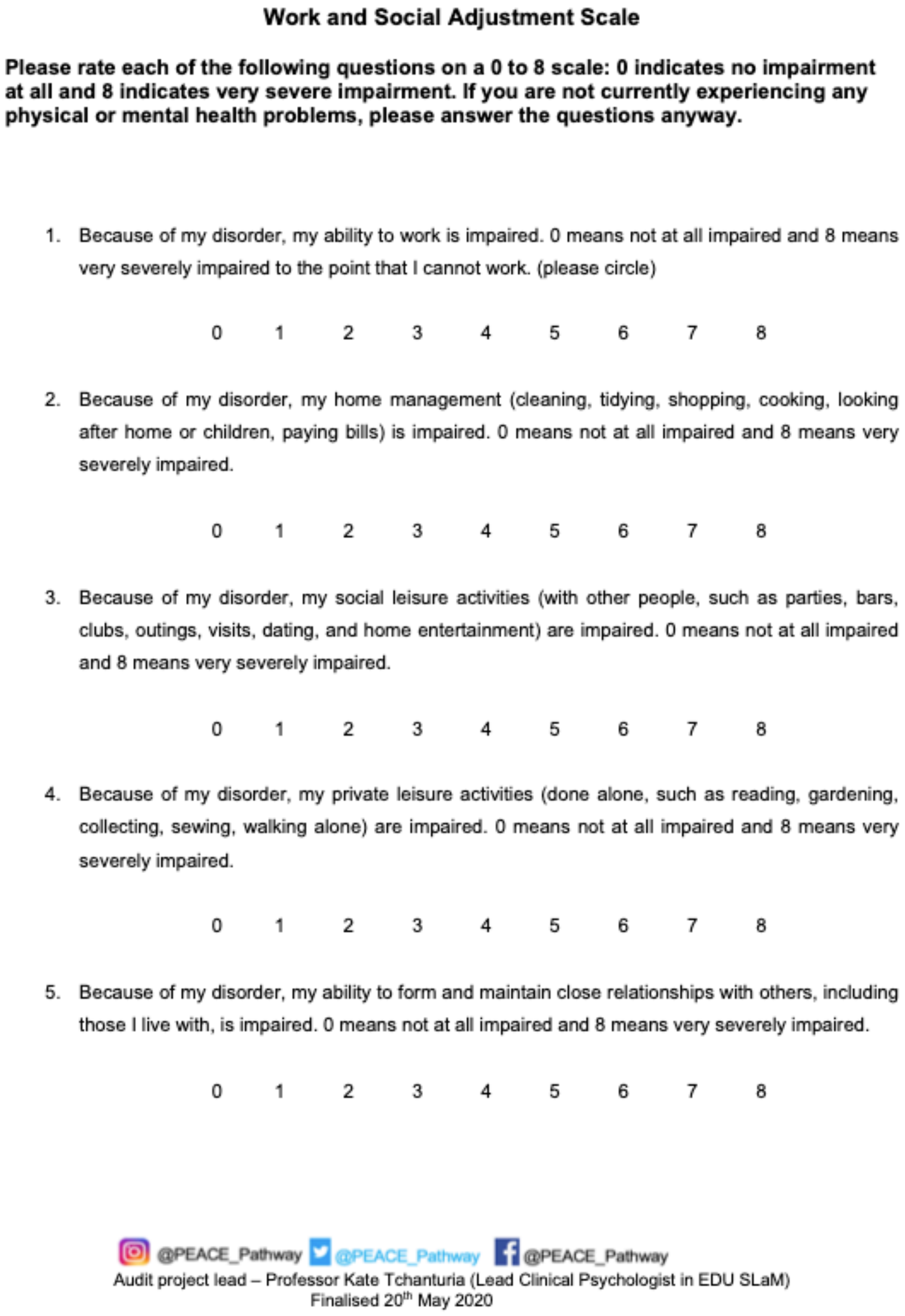
25. Have you taken diuretics (water tablets) as a means of controlling your shape or weight? No ☐ Yes ☐

26. How many times have you done this over the past four weeks? ☐

27. Have you exercised hard as a means of controlling your shape or weight? No ☐ Yes ☐

28. How many times have you done this over the past four weeks? ☐

	Over the past 4 weeks (28 days)	***Not at all***		**Slightly**		**Moderately**		**Markedly**
29.	Has your weight influenced how you think about (judge) yourself as a person?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
30.	Has your shape influenced how you think about (judge) yourself as a person?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
31.	How much would it upset you if you had to weigh yourself once a week for the next four weeks?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
32.	How dissatisfied have you felt about your weight?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
33.	How dissatisfied have you felt about your shape?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
34.	How concerned have you been about other people seeing you eat?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
35.	How uncomfortable have you felt seeing your body; for example, in shop window reflections, while undressing or taking a bath or shower?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
36.	How uncomfortable have you felt about others seeing your body; for example, in communal changing rooms, when swimming or wearing tight clothes?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐



Work and Social Adjustment Scale

Please rate each of the following questions on a 0 to 8 scale: 0 indicates no impairment at all and 8 indicates very severe impairment. If you are not currently experiencing any physical or mental health problems, please answer the questions anyway.

1. Because of my disorder, my ability to work is impaired. 0 means not at all impaired and 8 means very severely impaired to the point that I cannot work. (please circle)

0 1 2 3 4 5 6 7 8

2. Because of my disorder, my home management (cleaning, tidying, shopping, cooking, looking after home or children, paying bills) is impaired. 0 means not at all impaired and 8 means very severely impaired.

0 1 2 3 4 5 6 7 8

3. Because of my disorder, my social leisure activities (with other people, such as parties, bars, clubs, outings, visits, dating, and home entertainment) are impaired. 0 means not at all impaired and 8 means very severely impaired.

0 1 2 3 4 5 6 7 8

4. Because of my disorder, my private leisure activities (done alone, such as reading, gardening, collecting, sewing, walking alone) are impaired. 0 means not at all impaired and 8 means very severely impaired.

0 1 2 3 4 5 6 7 8

5. Because of my disorder, my ability to form and maintain close relationships with others, including those I live with, is impaired. 0 means not at all impaired and 8 means very severely impaired.

0 1 2 3 4 5 6 7 8

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Motivational Ruler

1. **Importance to change**. Ask yourself the following question: How important is it for you to change? What are your desires, reasons and needs for change? What score would you give yourself out of 10?

0 1 2 3 4 5 6 7 8 9 10

2. **Ability to change**. Ask yourself the following question: How confident are you in your ability to change? What score would you give yourself out of 10?

0 1 2 3 4 5 6 7 8 9 10

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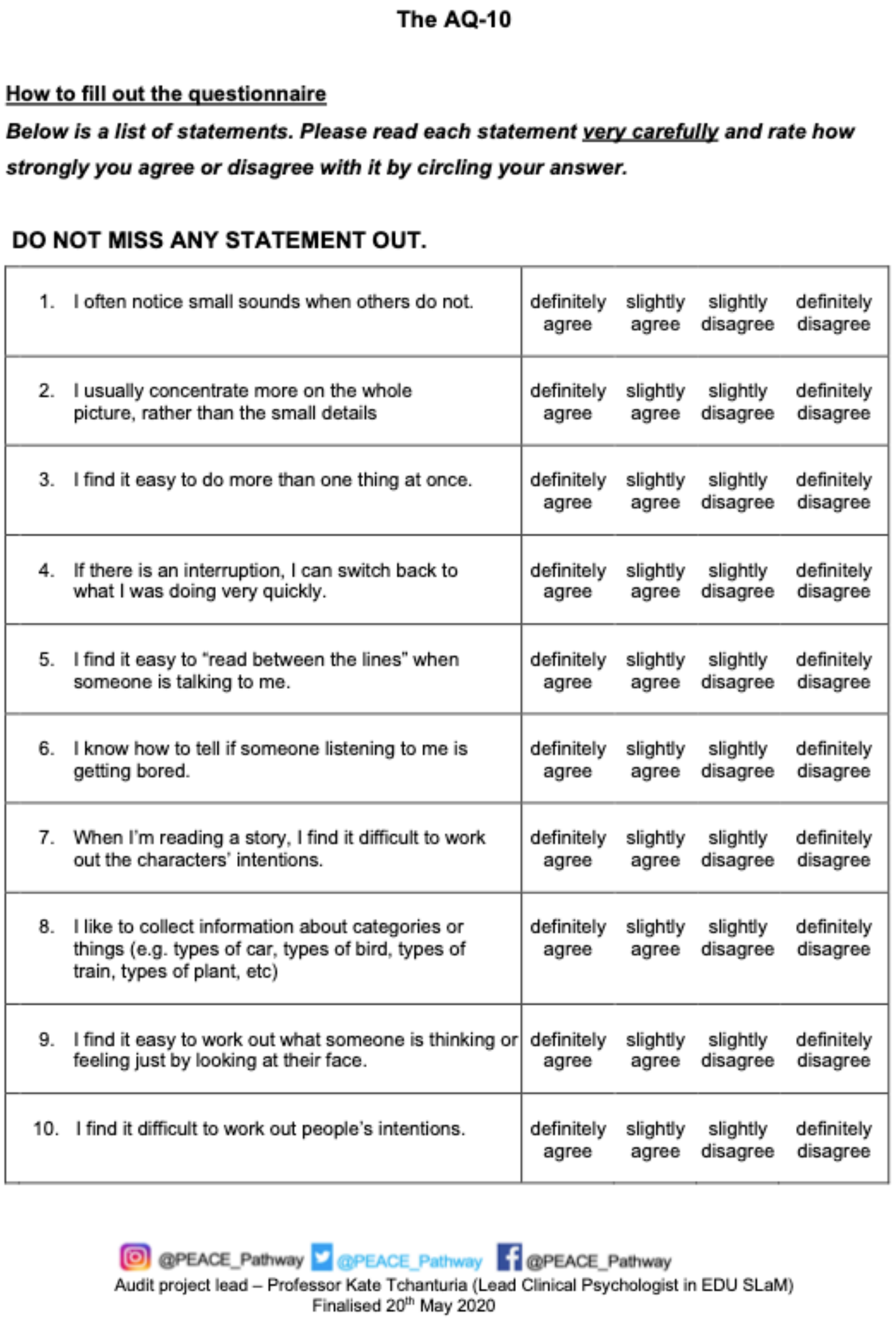

The AQ-10

How to fill out the questionnaire

Below is a list of statements. Please read each statement very carefully and rate how strongly you agree or disagree with it by circling your answer.

DO NOT MISS ANY STATEMENT OUT.

1. I often notice small sounds when others do not.	definitely agree	slightly agree	slightly disagree	definitely disagree
2. I usually concentrate more on the whole picture, rather than the small details	definitely agree	slightly agree	slightly disagree	definitely disagree
3. I find it easy to do more than one thing at once.	definitely agree	slightly agree	slightly disagree	definitely disagree
4. If there is an interruption, I can switch back to what I was doing very quickly.	definitely agree	slightly agree	slightly disagree	definitely disagree
5. I find it easy to "read between the lines" when someone is talking to me.	definitely agree	slightly agree	slightly disagree	definitely disagree
6. I know how to tell if someone listening to me is getting bored.	definitely agree	slightly agree	slightly disagree	definitely disagree
7. When I'm reading a story, I find it difficult to work out the characters' intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree
8. I like to collect information about categories or things (e.g. types of car, types of bird, types of train, types of plant, etc)	definitely agree	slightly agree	slightly disagree	definitely disagree
9. I find it easy to work out what someone is thinking or feeling just by looking at their face.	definitely agree	slightly agree	slightly disagree	definitely disagree
10. I find it difficult to work out people's intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree

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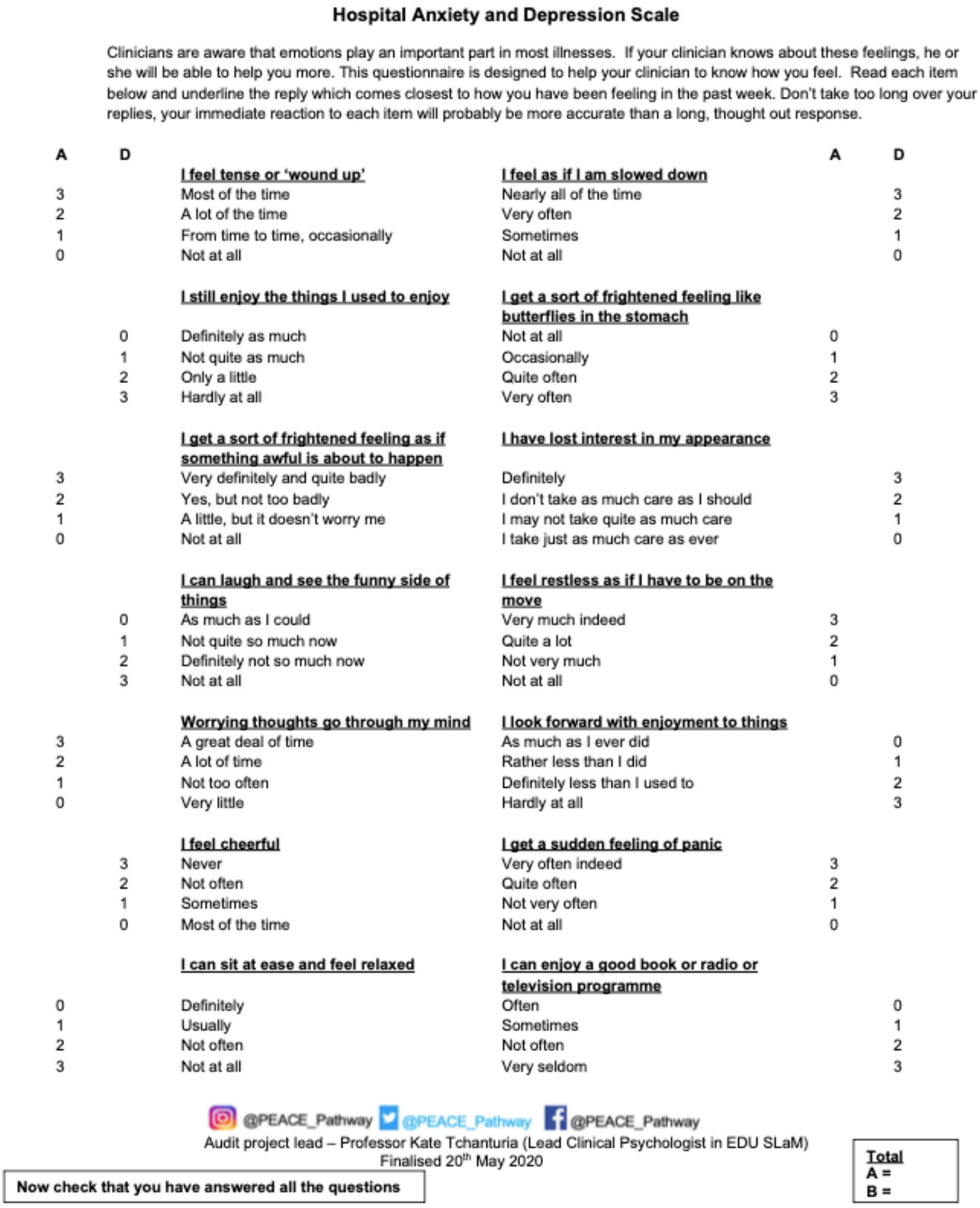

Hospital Anxiety and Depression Scale

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings, he or she will be able to help you more. This questionnaire is designed to help your clinician to know how you feel. Read each item below and underline the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought out response.

A	D			A	D
		I feel tense or 'wound up'	**I feel as if I am slowed down**		
3		Most of the time	Nearly all of the time		3
2		A lot of the time	Very often		2
1		From time to time, occasionally	Sometimes		1
0		Not at all	Not at all		0
		I still enjoy the things I used to enjoy	**I get a sort of frightened feeling like butterflies in the stomach**		
	0	Definitely as much	Not at all	0	
	1	Not quite as much	Occasionally	1	
	2	Only a little	Quite often	2	
	3	Hardly at all	Very often	3	
		I get a sort of frightened feeling as if something awful is about to happen	**I have lost interest in my appearance**		
3		Very definitely and quite badly	Definitely		3
2		Yes, but not too badly	I don't take as much care as I should		2
1		A little, but it doesn't worry me	I may not take quite as much care		1
0		Not at all	I take just as much care as ever		0
		I can laugh and see the funny side of things	**I feel restless as if I have to be on the move**		
	0	As much as I could	Very much indeed	3	
	1	Not quite so much now	Quite a lot	2	
	2	Definitely not so much now	Not very much	1	
	3	Not at all	Not at all	0	
		Worrying thoughts go through my mind	**I look forward with enjoyment to things**		
3		A great deal of time	As much as I ever did		0
2		A lot of time	Rather less than I did		1
1		Not too often	Definitely less than I used to		2
0		Very little	Hardly at all		3
		I feel cheerful	**I get a sudden feeling of panic**		
	3	Never	Very often indeed	3	
	2	Not often	Quite often	2	
	1	Sometimes	Not very often	1	
	0	Most of the time	Not at all	0	
		I can sit at ease and feel relaxed	**I can enjoy a good book or radio or television programme**		
0		Definitely	Often		0
1		Usually	Sometimes		1
2		Not often	Not often		2
3		Not at all	Very seldom		3

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Now check that you have answered all the questions

Total
A =
B =

Appendix 4.1 How to support adults with anorexia nervosa and autism: Qualitative study of clinical pathway case series

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How to support adults with anorexia nervosa and autism: Qualitative study of clinical pathway case series

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Introduction: Previous research has explored the overlapping presentation between autism and eating disorders (ED). This study aims to summarize the clinical challenges associated with co-occurring autism and anorexia nervosa (AN) based on clinicians' case notes and minutes from case discussions, to understand how to better support people with the comorbidity.

Method: Thematic analysis was conducted on de-identified notes on 20 cases with AN and autistic characteristics and minutes from case discussions. Themes relevant to clinical challenges in supporting those with the comorbidity were identified, and a thematic map was produced to visually represent the results.

Results: The key challenges faced by clinicians when treating patients with AN and autism included: communication difficulties, maintaining boundaries, autism screening, presence of other comorbidities, sensory difficulties, atypical presentation of eating difficulties, cognitive rigidity, and emotional difficulties. Adaptations to resolve some of these difficulties included exposure-based food experiments, keeping a record of patients' self-reported communication preferences, individual-level modification of communication style, and providing tools for patients to identify emotions.

Conclusions and implications: Further exploration to establish the effectiveness of the adaptations is warranted. Furthermore, tools for differentiating between ED, autism and other comorbidities are needed to help clinicians clarify the cause of a presenting symptom, and help them to best support and maintain boundaries with patients.

KEYWORDS
eating disorder, autism, comorbidity, treatment, adaptation

Introduction

Anorexia nervosa (AN) is an eating disorder (ED) associated with the highest mortality rate among all psychiatric disorders (1) and has an average prevalence rate of 0.3% among young women (2). It is characterized by an intense fear of gaining weight, behaviors interfering with weight gain and a distorted body image. Other types of ED include bulimia nervosa (BN), characterized by binging and purging behaviors, and binge-eating disorder (BED), characterized by recurrent episodes of binge eating without compensatory behaviors. They are relatively less researched than AN but are more common in the population with prevalence rates of at least 1% (3, 4).

People with ED commonly present with psychiatric and medical comorbidities, such as anxiety, OCD, substance use and personality disorders (5). In particular, the overlap between AN and autism has been more actively researched in recent years, as summarized in a framework by Kinnaird and Tchanturia (6). Similarities between the two conditions include dietary restriction and food selectivity (7, 8), difficulties in cognitive flexibility (9), social anhedonia (10, 11), and strong interests in and preoccupation with specific topics (12, 13). The estimated prevalence of autism symptomatology in ED populations ranges from 8 to 37% (14–17), and individuals with co-occurring ED and autism are at risk of poorer treatment outcomes (19, 20). Overall, these findings highlight the need for individualized ED treatment adapted to the needs of autistic individuals.

The Pathway for Eating disorders and Autism developed from Clinical Experience (the PEACE pathway; https://www.peacepathway.org/) was developed and implemented in the South London and Maudsley (SLaM) NHS Foundation Trust Adult Eating Disorders Service with the aim of improving care for patients with co-occurring ED and autism (21, 22). It is, to our knowledge, the first systemic attempt to adapt an ED service for this comorbidity. Since the pathway's instigation in 2019, adaptations have been introduced relating to clinician training, psychoeducation resources (newly developed for patients), patient screening, treatment environment (to make it more sensory-friendly) and food menus.

As part of the implementation of the PEACE pathway from 2019 to 2022, weekly team meetings [known as 'PEACE huddles'; (23)] have been held to discuss cases with the comorbidity, associated practical challenges and possible treatment adaptations. These discussions fed into further service adaptations supporting the continuous development of the PEACE pathway over time.

The aim of this study was to present a synthesis of clinical challenges associated with both autism and anorexia nervosa (AN) based on a review of the case notes and minutes from the huddle discussions, and to outline the team's approach to the subsequent adaptation of treatment. As a considerable body of research has already covered autistic features in AN as well as patients' experience accessing support (6, 18, 24, 25), it is hoped that this study will present the clinical reality faced by clinicians trying to individualize care for those with the comorbidity, and thereby inform decision-making and treatment adaptations for this population.

Methods

Study design

This study reports the results of a review of clinical case notes and team meeting minutes relating to patients with co-morbid ED and autism. The study was part of a service quality improvement project and permission to audit patient data was obtained from the Clinical Governance and Audit Committee in South London and Maudsley NHS Trust (032019) in April 2019. In accordance with the institutional requirements written consent from the participants was not required. All clinical notes were fully anonymised to protect patient privacy.

Setting and sample

As part of the PEACE pathway implementation process at the SLaM Adult Eating Disorders Service (including inpatient and day services) between September 2019 and March 2022, clinicians attended regular PEACE huddle meetings to discuss select patient cases with complex presentation. The "PEACE huddles", which were utilized as group supervision, provided attending clinicians with an opportunity to share thoughts and challenges about patients with autism and develop consistency in treatment implementation. Cases were discussed in huddles if they either had a previous diagnosis of autism or presented with autistic characteristics, and their treatment was considered challenging by the care team (e.g., atypical eating difficulties due to autism). All case notes were de-identified before they were shared among the team to aid discussion. Minutes from the discussion, which included suggestions for adaptations and feedback on what was helpful for the cases, were also circulated among the team after the huddles.

The de-identified clinical notes contained clinician-written case management notes, progress and updates, nursing notes, summary of challenges and exploration of autistic characteristics. At the ED service where the PEACE pathway was implemented, autistic characteristics were routinely explored for all patients admitted to the ED service using autism screening tools. Screening primarily involved application of the Autism Spectrum Quotient short version (AQ-10) (25, 26). Where deemed necessary by the care team, autistic characteristics were further explored using the Autism Diagnostic Observation Schedule Module 4 [ADOS; (27)] and/or the Social Responsiveness Scale, Second Edition [SRS-2; (28)], to provide more information for the care team and to guide treatment adaptation. In this study, both patients with a formal diagnosis of autism and those presenting with autistic characteristics will be referred to as individuals with "autism comorbidity" or "people with autism."

Data

This study collected data from de-identified clinical notes and minutes from the PEACE pathway team meetings, as both sources of information referred to treatment challenges, potential treatment adaptations to meet these challenges and feedback on adaptations that had been helpful. Thematic analysis (29, 30) was used to analyse clinicians' notes and minutes of the PEACE huddles to identify clinical challenges and adaptations in supporting adults with EDs and autism. ZL first read all case notes and minutes repeatedly to inductively generate and refine potential codes. Coded data were then analyzed to identify themes and subthemes relevant to clinical challenges and treatment adaptations in supporting those with the comorbidity, and a thematic map was developed to represent the themes and subthemes in a visual format. CH independently reviewed and checked the thematic map against the case notes. The final thematic map was reviewed and finalized in consultation with the principal author KT.

Results

Demographic characteristics

In total, 34 cases were discussed in the PEACE huddles. Thirteen cases were consultations by teams from other ED services and therefore excluded from analysis. One case discussion focused on scoring of the autism screening tools rather than patient presentation and was therefore excluded from the study. Table 1 shows the demographic characteristics of the remaining 20 cases that were included in the study.

The majority of cases were female ($n = 16$, 80%) and the mean age at contact with the service was 26 years (SD = 10.7, range 19–68). Half of the cases had a formal diagnosis of autism prior to contact with the ED service ($n = 10$, 50%), whilst the other half were flagged up by the AQ-10 or ADOS-2 as having high autistic characteristics and recommended to receive formal assessment at a specialist service ($n = 10$, 50%). In addition to autism or autistic characteristics, further co-morbidities were reported, the most common of which was generalized anxiety disorder (GAD; $n = 10$, 50%), obsessive-compulsive disorder (OCD; $n = 8$, 40%) and depression ($n = 8$, 40%). Other common co-morbidities included emotionally unstable personality disorder (EUPD; $n = 2$, 10%) and attention deficit hyperactivity disorder (ADHD; $n = 2$, 10%).

TABLE 1 Summary of demographic information.

	Cases (*n* = 20)
Gender, *n* (%)	
- Female	16 (80%)
- Male	4 (20%)
Ethnicity, *n* (%)	
- White British	17 (85%)
- White Other	1 (5%)
- Black African	1 (5%)
- Asian	1 (5%)
Age, mean (SD)	26 (10.7)
ED diagnosis, *n* (%)	
- AN restrictive subtype	13 (65%)
- Atypical AN	5 (25%)
- AN binge-purge subtype	2 (10%)
Number of co-morbidities (other than autism), mean (SD)	1.85 (1.2)

Clinical challenges with meeting the needs of adults with AN and autism

Figure 1 shows the main themes that emerged from analysis of the case notes and meeting minutes. Subthemes that are relevant and connected to each other (e.g. Autistic traits not being picked up by the screener, Late diagnosis of autism) are categorized under a broader key theme (e.g. Autism screening), which is visualized in Figure 1. In total, eight key themes relevant to the research question were identified: communication difficulties, boundary issues, issues related to autism screening, presence of comorbidities, sensory difficulties, atypical eating behaviors, cognitive rigidity, and emotional difficulties.

Communication difficulties

Communication difficulties were highlighted in most cases, with severity ranging from mild difficulties in articulating thoughts to selective mutism. Patients also had issues with open questioning and found it hard to answer broad and open questions like: "how can I help?". This affected patients' therapeutic engagement and posed challenges for the care team.

> "[The patient] struggles with trying to explain what [the patient] means, [and with] verbalizing ED… Difficult knowing if the patient understands, there is lots of nodding and it seems fairly superficial at times." (Case 20)
>
> "Communication has been a struggle. Some meetings may have some verbal input from [the patient], but this is rare." (Case 12)

> space for patients to process what others are saying. Can be a useful adaptation for patients with autistic characteristics." (Case 8)

Social isolation from peers was reported in all cases, within and outside treatment settings. This was sometimes accompanied by over-dependence on family carers and clinical staff, which was identified to be a major barrier to independent living and returning to the community after treatment completion.

> "[The patient] can find it really difficult to make decisions, [the patient] asks for mum's support with certain things e.g. which therapy [the patient] should do/what to pick from the menu." (Case 14)

Challenges in maintaining boundaries

Boundary issues were described in the majority of cases, with patients described as becoming over-dependent on therapeutic relationships, clinical teams having to adapt treatment in a way that was sometimes against ward protocol (e.g. allowing patients to touch or smell food without eating it, or to have headphones on during dinner time instead of social eating), and patients refusing change or treatment owing to a 'learned helplessness' mindset about autism (i.e., insisting that their autism means that they are not capable of making changes essential to recovery and independent living). These boundary issues would often leave the clinical team with the difficult decision of whether to accommodate some of the autism-related difficulties or further encourage changes in the recovery journey from ED.

> "[The patient's] sensory needs sometimes are in conflict with the ward protocol and other patients' needs…Team can struggle with when to accommodate and when to encourage for change." (Case 15)
>
> "Difficult to manage boundaries with [the patient]; Need to limit the number of adaptations which can be agreed." (Case 6)

Compromises were often made to meet patients in the middle. However, when over-accommodation could risk impeding patients' recovery from their ED, clinicians would try to limit the number of adaptations that can be agreed and challenge patients' mindset with transparent, goal-oriented conversations to encourage changes.

> "Challenge [patient's] mindset about ASD: positive mindset to manage and work on sensory sensitivities and other challenges autism brings, instead of a learned helplessness mindset (e.g., I have autism, I'm never going to be able to). Start by exploring strengths and gifts." (Case 15)

Screening of potential autism

Autism screening brought further challenges for clinicians within the ED service. In all cases concerned, the AQ-10 (26) was used as a pragmatic short screener for potential autism, sometimes accompanied by an ADOS Module 4 (27) interview when a qualified ADOS-trained member of the team was available, or by an SRS-2 self-report questionnaire when an ADOS-trained interviewer was not available. However, some patients scored below the threshold on the AQ-10 despite their strong presentation of autism or already having a formal diagnosis. Furthermore, the majority of patients were not aware of their potential presentation of autism prior to the screener and had limited knowledge about autism. Therefore, informing patients and their families about a positive result on the screening tools was often met with surprise, causing anxiety for the patient and their families and for the clinical team member involved.

> "…the results of the ADOS-2 created some anxiety for [the patient] and parents – they were left with questions needing a forum in which to raise them. Psychologist anxiety about leaving patient to process the report feedback and how best to support them." (Case 7)

In their reflection, clinicians noted the need for more autism-related psychoeducation and training, particularly on normalizing autism and feeding back autism screening results to families.

> "[R]eflections and what we learned included: how little people know about autism and the need for more psychoeducation; importance of being open with patients and families that we are trying to learn about the comorbidity; … identify patients' strengths and work with this; need for a learning training session on feeding back ADOS results to patients and carers and to normalize A[utism] S[pectrum] C[ondition]." (Case 7)

Comorbidities

Case notes and meeting minutes also documented the care team spending considerable time helping patients distinguish between problems caused by different comorbidities, such as between rigidity around food caused by autism and inflexible mealtime routines driven by obsessive-compulsive disorder (OCD), or between food avoidance caused by AN cognitions and sensory avoidance driven by autism. This was challenging because the cases presented with a variety of complex comorbidities (Table 1) and symptoms were often intertwined, sometimes fueling one another, making changes and recovery even more difficult.

> "Fairly clear on what is AN vs. autism/OCD but it is harder to differentiate Autism and OCD due to the common factor of rigidity to routines etc." (Case 16)
>
> "Comorbidities predate ED and are intertwined with it. [OCD] symptoms … daily focused on fear of being ill. … restricting food because [the patient] is worried about being ill. …Autism makes routines even more rigid." (Case 18)

Differentiating between behaviors caused by ED and other comorbidities is nevertheless important in establishing focus for treatment. Clinicians would work with patients collaboratively to differentiate between specific eating-related behaviors and identify those rooted in ED that required intervention.

> "Using napkins to wipe hands is ED/sensory related, does not like the feeling of food on fingers. …Not completing meals based on OCD obsession. …ASC related – needing foods to be a specific 'right temperature'." (Case 6)

Sensory difficulties

Sensory difficulties also made it more difficult for clinicians to treat patients with the comorbidity, particularly at mealtimes. These sensory difficulties included sensitivity to texture, taste, or smell of certain foods on the menu, and sensory overload due to environmental factors that affected therapeutic engagement, such as distraction by the noise or brightness of the surroundings.

> "Very sensitive to noise and lights. Describes [themselves] as having increased interoceptive awareness and [the patient] experiences lots of physical pain associated with this." (Case 9)
>
> "[The patient dislikes] flashing lights, loud noises, sudden noises such as clapping." (Case 20)
>
> "Hypersensitive to human sounds especially chewing food." (Case 14)

Clinicians reported that cases with sensory sensitivities found attending workshops on sensory wellbeing psychoeducation helpful. Sensory items and low stimulus quiet areas were made available for patient use. Clinicians also adapted the environment of individual therapy sessions, checking in with patients in the beginning of the sessions to confirm if they felt comfortable in the environment.

> "Attended the sensory wellbeing workshop and was really engaged with the content, and was able to complete the sensory booklet." (Case 19)
>
> "[The patient] would carry sensory items, and made use of low stimulus quiet areas." (Case 6)
>
> "[M]et prior to starting therapy to [help the patient] get accustomed to the therapeutic process, to the consulting room and for [the clinician] to adjust the consulting room accordingly (lights, window, fan and seating)." (Case 4)

Atypical eating behaviors

Cases presented with atypical eating behaviors, some caused by food-related sensory sensitivities and some by strict rules and routines around meals, which posed another challenge for the care team. Restricted food intake in EDs is typically connected to body image and fear of weight gain; however, in cases with co-occurring autism, food restriction could be due to other reasons such as the texture or smell of foods instead of the calorie content, or discomfort associated with swallowing or chewing, anxiety about eating with other people, and rigidity around timing of meals or the way food is prepared and served. In these cases, focusing on conventional targets for ED treatment, such as fear of weight gain, overlooks what could be the true cause of the atypical eating behaviors, creating barriers for patients' engaging in treatment.

> "Atypical presentation- Enjoys calorie dense foods. … i.e., oat milk, mash potato, peaches, rice pudding and rice, chocolate and ice cream." (Case 9)
>
> "Food: small range at any time and then tires and stops eating them, resulting in the range of acceptable meals ever shrinking (This seems to be common within ASD patients)." (Case 16)
>
> "At home, [the patient] eats just a small range of foods, eating the same foods repeatedly until [the patient] tires of them." (Case 2)
>
> "Highly anxious if something is presented differently than expected, i.e., crumbs falling off the Weetabix in [the patient's] bowl. … [Patient] has a preoccupation with numbers/measurements: i.e., precise measurements with fluid, weight, calories per day." (Case 10)

Noticing the patients' atypical food preferences, dietitians developed an alternative menu ('PEACE menu') that is calorie-matched to the standard menu on the ward but consists of more bland tasting food items that are more homogeneous in texture. Most items were also pre-packaged for consistency. Food experiments and gradual exposure to new food were also helpful for patients who struggled with unfamiliar foods.

> "Menu choices: Repetitive, bland foods, colors, textures and flavors. … [the patient] has been utilizing the alternative menu a lot." (Case 9)
>
> "Has found it very useful to have the alternative menu choices." (Case 15)

> "For [the patient] to explore food, sniffing/touching without having to eat it, [the clinician] has offered [the patient] to explore/play with a few new things from the menu which [the patient] would like to try." (Case 15)

Cognitive rigidity

Cognitive rigidity was also documented as a major challenge, particularly in terms of difficulty coping with setbacks and unpredictable changes in the environment, such as the sudden shift to the virtual setting owing to the Coronavirus pandemic. Patients who were more inflexible and rigid also tended to find it harder to break routines and showed more extreme emotional responses to such changes. Cognitive rigidity also made therapeutic engagement more difficult, as helping to push the patient toward change is often key to making progress.

> "[The patient] keeps a precise idea in [their] head of what each thing should look like and cannot seem to settle until [the patient] can see exactly how the staff have measured [the patient's] food out." (Case 10)
>
> "Change is a huge source of anxiety. [The patient] depends on routines, sameness and predictability." (Case 9)
>
> "[The patient] struggles with engagement because of rigidity; very concrete [thinking style] which makes it difficult for [the patient] to relate the CRT (Cognitive Remediation Training) exercises to real life. [Patient] attributes this to autism and says [the patient] 'is never going to change'." (Case 13)

The team tried to help patients cope with changes by providing clear rationale for the plans. Patients were notified of any plans or potential changes early on to manage uncertainty. Most administrative changes were also made in consultation with patients.

> "Most changes are collaborative. If major changes, the implementation is with some notice rather than straight away." (Case 6)
>
> "What works well: providing rationale for changes, boundaries in place, being clear on timeframes." (Case 7)

Clinicians sometimes found that their own approach could be influenced by their patients' rigid way of behaving and inadvertently also become increasingly detail focused within their own practice. They were able to use case discussion as an opportunity for reflection and calibration of the team's approach.

> "[The patient's] rigid way of behaving has led the team into becoming rigid and detail-focused as well, adding detailed conditions to [the patient's] passes just to avoid [the patient's] disruptive behaviors on the ward. The team will need to resist giving in to this and try to move to bigger picture and planning." (Case 10)

Emotional difficulties

In addition to some cases displaying more extreme emotional reactions to changes, some had difficulty identifying and articulating their emotions during therapy sessions, leading to poorer therapeutic engagement. Clinicians found that this made planning and delivering therapy more challenging, as they had to speculate about the patient's feelings and the best ways to proceed with therapy with limited patient input.

> "Perhaps [the patient] would agree to goals because I'd suggested them so sometimes it was tricky to work out what was meaningful to [the patient], especially as [the patient] didn't report having emotional responses to many things." (Case 2)
>
> "Emotions were not described well. 'Don't know how to answer, not sure I can', 'don't know how I feel'." (Case 20)

The team therefore incorporated an emotions list into their practice in order to help patients to identify and express their emotions. In addition, a "traffic light communication system" was used to help patients to express both their emotions and the ways in which they wished to be supported to the clinical team.

> "Developed Traffic Light Communication System for wider team. [Patient] had cards on bedroom door to indicate how [the patient] was feeling: Red = I am really struggling, approach me with the emotions list and ask me to mark what I am feeling; Amber = Today is difficult, check in on me and ask me how I am doing; Green = I am ok, everyone carry on as usual." (Case 12)

Discussion

This qualitative synthesis of case notes and PEACE huddle meetings provides a snapshot of the variety of challenges that clinicians face when treating complex patients with AN and autism, including communication difficulties, maintaining boundaries, issues related to autism screening, presence of comorbidities other than autism, sensory sensitivities, atypical eating behaviors, cognitive rigidity, and emotional difficulties.

Helping patients with communication and emotional difficulties

Research has pointed out that one of the key problems for individuals with autism is communication in a social context, particularly with peers (31, 32). The case notes in this study further demonstrate how communication difficulties can, in practice, affect group participation as well as therapeutic engagement. Furthermore, patients' inability to maintain social relationships with peers can lead to over-dependence on carers (33) and clinical staff, creating a major barrier to independent living after discharge.

Clinicians in this study tried different resources and treatment adaptations for communication difficulties. One example was the 'communication passport' (34), which is a one-page self-report document encompassing multiple aspects of communication, including a patient's preferred way to communicate, their sensory needs, their dislikes and their special interests and strengths. This worksheet was designed to help health professionals understand patients' preferred ways of communicating. Another adaptation described in the case notes was individual-level modification of communication style. For patients who struggled with open ended questions, which is not unusual in individuals with autism (35), multiple choice questions were sometimes used as an alternative.

Additionally, patients often found it challenging both to identify and to articulate their emotions. However, it should be noted that emotional difficulties are widely present in the overall ED population, rather than limited to those with autism comorbidity. Indeed, there is a large body of existing work on alexithymia in patients with ED (36) as well as autistic individuals (37). Thus, the adaptations and resources used to address emotional difficulties may be helpful to all patients with ED, with or without co-occurring autism. To help patients identify their emotions, Cognitive Remediation and Emotion Skills Training (CREST) (38) was delivered in both individual and group formats. CREST interventions have been shown to significantly improve alexithymia and motivation in patients with AN and autism (39). On the other hand, patients with difficulties articulating their thoughts and emotions were given options to use conversation cards or 'traffic light' communication system to indicate their emotions, or to represent their thoughts through art or diagrams instead. These methods received good feedback in several cases, but their validity should be explored further in future research.

Boundary maintenance in adapting treatment for autism and other comorbidities

Previous studies have discussed boundary crossings, which are defined as attempts to "adapt an existing therapeutic alliance to foster the patient's capacity to work in therapy" (40). Boundary crossings are usually benign modifications to accommodate reasonable requests and individualize treatment. They become problematic when there is a negative impact on patients, endangering their health, independence, and/or recovery (41). In the setting of this study, clinicians were highly attuned to the different needs of patients with the comorbidity and were open and prepared to make adaptations. As a result, difficulties maintaining rules and boundaries spanned most of the case notes reviewed. Clinicians in this study often found themselves facing the dilemma of whether to continue encouraging change in patient behavior for recovery from ED, or to make accommodations for autism-specific needs.

Rather than adhering rigidly to absolute boundaries in all situations, clinicians often endeavored to compromise with patients. Furthermore, they worked with patients collaboratively to investigate what was driving the presenting difficulty before deciding whether treatment boundaries could be adapted: whether it was an ED symptom that should be addressed, an autism-driven need that could be accommodated, or an autism-related difficulty that nevertheless should be managed to facilitate independent living. Clarifying the cause of patients' problems was a crucial step to developing a corresponding care plan. Previous research on a framework for differentiating between clinical features of autism and ED could be a useful guiding tool for clinicians facing similar dilemmas (6). In some cases, however, comorbidities other than autism (e.g., anxiety, OCD and EUPD) were also present and intertwined with autism and the ED. This is consistent with existing evidence of overlap between EUPD and autism (42) and OCD and autism (43). These comorbidities and ED often fuelled each other by contributing to similar patterns of thoughts and behaviors, making recovery even more difficult. Therefore, more work may be required for clinicians to differentiate between the symptoms and identify the best way to help patients. This suggests the need for an extensive guiding framework for differentiating between difficulties caused by ED, autism, and other common comorbidities such as OCD and EUPD.

Sensory difficulties, cognitive rigidity and atypical eating behaviors

Both sensory difficulties and cognitive rigidity were linked to atypical eating behaviors in people with AN and autism, suggesting that their presentation may be driven by autism-related sensory and cognitive difficulties rather than common ED symptomatology such as fear of weight gain. Adaptations were necessary in these cases since conventional treatment at the ED services targeted typical ED symptoms and ED-driven cognition. In some cases, patients' preferences for certain foods were based on the texture, temperature, or even color, instead of calorie content (e.g., preference for smooth-textured, high calorie foods like ice cream). Weight restoration, therefore, could be easier for these patients once a sensory friendly dietetic plan was in place, since their primary concern was not weight or body shape. This is consistent with previous research showing that inpatients with AN and high autistic characteristics showed more improvement in Body Mass Index (BMI) after treatment than peers without autism (44).

In some cases, patients also had rigid rules around eating and could be exceedingly selective, such as limiting intake to a few categories of foods or only eating pre-packaged food. Clinicians found food experiments and gradual exposure to novel foods helpful when patients presented with selective eating behavior. Such interventions are mostly used with avoidant/restrictive food intake disorder (ARFID) and aim to reduce anxiety related to food and eating, and the extent of food neophobia (45). People with autism share a similar presentation to people with ARFID, including a preference for familiar foods and an aversion to trying new things (46), which inspired the team to try food experiments with the patients. Recent research has also found that fussy eating partially mediates the associations between autism and the development of ED behaviors (47), suggesting that fussy eating may be a useful point for prevention and intervention.

One challenge, however, with introducing food experiments to an ED service, was its initial contradiction with usual practice where patients were expected to finish their meals instead of playing with food without eating it. Extensive team-wide discussions were held before all clinical staff reached consensus on which patients could utilize the food experiments and for how many sessions. The costs and resources required to deliver the intervention also need to be considered before food experiments can be made regular practice. Overall, although food experiments were found to be helpful with some of the cases with autism comorbidity, this is not yet validated and therefore warrants future testing.

Need for pragmatic autism screening tools suitable for ED services

This study also highlights a need for a pragmatic autism screening approach in ED services. The AQ-10 was used in the service for its brief format and convenience, and has the advantage of being a screening instrument to identify individuals who would benefit from a full autism assessment (9). However, its validity and reliability for use with this specific patient population are yet to be tested. Indeed, in some cases, patients previously had a formal autism diagnosis or deemed by clinicians to have a strong autistic presentation that would benefit from treatment adaptations, but still scored below the threshold on the AQ-10. Furthermore, it is still unknown whether the AQ-10 is specific enough to differentiate between autism and other common comorbidities such as social anxiety, given that certain items on the AQ-10 may tap into symptoms of social anxiety rather than autism. Clinical practice would benefit from future research focusing on pragmatic screening tools with higher specificity and sensitivity when used in this co-morbid population. Combined use of the AQ-10 with other self-report screening measures for increased validity, such as sensory sensitivity screening (48) or more detailed self-report measures like the Social Responsiveness Scale (28), should also be considered.

Limitations

This study focused on a relatively small number of cases and only half of the cases had formal diagnosis of autism, therefore, the findings of this case synthesis cannot be generalized to the wider population of patients with comorbid autism and ED. However, the clinical reality and challenges raised by the clinicians in this study provide important learnings for future treatment improvement and adaptations, as well as future research. The lack of a suitable autism screening tool was also noted for this clinical group. Future research should consider incorporating more valid screening tools, such as the longer version of AQ (49), the Camouflaging Autistic Traits Questionnaire [CAT-Q; (50)], or the Sensory Processing Measure, Second Edition [SPM-2; (51)] that investigate more of the behavioral aspects in this population. Furthermore, as the cases concerned were de-identified, it was not possible to trace the patients' clinical records to identify outcomes such as BMI improvement, limiting the range of reportable measures to complement clinicians' reports of what was helpful. However, ongoing evaluation of the PEACE Pathway will provide evidence on effectiveness to support its wider implementation.

Conclusions

Clinicians face a variety of challenges when providing care to patients with comorbid ED and autism, including dealing with communication difficulties, boundary issues, problems with autism screening, managing and differentiating comorbidities, sensory difficulties, atypical presentation of eating behaviors, cognitive rigidity, and emotional difficulties. The exploratory findings of this synthesis serve to generate hypotheses for future investigation to identify ways in which health professionals can address these difficulties and develop protocols for dealing with clinical dilemmas in adapting treatment.

Data availability statement

The data analyzed in this study is subject to the following licenses/restrictions: The original case notes are not available in order to protect patient privacy. The summarized datasets generated for this study are available from the corresponding author on reasonable request. Requests to access these datasets should be directed to zhuo.li@kcl.ac.uk.

Ethics statement

The studies involving human participants were reviewed and approved by the Clinical Governance and Audit Committee at South London and Maudsley NHS Trust. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

ZL analyzed, interpreted the data, and was a major contributor in producing the manuscript. CH-H co-analyzed data and contributed to editing of the manuscript. KT is a principal investigator of the PEACE pathway project and conceived of the presented study idea. KT and SB co-supervised the study and contributed to the drafting of the manuscript and interpretation of results. All authors read and approved the final manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Publisher's note

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Appendix 5.1 In-person and online sensory wellbeing workshop for eating disorders: updated case series

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RESEARCH **Open Access**

In-person and online sensory wellbeing workshop for eating disorders: updated case series

Zhuo Li[1†], Victoria Holetic[2†], Jessica Webb[2], Dimitri Chubinidze[1,3], Sarah Byford[4] and Kate Tchanturia[1,2,3*]

Abstract

Background A one-off sensory wellbeing workshop has been developed to help patients with eating disorders (ED) manage sensory sensitivities. The aim of this study was to evaluate and compare the outcomes of the workshop in online versus face-to-face (F2F) formats among a sample of patients with ED.

Methods Cumulative link models were applied to the outcome measures (awareness of sensory wellbeing, awareness of strategies to enhance sensory wellbeing, and confidence in managing sensory wellbeing) to test the differences between online and F2F workshops. Participants' ratings of usefulness of the workshop were also compared between online and F2F workshops.

Results A total of 14 workshops (4 online and 10 F2F) were run from 2020 to 2023. All participants reported significant and substantial improvements in all outcome measures. There was no significant difference in outcomes between online and F2F workshops. The majority of patients rated the workshops as useful.

Conclusions Both online and face-to-face formats of the sensory workshop led to improvement in sensory wellbeing management for patients with ED. Future studies are warranted to test the impact of the workshop on ED treatment outcomes.

Plain English summary

People with eating disorders often have sensory issues, which can include being too sensitive to some senses (hearing, smell or taste, for example) or not sensitive enough. Explaining how the sensory system works and developing helpful strategies to manage sensory difficulties could be beneficial in the process of therapy. To try and support this, clinicians and researchers designed a sensory wellbeing workshop to help people become more aware of their sensory wellbeing and teach them strategies to manage their sensory wellbeing. The workshop can be delivered online or face-to-face. This study examined the feedback for online and face-to-face workshops. We found that both formats were helpful for people with eating disorders. We also discuss possible ways to develop and test the workshop further in order to better support patients with sensory difficulties.

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Keywords Eating disorder, Sensory system, Sensory wellbeing, Group, Workshop

Introduction

Sensory disturbances in patients with eating disorders (ED), particularly anorexia nervosa (AN), have been widely studied in recent years [9, 12]. Some argue that sensations are commonly muted in individuals with AN, leading to increased reliance on other external cues and rules to regulate eating behaviour [19], whereas others have identified sensory hypersensitivities in AN [30] which can lead to sensory avoidance. For example, studies have found that patients with AN had lower olfactory threshold [25] and increased smell capacity [7, 20] than controls, which could make certain sensations (e.g. strong smell of food) exceedingly intolerable. Moreover, difficulties in interpreting and tolerating these sensations can affect emotional regulation, as individuals may not be able to appropriately guide emotional reactions using body signals [16]. These individuals may then use the ED as a maladaptive coping strategy for negative emotions.

Among individuals with ED, research has also identified a subgroup with a comorbidity of autism that have a more complex presentation [3, 13]. There have been consistent findings of a relationship between sensory processing and eating behaviours in autistic individuals [17], as well as association between autism, sensory processing, and illness severity in individuals with ED [22]. Sensory difficulties are present in 90% of children and adults with autism [14], which could exacerbate sensory issues when comorbid with ED. Indeed, patients with both conditions exhibit heightened sensory sensitivities in areas of smell, taste, vision, and texture [10, 17], leading to maladjustment to standard treatment settings and active avoidance of certain foods [15].

To support patients with hyper- or hypo-sensitivities, it is important to provide a space, psychoeducation and materials to explore their sensory needs. Therefore, a one-off sensory wellbeing workshop was developed by the PEACE (Pathway for Eating disorders and Autism developed from Clinical Experience) pathway [27], (for details of the pathway: www.peacepathway.org) based on previous research as well as perspectives of people with lived experience of sensory sensitivities [10, 11]). This workshop combines psychoeducational materials and practical activities, with the aim to improve sensory awareness and provide sensory management strategies to support sensory wellbeing. We previously conducted a pilot evaluation of the sensory workshop [28] to examine its feasibility and discuss possible areas for development of the workshop. Significant improvement was found in all post-workshop measures with large effect sizes, indicating possibility for the workshop to be delivered as part of ED treatment. Areas of improvement were also identified, including the need for longer workshop duration, more activities, collaboration across clinical services, and possibly introducing a follow up session. Given the limitations of sample size in the pilot study, we have since organised more workshops that are longer in duration, delivered online and in person across clinical services, offering enriched psychoeducational content and activities based on the feedback we received from pilot workshops.

Psychological work should be based in evidence to ensure they are of significant clinical benefit for patients [24]. Therefore, this follow-up study aims to: 1) generate more practice-based experience for the sensory workshop by conducting a case series with an increased sample size; and 2) further investigate the impact of workshop format by comparing the outcomes of face-to-face and online workshops.

Methods

Participants

All participants of the study were adult patients with an established DMS-5 [1] diagnosis of ED, admitted to the South London and Maudsley NHS Foundation Trust (SLaM) National Eating Disorder Service and South West London and St George's Mental Health NHS Trust Specialist Eating Disorder Service. Participants who did not complete the pre-workshop or post-workshop measures were excluded from analysis.

Measures

All participants were given a pre-workshop questionnaire to complete at the start (T1) of the workshop, and a post-workshop questionnaire at the end (T2). Full questionnaires can be found in the Additional file 1: Appendix. The pre- and post-workshop questionnaires consisted three Likert scale items asking participants to rate their awareness of their own sensory wellbeing ("How aware are you of your sensory wellbeing?"), awareness of strategies to enhance sensory wellbeing ("How aware are you of the strategies to enhance your sensory wellbeing?"), and their confidence in managing their own sensory wellbeing ("How confident do you feel to manage your sensory wellbeing?"). The post-workshop questionnaire contained an additional question asking participants to rate the usefulness of the workshop ("How useful was this sensory workshop?"). All questions used a 5-point Likert scale ranging from 1 ("Not aware/confident/useful at all") to 5 ("Really aware/confident/useful"). By comparing participant responses before and after the workshop, we aimed to evaluate the change in participants' self-awareness and abilities to manage their sensory wellbeing. Furthermore, by including a question on usefulness in the post-workshop questionnaire, we can gauge participant satisfaction which is valuable for the workshop's future refinement.

Procedure

Detailed procedure and protocol of the sensory workshop can be found in the pilot evaluation by Tchanturia et al. [28]. In brief, the workshop was advertised to all patients in the services through poster and community meetings. Attendance was voluntary. The in-person workshop begins with psychoeducation of the different senses and discussion of sensory experiences, followed by two exercises: an exploration of different materials to identify one's own sensory preferences, and a do-it-yourself (DIY) activity of creating a sensory item of choice, for example a glitter jar, a scented hand cream or choose materials which have soothing effect when touched (fluffy, firm, soft textiles). Take home materials such as further psychoeducational worksheet and tools to communicate sensory preferences were also provided. At the start and end of the workshop, participants were asked to complete the pre (T1) and post (T2) workshop questionnaires. The in-person workshops lasted for a duration of two hours and were facilitated by two to three members of clinical staff.

During the COVID-19 pandemic, the sensory workshop was adapted for online delivery via Microsoft Teams and run from December 2020 to April 2022. The psychoeducational content was adapted to a PowerPoint presentation, and discussions were facilitated online. An interactive presentation software, named Mentimeter, was used to facilitate discussions. Following psychoeducation, the Mentimeter tool was utilised to prompt participants to write and post answers freely to two questions: 'what senses are comforting to me?' and 'what senses bother me?', and the answers were discussed as a group. For the DIY element, participants were encouraged to identify and prepare their own sensory items for the exercises. Participants who did not have items at hand would discuss and describe the sensory items they found helpful. Electronic versions of the pre- and post-workshop feedback questionnaires were distributed, and the take home materials were circulated after the workshop via e-mail. The online workshop ran for one and a half hours, shorter than the in-person workshop as material preparation time was deducted, and was facilitated by two to three members of the clinical team.

Overall, the two workshop formats differ most significantly in the provision of materials for the practical element. The in-person workshop includes a hands-on activity of making a sensory item using materials provided by facilitators, whereas in the online format participants were required to bring or discuss their favorite sensory items. To ensure participant engagement, break out rooms of smaller groups were used in online workshops, with one facilitator in each break out room leading the discussion.

Analysis

Within-group analysis was conducted using Wilcoxon signed ranks tests to examine improvement on each measure in in-person and online workshops individually. Furthermore, between-group analysis was conducted to investigate the effect of workshop format for each outcome measure (awareness of sensory wellbeing, awareness of strategies to enhance sensory wellbeing, and confidence in managing sensory wellbeing) using cumulative link mixed models fitted with the Laplace approximation, the most popular class of ordinal regression models, due to its suitability for repeated measures ordinal data analysis [5]. Group (online vs face-to-face) and time (T1 and T2) and the interaction between them were included as explanatory variables and individual identity as random variable. In addition, for the 'usefulness' measure which is only answered once at post-workshop, a Mann-Whitney U test is used to compare between online and face-to-face workshops. Data were analysed using IBM SPSS software (Version 28) and the clmm function in the ordinal package for R [21].

Results

In total, 14 workshops (4 online and 10 face-to-face) including 86 participants (26 online and 60 face-to-face) were run from February 2020 to May 2023. The number of participants for each workshop ranged from 2 to 10. Eighty-one patients (23 online and 58 face-to-face) submitted anonymous feedback at T1 and/or T2. Among them, feedback was partly missing (in either pre- or post-workshop measure) for 10 (43.5%) online participants and 5 (8.6%) face-to-face participants. These participants were excluded by case from analysis. As a result, a total of 66 valid responses (13 online and 53 face-to-face) were included in the analysis. Their baseline characteristics are summarised in Table 1. There was no significant difference between online and face-to-face participants in their baseline characteristics.

Outcomes are summarised in Table 2 and visualised in Fig. 1a–c. Both face-to-face and online workshops saw

Table 1 Baseline characteristics of participants in online and face-to-face (F2F) workshops

	Online (N = 13)	F2F (N = 53)
Age (years), mean (SD)	23.2 (4.1)	25.8 (7.9)
Missing	2 (15.4%)	7 (13.2%)
Diagnosis, n (%)		
AN restrictive	9 (69.2%)	32 (60.4%)
AN binge-purge	2 (15.4%)	9 (17%)
AN atypical	0	2 (3.7%)
Bulimia nervosa	0	1 (1.9%)
Binge eating disorder	0	1 (1.9%)
Other specified feeding and eating disorder (OSFED)	1 (7.7%)	1 (1.9%)
Missing	1 (7.7%)	7 (13.2%)
Gender, n(%)		
Female	13 (100%)	45 (84.9%)
Male	0	0
Other	0	1 (1.9%)
Missing	0	7 (13.2%)
BMI on admission, mean (SD)	16.35 (2.45)	15.35 (4.63)
Missing, n(%)	2 (15.4%)	7 (13.2%)
Ethnicity		
White British	12 (92.3%)	36 (67.9%)
White Irish	0	1 (1.9%)
White other	0	3 (5.7%)
Black Afro-Caribbean	0	2 (3.8%)
Black British	0	1 (1.9%)
Asian (Indian)	1 (7.7%)	0
Mixed	0	3 (5.7%)
Missing	0	7 (13.2%)

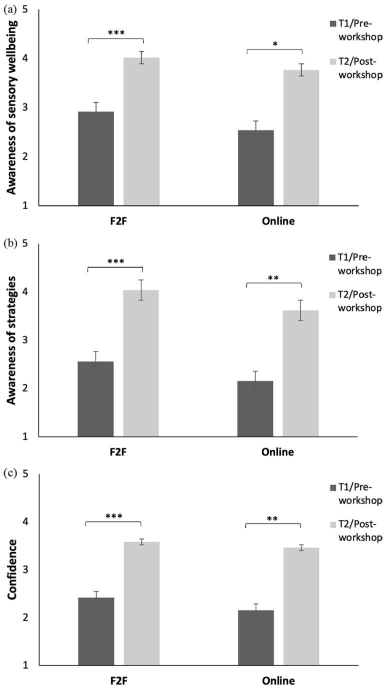

Fig. 1 Comparison of face-to-face (F2F) and online workshop scores for **a** Awareness of sensory wellbeing, **b** Awareness of strategies to enhance sensory wellbeing and **c** Confidence in managing sensory wellbeing. *Note* *$p < 0.05$, **$p < 0.01$, ***$p < 0.001$

statistically significant improvement in all measures with large effect sizes.

Table 3 shows the results of cumulative link models for all measures. Time had a significant effect on awareness of sensory wellbeing ($p = 0.019$), awareness of strategies to manage sensory wellbeing ($p < 0.001$), and confidence in managing sensory wellbeing ($p = 0.038$), suggesting that participants improved significantly on all measures. Neither workshop format nor the interaction between time and workshop format had a significant impact on the outcomes, suggesting that improvement on the

Table 2 Summary of pre-workshop (T1) and post-workshop (T2) participant feedback

Measure	Workshop format	T1		T2		Difference		
		M	SD	M	SD	*Z*	*p*	Cohen's *d*
Awareness of sensory wellbeing	F2F	2.92	1.03	4.00	0.76	− 5.21	< .001	1.08
	Online	2.54	1.13	3.77	0.73	− 2.55	.011	0.95
Awareness of strategies	F2F	2.49	1.12	4.02	0.69	− 5.65	< .001	1.25
	Online	2.15	0.90	3.62	0.77	− 3.13	.002	1.88
Confidence	F2F	2.38	0.88	3.51	0.80	− 5.56	< .001	1.15
	Online	2.15	1.14	3.46	0.97	− 2.85	.004	1.27

Table 3 Summary of cumulative link models for all workshop measures

	Awareness of sensory wellbeing			Awareness of strategies			Confidence		
	Coefficient	**SE**	***p***	**Coefficient**	**SE**	***p***	**Coefficient**	**SE**	***p***
Time (T1 vs. T2)	2.66	1.14	.019*	3.87	1.13	< .001***	2.36	1.14	.038*
Format (F2F vs. online)	−0.85	0.76	.266	−0.66	0.64	.302	−0.97	0.79	.224
Time x Format	0.14	0.87	.874	−0.39	0.81	.629	0.79	0.89	.372

* $p < 0.05$, **$p < 0.01$, ***$p < 0.001$

outcomes was not significantly different between in-person and online workshops.

In terms of post-workshop ratings of usefulness, 51 (96.2%) participants of the face-to-face workshop and 12 (92.3%) participants of the online workshop rated it 3 (“Quite useful”) to 5 ("Really useful"). The mean rated usefulness was 4.01 for face-to-face and 3.77 for online workshops. Mann-Whitney test showed that the two workshop formats did not differ significantly in reported usefulness ($U = 265$, $p = 0.366$).

Discussion

In this paper, we provide updated results for the sensory wellbeing workshop since the publication of its pilot evaluation [28]. Overall, the results are in line with the original paper, with participants reporting significant and substantial improvements in all measures (awareness of sensory wellbeing, awareness of strategies to manage sensory wellbeing, and confidence in managing sensory wellbeing) at post-workshop. Our results contribute to the growing body of literature that attests to the positive patient experiences and outcomes associated with group therapies [18, 23, 26], and continues to demonstrate the feasibility of incorporating group workshops as adjunct elements within ED treatment programs [28].

Furthermore, our results provide support for online provision, with no difference in outcomes between workshops delivered in person and online. This finding highlights the adaptability of the workshops and their potential for broader dissemination. However, it is essential to consider the practical differences between the formats. In-person workshops create a more hands-on and interactive environment, which facilitates better demonstrations of sensory items and encourages social interaction among participants. Conversely, online workshops may face challenges in achieving the same level of engagement and interaction as face-to-face sessions. Future studies comparing between the two workshop formats on the level of participant engagement are warranted. Despite these potential challenges, the online format offers increased accessibility and flexibility, particularly for those who may encounter barriers to attending in-person workshops. Furthermore, the following recommendations may help enhance the delivery of online sensory wellbeing workshops: (1) Streamlined material acquisition: It would be beneficial to offer pre-assembled material packs for participants who may encounter challenges in obtaining the necessary items themselves. This approach ensures that all attendees have the requisite resources for the online workshop. (2) Workshop automation: to aid item demonstrations in the online workshops, we suggest incorporating pre-recorded content, interactive tools, or self-paced activities in the workshop. This approach will foster a more streamlined and efficient experience while preserving engagement and interactivity. (3) Introducing breaks: As the focus on psychoeducation in online workshops can be mentally taxing for participants, regular short breaks could be introduced into the workshop, for example in between the psychoeducation and discussion sessions.

Research is sparse when investigating sensory processing within ED behaviours. However, previous studies have demonstrated that individuals with ED have more sensory disturbances than healthy controls [30]. For example, Gaudio et al. [8] found that individuals with AN may have multisensory impairments regarding their body perception, including both tactile and proprioceptive sensory components. Other studies have demonstrated that individuals with ED may have higher sensory sensitivities or even avoid sensory experiences and appear less able to appropriately identify satiety sensations [6, 19] or recognise internal signals relating to stress such as increased heart rate [29]. A more recent study showed that those with AN had significantly lower sensory registration and seeking behaviour, along with increased sensitivity and sensory avoidance compared to healthy controls [22]. It is worth noting that most of the work have a focus on participants with AN. We have included patients with all EDs in the current study but the majority of patients had AN, which reflects the patient demographics at the ED service. Future studies should consider including different patient groups to investigate the impact of addressing sensory difficulties in patients with bulimia nervosa or binge eating disorder.

Furthermore, understanding subjective body experience and its linkage with emotional awareness and regulation is crucial when challenging ED symptomology and cognitive distortion in patients with EDs. Previous work has linked sensory processing impairment with self-disgust in AN as well as BN [2]. It is important to note that as well as the relentless pursuit for the 'perfect' body, patients may also be motivated to maintain disordered eating to alter their body experiences [30]. There is also evidence that individuals with AN have deficits in integrating visual and proprioceptive information, which may contribute to the distorted body image in AN [4]. Therefore, sensory processing difficulties could be a crucial target when addressing the maintenance factors of the illness. Following this early stage evaluation of the sensory workshop, further research is needed, perhaps on a more longitudinal scale, to measure the impact of addressing sensory experience on ED treatment outcomes.

The present study is limited by the sample size for online workshops as well as missing data. Furthermore, feedback was partly incomplete for 43.5% of online participants and 5.9% of face-to-face participants, suggesting that participants of the face-to-face workshops were more likely to fill in the outcome measures than those of the online workshops. Methods for online feedback collection may need to be improved, and findings comparing the two workshop formats therefore need to be interpreted with caution. More rigorous trials of the workshop need to be conducted in the future, incorporating a wider range of outcome measures (including ED symptom measures) as well as a control group to quantify outcomes.

Conclusion

Both online and face-to-face formats of the sensory workshop led to improvement in awareness of sensory wellbeing and confidence in managing sensory wellbeing for patients with ED. Future studies are warranted to investigate the impact of the workshop on ED treatment outcomes.

Abbreviations

ED	Eating disorder
AN	Anorexia nervosa
F2F	Face to face
ARFID	Avoidant/restrictive food intake disorder

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s40337-023-00834-8.

Additional file 1: Sensory wellbeing workshop feedback survey.

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Author contributions

KT designed and directed the project. VH, JW, ZL, and KT ran the workshops and collected data; ZL carried out the data analysis and drafted the manuscript; VH provided critical feedback and shaped the manuscript; all authors reviewed and approved the final manuscript. KT and SB co-supervised ZL.

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Availability of data and materials

All data generated or analyzed during this study are available upon request.

Declarations

Ethics approval and consent to participate

Patients' anonymous feedback was collected as part of routine clinical practice on the Eating Disorders Unit; permission to audit patient data was obtained from the Clinical Governance and Audit Committee in South London and Maudsley NHS Trust (032019) in April 2019.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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Appendix 5.2 Sensory wellbeing workshop pre-workshop (T1) and post-workshop (T2) questionnaires

Please complete this section at the start of the sensory workshop:
(Please indicate the extent to which you agree with each statement by circling the number from 1 to 5)

How aware are you of your sensory sensitives?

Not aware at all		Quite aware		Really aware
1	2	3	4	5

How aware are you of the strategies to manage your sensory sensitives?

Not aware at all		Quite aware		Really aware
1	2	3	4	5

How confident do you feel to manage your sensory sensitivities?

Not confident at all		Quite confident		Really confident

Please complete this section at the end of the sensory workshop:
(Please indicate the extent to which you agree with each statement by circling the number from 1 to 5)

How aware are you of your sensory sensitives at the end of this workshop?

Not aware at all		Quite aware		Really aware
1	2	3	4	5

How aware are you of the strategies to manage your sensory sensitives as a result of the workshop?

Not aware at all		Quite aware		Really aware
1	2	3	4	5

How confident do you feel to manage your sensory sensitivities following the sensory workshop?

Not confident at all		Quite confident		Really confident
1	2	3	4	5

How useful was this sensory workshop?

Not useful at all		Quite useful		Really useful
1	2	3	4	5

What did you like most about this sensory workshop?

……

……

Any other comments?

……

……

Appendix 7.1 A novel approach for autism spectrum condition patients with eating disorders: Analysis of treatment cost-savings

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WILEY

BRIEF REPORT

A novel approach for autism spectrum condition patients with eating disorders: Analysis of treatment cost-savings

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Abstract

Objective: In the current economic context, it is critical to ensure that eating disorder (ED) treatments are both effective and cost-effective. We describe the impact of a novel clinical pathway developed to better meet the needs of autistic patients with EDs on the length and cost of hospital admissions.

Method: The pathway was based on the Institute for Healthcare's Model of Improvement methodology, using an iterative Plan, Do, Study, Act format to introduce change and to co-produce the work with people with lived experience and with healthcare professionals. We explored the change in length and cost of admissions before and after the pathway was introduced.

Results: Preliminary results suggest that the treatment innovations associated with this pathway have led to reduced lengths of admission for patients with the comorbidity, which were not seen for patients without the comorbidity. Estimated cost-savings were approximately £22,837 per patient and approximately £275,000 per year for the service as a whole.

Conclusion: Going forward, our aim is to continue to evaluate the effectiveness and cost-effectiveness of investment in the pathway to determine whether the pathway improves the quality of care for patients with a comorbid ED and autism and is good value for money.

KEYWORDS

autism spectrum disorders, eating disorders, health economics, treatment

1 | INTRODUCTION

In the current economic context, resources available to the public health system have become increasingly scarce and more precious than ever. Anorexia nervosa (AN), a severe eating disorder (ED) associated with great risk to physical health (NICE, 2017), can be associated with long hospital stays, which are costly to the National Health Service (NHS). However, several researchers have demonstrated evidence of the benefits of short hospital stays (Herpertz-Dahlmann et al., 2014; Strandjord, Sieke, Richmond, Khadilkar, & Rome, 2016). Indeed, the National Institute for Health and Care Excellence guidelines recommend only 4–6 weeks of hospital admission for patients requiring inpatient treatment for AN.

One of the challenges in treating AN and ensuring the duration of hospitalisation is kept brief, is the common complex presentation of one or more comorbid psychiatric disorders. Recent research has demonstrated that many patients with AN (between 20–37%) have a diagnosed or suspected autism spectrum condition (ASC; Westwood & Tchanturia, 2017). It is important to note that although autism spectrum disorder (ASD) is the term used for medical diagnosis, we use instead the term ASC, which is preferred by our patients (Kenny et al., 2016).

Over the past 8 years, we have collected data from clinical audit records for an adult inpatient ward for ED (the South London and Maudsley NHS specialist ED service). We found that autistic people with comorbid ED had longer durations of stay in hospital and poorer clinical outcomes upon discharge, including higher levels of depression and anxiety and lower levels of work and social functioning, when compared to non-autistic patients with EDs (Tchanturia, Adamson, Leppanen, & Westwood, 2019).

The purpose of this brief report is to explore the impact of the development of a novel clinical pathway for patients with comorbid ED and ASC: The Pathway for EDs and Autism developed from Clinical Experience (PEACE pathway) on the length and cost of hospital admissions before and after the pathway was introduced.

2 | METHODS

In 2018, the Health Foundation supported us with a £75,000 grant to conduct training with experts in the field of ASC. This funding was used to provide our multi-disciplinary ED team with training in the administration of gold-standard measures of ASC, such as the Autism Diagnostic Observation Schedule, second Edition (ADOS-2; Lord et al., 2012) and the Autism Diagnostic Interview-Revised (Rutter, le Couteur, & Lord, 2003), and to provide our clinical multi-disciplinary team with relevant training in adapting multiple treatments for the needs of autistic patients or those with high autistic traits.

In total, we have provided up to 20 training events for the multi-disciplinary health care team, including training focused on individual therapy adaptation, some focused on specific characteristics often seen in autistic patients, such as sensory sensitivities, and some focused on PEACE implementations and how to apply and maintain these. In addition, we invested in materials necessary to create a more ASC-friendly ward environment, including redecorating the ward to create a neutral colour scheme, developing a 'sensory box' for patients with items such as weighted blankets and sensory toys, and we began hosting wellbeing groups for autistic patients and for those without autistic traits together with members of the multi-disciplinary team to support sensory difficulties and enhance social communication (e.g., introducing communication passports and other strategies).

Highlights

- Autism spectrum condition (ASC) patients with a comorbid eating disorder (ED), tend to require longer hospital stays than ED patients without this comorbidity.
- We co-produced a novel clinical pathway for patients with the ASC/ED comorbidity with service users and clinicians following a needs assessment.
- The implementation of this novel clinical pathway is associated with shorter hospital stays and lower costs of admission for patients with the ASC/ED comorbidity.

Based on the knowledge attained from the training provided by experts in the ASC field, our ED clinicians have adapted their understanding of comorbidity treatment to incorporate this. As a clinical team, we have revised psychological treatment protocols to be more flexible for the specific, individual needs of this patient group. This includes making sure that we spend more time on engagement in psychological work to allow rapport to build, as well as revising and adapting specific therapeutic exercises to make them more concrete and tangible. When appropriate, we do this using non-verbal materials and aim to utilise patients' strengths, which is especially important when thinking about their communication styles where we encourage them to express themselves in ways, they feel comfortable, be this through artwork or experiential work. As a result of the training, we have adapted how all modalities of treatment provided by the multi-disciplinary team take place. With guided materials, clinicians are supported in making individual sensory adaptations and thinking holistically about the individual, and the strengths that come with their autism.

Adaptations began in January 2018 with the implementation of ADOS-2 assessment for ASC and the full PEACE pathway was available from January 2019 (see Figure 1 for a full outline of the timeline for the changes implemented). To explore the impact of the pathway on hospital admissions and the cost of these admissions, we collected data on hospital admissions from clinical records for 6 years before the new pathway was introduced (January 1, 2012–December 31, 2017) and 2 years after the new pathway was introduced (January 1, 2018–December 31, 2019) for ASC patients. We compared this

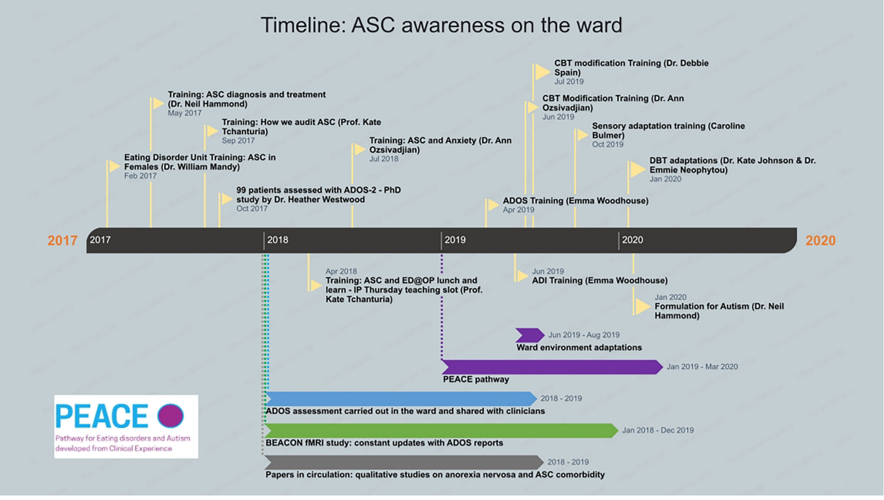

FIGURE 1 Timeline of activities implemented through the PEACE pathway. ASC, autism spectrum condition; PEACE, Pathway for Eating disorders and Autism developed from Clinical Experience [Colour figure can be viewed at wileyonlinelibrary.com]

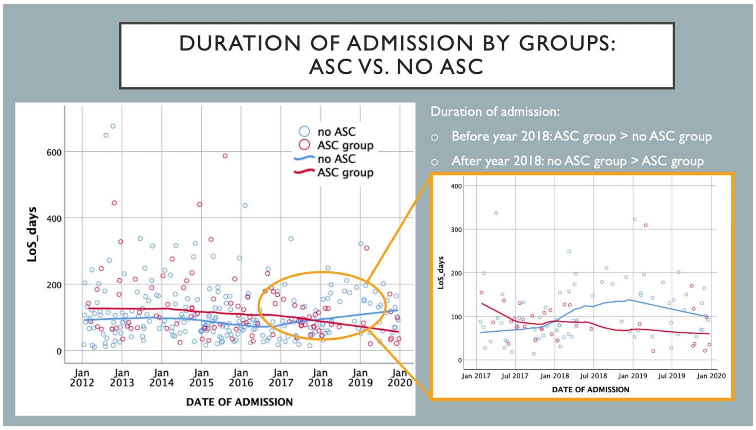

FIGURE 2 Duration of admission by patient group. ASC, autism spectrum condition [Colour figure can be viewed at wileyonlinelibrary.com]

with the same data for patients without co-morbid ASC combined with those not assessed for ASC, to provide a conservative comparison. We estimated the average cost of these admissions by applying the national average unit cost per night for patients admitted to adult specialist ED services for the financial year 2018/19 (£532.32), taken from the National Schedule of NHS Costs (https://improvement.nhs.uk/resources/national-cost-collection/#ncc1819).

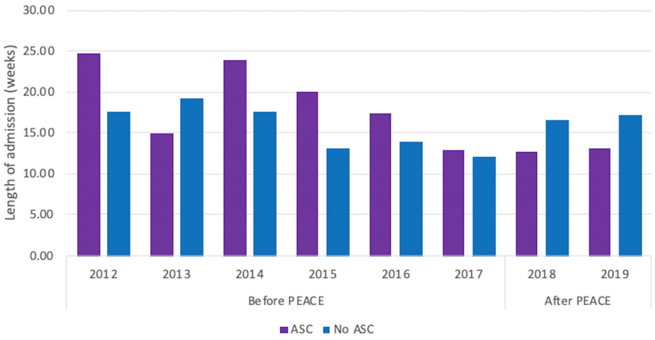

FIGURE 3 Length of admission in weeks by patient group [Colour figure can be viewed at wileyonlinelibrary.com]

3 | RESULTS

Figures 2 and 3 present the duration of admissions data for ASC and non-ASC patients with EDs who were admitted between January 2012 and December 2019. The figures show a clear reduction in the average duration of admissions for those with co-morbid ASC since the PEACE pathway started. Mean length of admissions for patients admitted during the 6 years before the implementation of the PEACE pathway was higher for ASC patients with EDs (133 days; 19 weeks) than those without comorbid ASC (109 days; 16 weeks). This pattern reversed in the 2 years following the implementation of the PEACE pathway (comorbid ASC 90 days; 13 weeks vs. no ASC 118 days; 17 weeks).

In terms of cost, the mean cost per admission prior to the implementation of the PEACE pathway was almost £13,000 higher for ASC patients with EDs (£70,925 per patient) compared to non-ASC patients (£58,218 per patient). After the implementation of the pathway, the average cost of admissions was almost £15,000 lower for those ASC patients with EDs (£48,087 per patient) compared to those without comorbid ASC (£62,896 per patient). Given a reduction in mean cost per admission of £22,837 per ASC patient with an ED after the implementation of the pathway compared to before implementation, and an average of 12 ASC patients with EDs admitted per year, estimated total savings are in the region of £275,000 per year.

4 | DISCUSSION

Initial indications suggest that a modest investment in staff training and adaptations to treatments and wards to better meet the needs of autistic patients can reduce the length of hospital admissions for these complex co-morbid cases and generate cost savings in the region of £275,000 per year for the service as a whole.

However, what is harder to count, but nevertheless of great importance, is the treatment experience of patients and carers, reflected in their positive feedback and improvements in outcomes. A formal assessment of satisfaction with the PEACE pathway and outcomes for autistic patients with EDs has not yet been undertaken, but initial indications from discharged patients are positive. For example, one PEACE patient noted:

> 'The adaptations to my individual psychology sessions have really helped me engage in treatment for the first time as it has taken into account all of my autism and eating disorder needs'.

A further important aim of the PEACE pathway implementation was to increase the confidence of the clinical team. Over the course of the PEACE project, we have evaluated each training session in terms of clinicians' confidence and ability to adapt treatment to benefit those with comorbid autism. Evaluation of 100 training attendees suggested that confidence of clinicians in supporting this comorbidity increased on average from 46 to 68%. In addition to these promising figures, qualitative evaluations from the clinical team give a richer understanding of the benefits. For example, comments from clinicians include the following:

> 'The PEACE pathway has really helped me to think about the specific needs of people in our treatment settings with the additional challenges of Autism symptoms and how we can best make adaptations to make the experience more manageable and treatment more effective'.

> 'Training taught me how to be more inclusive and individualise, how to be creative in making materials, that it is ok to simplify materials'.
>
> 'I think the strongest aspect of the training was the focus on practical examples about how to explain sometimes complex/abstract theoretic concepts to autistic patients in a concrete way'.

We are still in the early stages of developing and accessing the effectiveness and cost-effectiveness of our novel clinical pathway. Going forward, our aim is to continue to explore whether investment in the PEACE pathway will ultimately make a significant difference in improving the quality of care for patients with the ASC/ED comorbidity and can do this in a cost-saving manner.

ACKNOWLEDGEMENTS

The Health foundation an independent charity committed to bring better health care for people in the United Kingdom (Ref: AIMS ID): 1115447 and the Maudsley Charity for their support. Maudsley Charity is an independent NHS mental health charity which works in partnership with patients and families, clinical care teams and researchers at South London and Maudsley NHS Foundation Trust, the Institute of Psychiatry, Psychology and Neuroscience, King's College London, and community organisations, with a common goal of improving mental health, to support innovation, research, and service improvement.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data will be made available upon reasonable request to the corresponding author.

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Appendix 8.1 Clinicians interview consent form

CONSENT FORM FOR PARTICIPANTS IN RESEARCH PROJECTS

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research

Title of project: Clinicians' experiences of PEACE pathway, a care pathway for autism and eating disorders	
Ethical review reference number: MRSP-21/22-28800	**Version number: 29/03/22**

	Tick or initial
1. I confirm that I have read and understood the information sheet "**PIS_Final Version (1) 29032022"** for the above project. I have had the opportunity to consider the information and asked questions which have been answered to my satisfaction.	
2. I consent voluntarily to be a participant in this project and understand that I can refuse to take part and can withdraw from the project at any time, without having to give a reason.	
3. 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 under the terms of UK data protection law, including the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018.	
4. I understand that my information may be subject to review by responsible individuals from the College for monitoring and audit purposes.	
5. I understand that confidentiality and anonymity will be maintained, and it will not be possible to identify me in any research outputs.	
6. I consent to my participation in the research being recorded (audio recorded when the interview is conducted in person, or recorded using the 'start recording' function when via Teams).	

Name of Participant **Date** **Signature**

Name of Researcher **Date** **Signature**

Final version (1) 29032022

Appendix 8.2 Clinicians interview information sheet

INFORMATION SHEET FOR PARTICIPANTS

King's College Research Ethics Committee (CREC) Ref: MRSP-21/22-28800

Researcher name: Zhuo Li

Supervisors: Professor Kate Tchanturia, Professor Sarah Byford

This study is part of a PhD project: evaluation of the Pathway for Eating disorders and Autism developed from Clinical Experience (PEACE Pathway).

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Study Title: Clinicians' experiences of PEACE pathway, a care pathway for autism and eating disorders

What is the purpose of the study?

The purpose of the study is to:

- Understand how PEACE Pathway training and participation have affected the experiences of clinicians treating those with eating disorders and autism.
- Understand what treatment recommendations or adaptations by PEACE Pathway have been effective in treating the comorbidity
- Investigate if there are issues that remain unsolved for clinicians when treating the comorbidity

Why have I been invited to take part?

You are being invited to participate in this study because you have worked or are currently working within the SLaM inpatient or day services teams, and have actively participated in the development and/or implementation of the PEACE pathway.

What will happen if I take part?

If you choose to take part in the study, you will be asked to participate in an interview with me, Zhuo Li. In the interview, you will be asked about your experience with different elements of the PEACE Pathway, and your suggestions for how the pathway might be improved. Participation will take place either virtually via Teams, or at a location you prefer. The time it takes for an interview varies, depending on how much you have to say, but most interviews will last 30 minutes to an hour. If you want to stop the interview at any time, you can do so without giving any reason at all.

Do I have to take part?

Participation is completely voluntary and you will have the right to withdraw anytime. Choosing not to take part will not disadvantage you professionally. Once you have read the information sheet, please contact me if you have any questions that will help you make a decision about taking part. If you decide to take part, I will ask you to sign a consent form and you will be given a copy of this consent form to keep.

PIS_Final Version (1) 29032022

What if I change my mind about taking part?

You are free to withdraw from the research at any point in time and will not be required to reveal the reason for discontinuation. You have the option to withdraw your data from the study, up until January 2023, when the analysis will be written up. If you choose to withdraw from the study, none of the information you have given thus far will be retained. If you decide to leave after an interview has already taken place, any recordings and transcripts of the interview would be destroyed. If you decide that this is something that you would like to do, please directly contact me at zhuo.li@kcl.ac.uk.

Will my information be confidential?

Any data you provide will be processed in accordance with UK data protection law including the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. During the research, the transcript will be fully anonymised where participant names will be substituted with a code number, and any personal identifiable information will be removed. No identifiable personal information will be published. The digital recording and the transcript would be kept in a secure place at 103 Denmark Hill, IoPPN.

Your rights to 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. Your right of access can be exercised in accordance with the General Data Protection Regulation. If you wish, a copy of the interview transcript and/or the recording can be provided if requested, this may help you decide whether you want your interview to be made available to use for research.

You also have other rights including rights of correction, erasure, objection, and data portability. Questions, comments and requests about your personal data can be sent to the King's College London Information Compliance team info-compliance@kcl.ac.uk.

What will happen to the results of the study?

The results of the study will be:

a. summarised in a final dissertation as part of the requirements for a PhD
b. published in peer-reviewed scientific journals
c. presented at conferences

You will not be identifiable in any outputs from the study.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact Zhuo Li at zhuo.li@kcl.ac.uk or +447529813515.

What if I have further questions, or if something goes wrong?

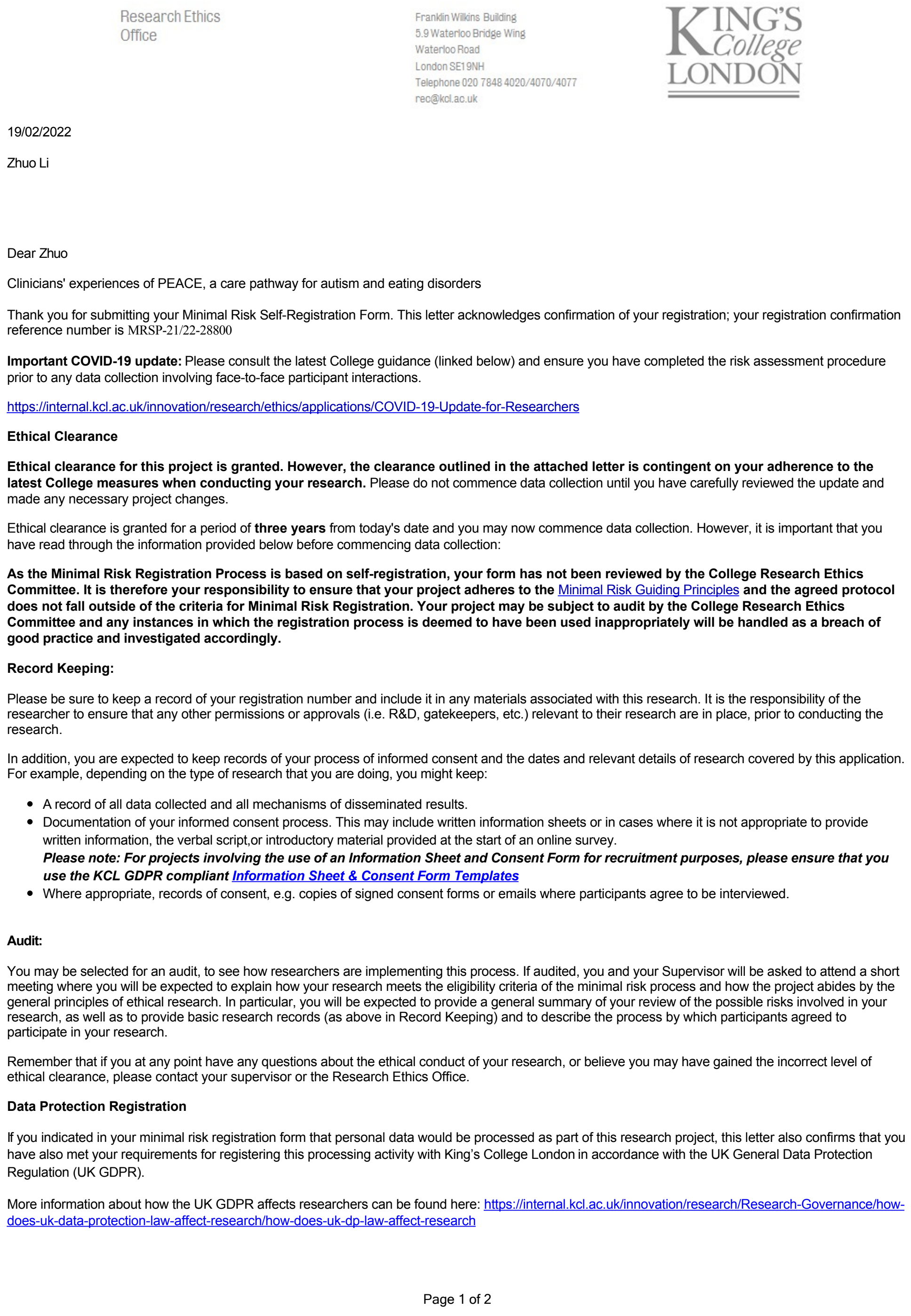
If this study has harmed you in any way, or if you wish to make a complaint about the conduct of the study, please report directly to the Research Integrity Office at:

Email: Research-integrity@kcl.ac.uk

Contact number: +44 (0)20 7848 1288

Thank you for reading this information sheet and for considering taking part in this research!

Appendix 8.3 Ethical clearance letter



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

19/02/2022

Zhuo Li

Dear Zhuo

Clinicians' experiences of PEACE, a care pathway for autism and eating disorders

Thank you for submitting your Minimal Risk Self-Registration Form. This letter acknowledges confirmation of your registration; your registration confirmation reference number is MRSP-21/22-28800

Important COVID-19 update: Please consult the latest College guidance (linked below) and ensure you have completed the risk assessment procedure prior to any data collection involving face-to-face participant interactions.

https://internal.kcl.ac.uk/innovation/research/ethics/applications/COVID-19-Update-for-Researchers

Ethical Clearance

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.

Ethical clearance is granted for a period of **three years** from today's date and you may now commence data collection. However, it is important that you have read through the information provided below before commencing data collection:

As the Minimal Risk Registration Process is based on self-registration, your form has not been reviewed by the College Research Ethics Committee. It is therefore your responsibility to ensure that your project adheres to the Minimal Risk Guiding Principles and the agreed protocol does not fall outside of the criteria for Minimal Risk Registration. Your project may be subject to audit by the College Research Ethics Committee and any instances in which the registration process is deemed to have been used inappropriately will be handled as a breach of good practice and investigated accordingly.

Record Keeping:

Please be sure to keep a record of your registration number and include it in any materials associated with this research. It is the responsibility of the researcher to ensure that any other permissions or approvals (i.e. R&D, gatekeepers, etc.) relevant to their research are in place, prior to conducting the research.

In addition, you are expected to keep records of your process of informed consent and the dates and relevant details of research covered by this application. For example, depending on the type of research that you are doing, you might keep:

- A record of all data collected and all mechanisms of disseminated results.
- Documentation of your informed consent process. This may include written information sheets or in cases where it is not appropriate to provide written information, the verbal script,or introductory material provided at the start of an online survey.
  Please note: For projects involving the use of an Information Sheet and Consent Form for recruitment purposes, please ensure that you use the KCL GDPR compliant Information Sheet & Consent Form Templates
- Where appropriate, records of consent, e.g. copies of signed consent forms or emails where participants agree to be interviewed.

Audit:

You may be selected for an audit, to see how researchers are implementing this process. If audited, you and your Supervisor will be asked to attend a short meeting where you will be expected to explain how your research meets the eligibility criteria of the minimal risk process and how the project abides by the general principles of ethical research. In particular, you will be expected to provide a general summary of your review of the possible risks involved in your research, as well as to provide basic research records (as above in Record Keeping) and to describe the process by which participants agreed to participate in your research.

Remember that if you at any point have any questions about the ethical conduct of your research, or believe you may have gained the incorrect level of ethical clearance, please contact your supervisor or the Research Ethics Office.

Data Protection Registration

If you indicated in your minimal risk registration form that personal data would 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 in accordance with the UK General Data Protection Regulation (UK GDPR).

More information about how the UK GDPR affects researchers can be found here: https://internal.kcl.ac.uk/innovation/research/Research-Governance/how-does-uk-data-protection-law-affect-research/how-does-uk-dp-law-affect-research

Please note that any changes to the storage, management, or type of personal data being collected should also be included in a modification request.

We wish you every success with your project moving forward.
With best wishes,

The Research Ethics Office

On behalf of the College Research Ethics Committee

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