From Repeat Diabetic Ketoacidosis to Expert by Experience: Exploring the Highs and Lows of Living with Type 1 Diabetes

Allcock, Bethan

Award date:
2020

Awarding institution:
Bangor University

From Repeat Diabetic Ketoacidosis to Expert by Experience: Exploring the Highs and Lows of Living with Type 1 Diabetes

Allcock, Bethan

Award date:
2020

From Repeat Diabetic Ketoacidosis to Expert by Experience:

Exploring the Highs and Lows of Living with Type 1 Diabetes

Bethan Allcock

North Wales Clinical Psychology Programme

PRIFYSGOL
BANGOR
UNIVERSITY

Submitted in partial fulfilment of the requirements for the degree of

Doctor of Clinical Psychology

June 2020

Contents

Acknowledgements

I would like to extend my heartfelt thanks to every person who has helped me in reaching this point, and in completing this thesis. To the young adults who so kindly participated in the empirical study, I hope I have been able to capture your voices half as eloquently and powerfully as you have used them in shaping services for the better. To my clinical research supervisor, Rose Stewart, who ignited my interest in diabetes psychology and deepened my passion for expert by experience involvement. Thank you so much for your generosity of time, invaluable insights, and unwavering support and compassion over the course of this work. To my academic research supervisor, Mike Jackson, for sharing your research expertise and wisdom, as well as for your reassurance and endless patience. To my Training Coordinator, Renee Rickard. I will forever be grateful for your continued support, encouragement, and nurturance throughout the three years of my training.

Massive thanks also to my radical and hilarious cohort of cohesion, for the laughs, the solidarity and friendship. To my kind, lovely Mum, for her absolute belief in me. You have always been my most fierce supporter. To Lewys, for keeping my feet on the ground, reminding me of what really matters, and for keeping me in endless supply of things to binge-watch. To Paul, for being my best friend and my rock, for keeping me going, for your skills in graphic design, for teaching me the benefits of commas and, most importantly, for keeping me fed. To Percy, my adorable and loyal companion. You really are the best boy.

Finally, I dedicate this thesis to my wonderful Dad, to whom I owe so much. I know you would be so proud. You are truly missed.

Thesis Abstract

This thesis explores pertinent issues regarding the psychological, social, and physical wellbeing of people living with type 1 diabetes. Chapter one presents a narrative systematic review of 22 studies concerning the psychosocial factors associated with repeat diabetic ketoacidosis (an acute and life-threatening complication of diabetes) in type 1 diabetes. Although considerable variance was noted across studies with regards to design, quality and outcomes measured, some consistent psychosocial factors were observed to be implicated in the cycle of repeat diabetic ketoacidosis. These comprised: female gender, adolescent to young adult age range, lower socioeconomic status, and poor mental health. Themes also emerged around ethnicity and, in children and young people, family, social and behavioural issues. However, firm conclusions could not be drawn about these additional themes due to particularly poor methodological rigour and scant research. Recommendations were made for enhanced monitoring and support for individuals within particularly 'at risk' groups.

Chapter two presents a grounded theory study exploring the personal impact of expert by experience activity on young adults living with type 1 diabetes. A theory of empowerment through expert by experience activity was developed, grounded in interviews with seven participants. The theory proposes that engagement in expert by experience activity empowers individuals psychologically, socially, and in their condition management; and may lead to increased confidence and autonomy across multiple areas of their lives. These findings, in addition to existing research demonstrating the service-level benefits of expert by experience involvement, may have important implications for diabetes services to support expanding their programme of expert by experience involvement to benefit all stakeholders.

Chapter three discusses further implications emerging from the first two chapters regarding future research, theory development, and clinical practice. It concludes with a reflective commentary on the research process.

Chapter 1 – Literature Review

Psychosocial factors associated with repeat diabetic ketoacidosis in people living with type 1 diabetes: A systematic review

Repeat diabetic ketoacidosis in type 1 diabetes: Psychosocial associations

Bethan Allcock[1]| Rose Stewart[2]| Mike Jackson[1]

[1]North Wales Clinical Psychology Programme, School of Psychology, Bangor University, Bangor, UK

[2]Young Adult Diabetes Service, Wrexham Maelor Hospital, Betsi Cadwaladr University Health Board

Correspondence

Rose Stewart

Email: Rose.Stewart@wales.nhs.uk

Abstract word count: 226

Manuscript word count: 4965

This paper has been prepared in accordance with the submission guidelines for *Diabetic Medicine:* https://onlinelibrary.wiley.com/page/journal/14645491/homepage/forauthors.html

What’s new?

- Repeat diabetic ketoacidosis is a serious diabetes complication associated with significant mortality, quality of life, and cost implications.
- This is the first systematic review examining the psychosocial factors associated with repeat diabetic ketoacidosis in type 1 diabetes.
- Overall, repeat diabetic ketoacidosis appeared most common in individuals who were younger, female, from lower socioeconomic backgrounds, and with poorer mental health.
- Healthcare professionals may wish to consider enhanced monitoring and support for the above identified ‘at risk’ groups.
- There are also implications for targeted interventions aimed at reducing dynamic risk factors such as mental health difficulties.

Abstract

Aims: To systematically review the literature concerning the psychosocial factors associated with repeat diabetic ketoacidosis for people living with type 1 diabetes.

Methods: PsycInfo, Web of Science, CINAHL, PubMed and ASSIA were searched according to a registered study protocol (PROSPERO CRD42020167381). Data were extracted into a coding spreadsheet and findings were synthesised narratively. Included papers were also subject to a quality assessment.

Results: The search yielded 548 unique articles, of which 22 met inclusion criteria for this review. There was considerable variance across studies with regards to design, quality, and outcome measured. Nevertheless, there was relatively consistent evidence to suggest that repeat diabetic ketoacidosis in type 1 diabetes is associated with female gender, adolescent to young adult age range, lower socioeconomic status, and poor mental health. Some evidence was also observed for the role of ethnicity and, for children and young people at least, family, social and behavioural issues. However, this was limited by issues of methodological rigour and scant investigation.

Conclusions: The review identified four psychosocial factors that appear to play a key role in the cycle of repeat diabetic ketoacidosis. Individuals with these factors present may benefit from targeted support and interventions by specialist healthcare professionals. Knowledge and understanding in this area would be considerably enhanced via increased use of prospective study designs and greater consistency in the operationalisation of variables across studies.

KEYWORDS

diabetes mellitus, type 1; diabetic ketoacidosis; mental health; psychological distress; psychology; social class; systematic review

1 | INTRODUCTION

Diabetic ketoacidosis is an acute complication of diabetes that constitutes a serious medical emergency and significant mortality risk.[1] It is associated with insulin deficiency and characterised by uncontrolled hyperglycaemia, metabolic acidosis, and raised ketone levels.[2] Although diabetic ketoacidosis can develop in people living with type 1 *and* type 2 diabetes, its presentation is rather different between the two: whilst it is more commonly associated with type 1 diabetes, it tends to present more severely in people living with type 2 diabetes (particularly for those who are older or overweight).[3] Further, it is most commonly triggered by insulin omission in people living with type 1 diabetes, and by infection in people living with type 2 diabetes.[4] Given such key differences, research into diabetic ketoacidosis is often stratified by type of diabetes.[5] This paper focuses on diabetic ketoacidosis in the context of type 1 diabetes only, where its overall prevalence is estimated to range from 50 to 100 events per 1000 individuals living with type 1 diabetes.[6]

Left untreated, diabetic ketoacidosis can lead to coma and even death.[7] It has been identified as the leading cause of death for people living with type 1 diabetes under the age of 50 in the UK.[8] However, with treatment, the mortality rate is relatively low, at 0.16% of inpatient admissions.[9] Indeed, there have been significant advances in the medical management and treatment of diabetic ketoacidosis over the last decade.[10] Nevertheless, Gibb and colleagues[9] observed that the mortality rate is substantially higher for individuals with repeat episodes of diabetic ketoacidosis than for those with a single episode, with six-year follow-up mortality rates of 23.4% and 5.2% respectively. This is particularly concerning given that two-thirds of inpatient admissions for diabetic ketoacidosis in the UK are from repeat diabetic ketoacidosis.[11] Furthermore, repeat diabetic ketoacidosis has a significant impact on the quality of life of both the person with type 1 diabetes, and those around them.[12] In addition to these human costs, diabetic ketoacidosis is expensive to treat: cost analyses in 2014 indicated that the average cost per episode in the UK was £2064 per patient for adults[13] and £1387 for adolescents.[14]

As noted previously, the leading precipitant of diabetic ketoacidosis in people living with type 1 diabetes is insulin omission.[4] As such, diabetic ketoacidosis in these circumstances is triggered by ‘human error’ (rather than an underlying medical condition) and is therefore preventable.[2] Although occasional insulin omission may happen inadvertently in the context of a busy lifestyle, the significant personal impact of diabetic ketoacidosis is such that simple oversights are unlikely to be the cause of repeat diabetic ketoacidosis.[12] It is therefore pertinent to further investigate which factors may be associated with repeat diabetic ketoacidosis. Previous research indicates that a number of psychosocial factors, such as gender, age, psychological wellbeing and socioeconomic status are implicated in the frequent recurrence of diabetic ketoacidosis; synopses of which have been outlined in two recent narrative summaries of the literature.[15,16] However, the evidence base has yet to be reviewed and synthesised systematically with reference to individuals living with type 1 diabetes.

Therefore, this paper aims to systematically review the literature to address the following research question: *what is our current understanding of the relationship between psychosocial factors and repeat diabetic ketoacidosis in people living with type 1 diabetes?* Given that diabetic ketoacidosis is avoidable *and* associated with significant costs, it is imperative that the issues underpinning it are better understood. In this way, appropriate prevention or intervention measures can be developed and savings (human and financial) may be made.[17]

2 | METHODS

2.1 | Protocol and registration

This review was prepared in line with the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) guidelines[18] (Appendix A) and registered prospectively with the international prospective register of systematic reviews (PROSPERO registration number CRD42020167381).

2.2 | Eligibility criteria

To be eligible for inclusion in this review, papers were required to report on the association between psychosocial factors and repeat diabetic ketoacidosis in people of any age living with type 1 diabetes. Mixed studies including people with other types of diabetes were required to stratify between diabetes type. However, as noted by Garrett et al.,[16] repeat diabetic ketoacidosis received considerable research attention between 1976 and 1991, where it was studied as part of the phenomenon of 'brittle diabetes' (a term that has now fallen out of common usage, previously defined as diabetes associated with constant life disruptions due to hypo- or hyperglycaemia[19]). Although people living with type 2 diabetes could experience 'brittle diabetes' if they become insulin dependent, the condition is far more prevalent in people living with type 1 diabetes.[20] The body of literature on 'brittle diabetes' did not clearly differentiate between type of diabetes, though it seems likely that the vast majority of their participants would have been diagnosed with type 1 diabetes.[16] To avoid omitting a pertinent body of literature based on terminology use, the decision was taken to include studies using the term 'brittle diabetes', as long as they concerned repeat diabetic ketoacidosis in that context. In addition, studies using the definition 'insulin-dependent diabetes mellitus' were also considered for review if they met the other inclusion criteria. Studies were required to be peer reviewed original research and available in English. Qualitative and quantitative studies were eligible for inclusion, but case studies were excluded to reduce the likelihood of bias or poor generalisability. There were no restrictions on date of publication. All studies meeting these criteria were considered for inclusion in the review, regardless of whether they specifically aimed to investigate the psychosocial factors associated with repeat diabetic ketoacidosis.

2.3 | Information sources

The following databases were initially searched from their date of inception to 2nd February 2020: PsycInfo, Web of Science, CINAHL, PubMed and ASSIA. The search was repeated on 25th April 2020, prior to final analyses, to retrieve any further studies for inclusion. The reference lists of included papers and existing review articles were also hand-searched to source additional articles.

2.4 | Search

The search terms were based on key terms identified in known papers on the topics of interest and were developed in collaboration with professionals in the diabetes field and the local subject librarian. Search terms were as follows: Recur* (OR repeat* OR readmi*) combined with diabetic ketoacidosis (OR DKA OR diabetic acidosis OR diabetic ketosis OR ketoacidosis) and psycho* factor* (OR social Factor* OR Quality of Life OR Wellbeing OR Psych* OR Mental Illness OR Mental Health OR Depress* OR Anx* OR Stress OR Distress OR Trauma* OR Suicid* OR Drug OR Substance OR Alcohol OR Socioeconomic OR Poverty OR Depri* OR Homeless* OR Family OR Support). Where available, subject indexing for individual databases were incorporated into the search string.

2.5 | Study selection

Search results were exported to ProQuest RefWorks and duplicates removed. Titles and abstracts of the remaining studies were screened for eligibility by the first author. To promote accuracy and precision in the implementation of inclusion-exclusion decisions,[21] the titles and abstracts of a random sample of 30 papers (5.5% of the total records screened) were screened by the second author: 100% interrater reliability was achieved. The full text of potentially eligible articles was then screened by the first author to produce the final list of included studies.

2.6 | Data extraction and synthesis

Data extraction was completed independently by the first author, using a coding spreadsheet. Extracted data consisted of: study location, design, rationale, sample size, participant demographics (gender, age, etc), how repeat diabetic ketoacidosis was defined within the study, the main findings pertinent to this literature review and the main limitations of the study. Due to the heterogeneity between study designs and variance between psychosocial outcomes measured, it was not appropriate to conduct a meta-analysis. Instead, a narrative synthesis was conducted to summarise key findings, focusing on the relationship between psychosocial factors and repeat diabetic ketoacidosis.

2.7 | Assessment of risk of bias

Study quality was assessed independently by the first author using QualSyst, a peer-reviewed standardised measure of internal validity, designed for use across a broad range of study designs.[22] It was selected for use in this review due to the heterogeneity of study designs across the included papers. Although tools designed for heterogenous study designs may not be as sensitive as tools aimed at specific designs,[23] the decision was taken not to use separate tools for each design to allow for greater comparability of quality assessment. QualSyst operates a scoring system, whereby studies are allocated scores of 0-2 across 14 criteria, depending on whether the criteria are met (score=2), partially met (score=1), or not met (score=0). These scores are then summed to produce a summary score indicating the overall quality of the study.[22] However, summary scores may not constitute an accurate reflection of a study's quality: for instance, because equal weighting is afforded to each item, studies with a single but significant flaw would be allocated higher summary scores than studies with a small number of minor flaws.[24] Consequently, QualSyst was used to supplement quality appraisal in addition to qualitative critical appraisal undertaken by the first author. No studies were excluded from the review for reasons of poor quality, but this information was considered during data synthesis, with less weight given to the findings of poorer quality studies.

3 | RESULTS

3.1 | Study selection

As depicted in Fig. 1, the database search identified 701 papers and 16 additional papers were identified through other sources. After duplicates were removed, 548 papers were subject to abstract and title screening and 453 papers were excluded at that point. Ninety-five articles were then screened in full, and 73 of them excluded for reasons outlined in the flow diagram. The remaining 22 studies met criteria for inclusion in the qualitative synthesis.

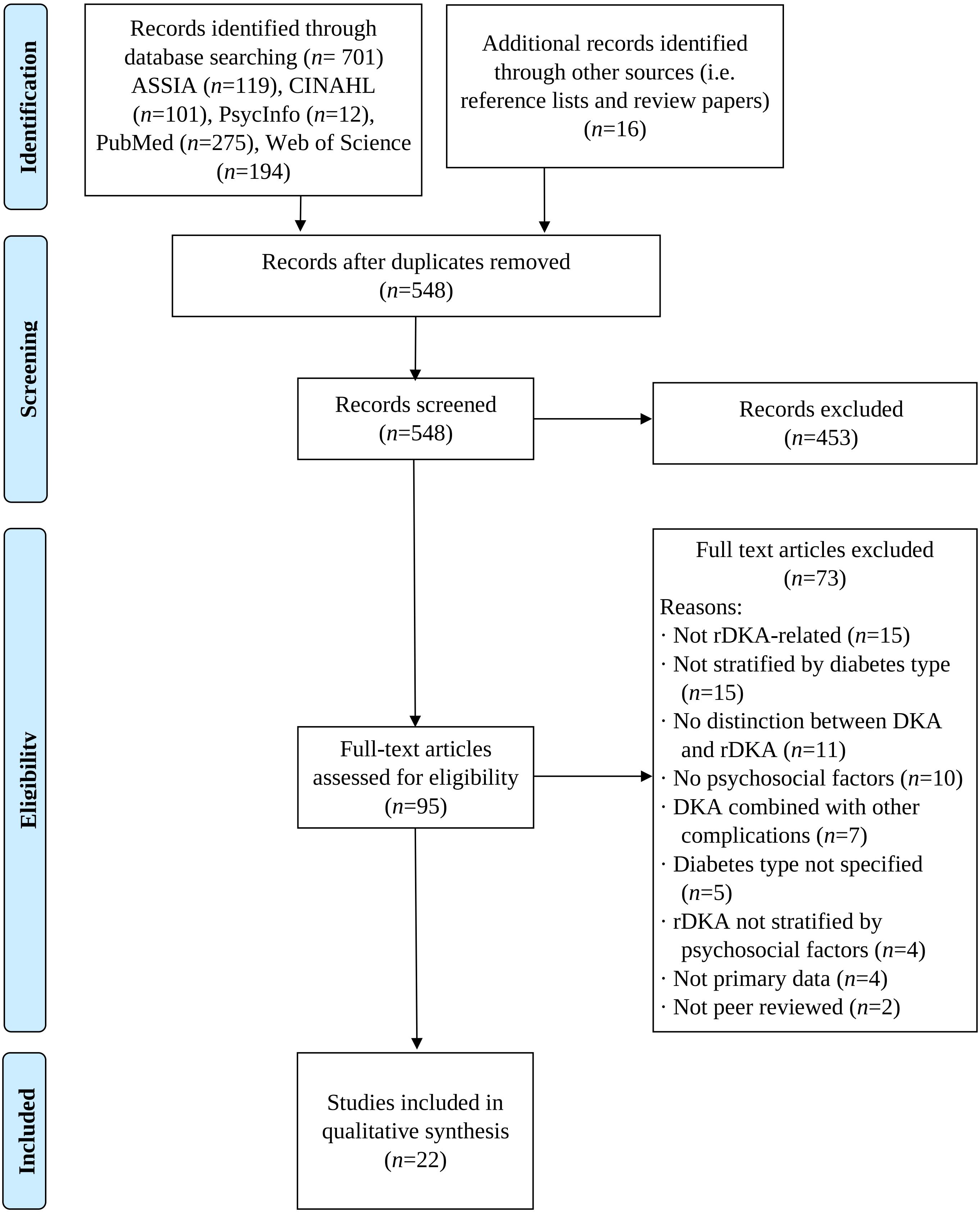


Figure 1. PRISMA flow diagram of the systematic review process

---

Abbreviations: DKA, diabetic ketoacidosis; rDKA, repeat diabetic ketoacidosis

3.2 | Study characteristics

Data extracted from the 22 studies are presented in Table 1. The studies were published between 1984 and 2020 and included participants from nine countries. Most of the studies concerned participants in the US (*n*=10)[29,32-35,39,41-44] and the UK (*n*=6),[9,11,26,37,38,45] with the remaining studies based in Canada (*n*=1),[31] Australia (*n*=1),[25] New Zealand (*n*=1),[30] Austria and Germany (*n*=1),[36] China (*n*=1)[40] and Turkey (*n*=1)[28]. Whilst sample sizes ranged from 30 to 264 687, most studies included over 100 participants (*n*=17),[9,11,25,26,28,29,31,33,34,36,38,39-43,45] eight of which included over 1000 participants. Across studies, participant ages ranged from 0 to 85. Three studies included participants from across the lifespan,[33,38,45] whereas four studies included only participants aged 18 and over.[11,31,34,40] Seven studies reported only on participants aged up to 18.[25,28,29,32,39,41,44] The distinction between child and adult participants was less clear in five studies, with one including people aged 16 and over,[30] one including only 17-25 year olds,[26] and three including only participants aged 21 and under.[36,42,43] Age range was not specified in three studies.[9,35,37] There was little consistency between studies in how they conceptualised repeat diabetic ketoacidosis: some studies focused on repeat episodes within one year,[11,29,34-36,41,44] others considered repeat episodes within the study period,[26,30-33,40,43,45] others concerned repeat episodes across the lifespan,[9,25,37,39,42] whilst others offered no definition.[28,38] Finally, 19 studies specified that participants had a diagnosis of type 1 diabetes, whereas the remaining three described participants as living with insulin-dependent diabetes. The latter three studies were amongst the oldest in the sample, being published between 1984 and 1996.[37-39]

Table 1. Key data extracted from each of the studies included in the qualitative synthesis

Authors, year, location	Study design and rationale	Sample	Definition of repeat diabetic ketoacidosis	Findings regarding psychosocial factors and repeat diabetic ketoacidosis	Main limitations
Ampt et al. (2019)[25] Australia	Longitudinal population-based study To determine incidence, prevalence, and risk factors for diabetic ketoacidosis in children living with type 1 diabetes	5176 children living with type 1 diabetes Age range: 0-14 years 2579 female, 2597 male	More than one documented hospital admission for diabetic ketoacidosis	Repeat admissions for diabetic ketoacidosis were more likely to occur in females (OR 1.47, 95% CI 1.24-1.79) and those from disadvantaged neighbourhoods (OR 1.26, 95% CI 1.02-1.79)	Use of pre-recorded data precludes ability to control for potential confounds
Bryden et al. (2003)[26] UK	Longitudinal cohort study To assess the influence of early behavioural and psychological factors on outcomes related to type 1 diabetes	113 young adults living with type 1 diabetes Age range: 17-25 years 62 female, 51 male (77% followed-up at time 2)	Not specified - repeated diabetic ketoacidosis admissions over the study period (mean follow-up= 11.2 years, SD=2.5)	Psychiatric symptoms at baseline (as derived from the Global Severity Index (GSI) of the self-report Symptom Checklist, SCL-90,[27] were predictive of repeat diabetic ketoacidosis at follow-up (OR 9.1, 95% CI 2.9–28.6, *P*<0.001)	GSI does not indicate the nature of ‘psychiatric symptoms’ experienced 23% ‘drop out’ Relatively small sample
Cebeci et al. (2012)[28] Turkey	Retrospective chart review To determine clinical and biochemical features of diabetic ketoacidosis in type 1 diabetes across different age groups	111 children and adolescents living with type 1 diabetes Age range: 0.9-17.3 years 64 female, 47 male	Not specified, but uses the term ‘recurrent diabetic ketoacidosis’	Sixty-four percent of those with repeat diabetic ketoacidosis were female (*n*=7)	No statistical analysis related to the variable of interest for this review. Relatively small sample capturing few repeat episodes Use of pre-recorded data precludes ability to control for potential confounds
Cohn et al. (1997)[29] US	Retrospective analysis of discharge data To investigate gender differences in hospitalisations for insulin-dependent diabetes	1676 children and young people living with type 1 diabetes Age range: 0-18 years 924 females, 752 males	Not specified. However, study focused on all hospitalisations within one year.	Repeat diabetic ketoacidosis significantly more likely to occur in females than males (23.5% vs 14.2%, *P*<0.001), with the largest female excess in adolescents	Use of pre-recorded data precludes ability to control for potential confounds

Table 1. *Continued*

Authors, year, location	Study design and rationale	Sample	Definition of repeat diabetic ketoacidosis	Findings regarding psychosocial factors and repeat diabetic ketoacidosis	Main limitations
Cooper et al. (2016)[30] New Zealand	Retrospective case-control examination of medical records To investigate risk factors for repeat diabetic ketoacidosis hospital admissions in people living with type 1 diabetes	80 young people and adults living with type 1 diabetes Age range: 16-72 years 40 female, 40 male	One or more subsequent admissions within 60 months of the index diabetic ketoacidosis admission	No significant differences found between people with single versus repeat diabetic ketoacidosis in terms of comorbid psychiatric illness (17.5% vs. 7.5%, *P*=0.18), alcohol abuse (33% vs. 24%, *P*=0.46) or substance abuse (15% vs. 5%, *P*=0.14).	Psychiatric comorbidity and substance use recorded inconsistently Relatively small sample Use of pre-recorded data precludes ability to control for potential confounds
Del Degan et al. (2019)[31] Canada	Retrospective cohort file review To investigate factors associated with repeat diabetic ketoacidosis in type 1 diabetes	212 adults living with type 1 diabetes Age range: Not recorded (18+) 102 female, 110 male	Not specified - repeated diabetic ketoacidosis admissions over the study period (10 years)	No differences were observed between individuals with repeat and single episodes of diabetic ketoacidosis in terms of age (repeat M=36 years, SD=12.2, single M=37.7 years, SD=15.2, *P*=0.41), low socioeconomic status (repeat: 40%, single: 29.2%, *P*=0.25), nor presence of an eating disorder (repeat: 1.4%, single: 2.1%, p=1.0). Also, no significant difference with regards to gender, though there was a trend towards a greater male prevalence in the repeat group (60.6% compared to 47.5% in single, *P*=0.08) In bivariate regression, diagnosis of a psychiatric illness (OR 2.84, 95% CI 1.56-5.16, *P*<0.01) and alcohol/illicit drug use (OR 2.81, 95% CI 1.55-5.07, *P*<0.01) emerged as risk factors for repeat diabetic ketoacidosis, but these findings did not retain statistical significance in multivariate regression.	Data pertaining to socioeconomic status often missing from files Use of pre-recorded data precludes ability to control for potential confounds Low presence of factors such as eating disorders and ethnic minority status in the overall sample precluded ability to fully explore their impact

Table 1. *Continued*

Authors, year, location	Study design and rationale	Sample	Definition of repeat diabetic ketoacidosis	Findings regarding psychosocial factors and repeat diabetic ketoacidosis	Main limitations
Dumont et al. (1995)[32] US	Prospective cohort study To assess the impact of psychosocial factors on risk of recurrent type 1 diabetes complications	61 children and young people living with type 1 diabetes Age range: 9-16 years 30 female, 31 male	At least two episodes of diabetic ketoacidosis across the study period (8 years)	Based on 9 individuals noted to have experienced repeat diabetic ketoacidosis: No associations with age or social class. Females more likely to experience repeat episodes than males ($P<0.05$). In females, repeat episodes were associated with both internalising and externalising behaviour problems ($P<0.05$ and $P<0.001$, respectively), poorer peer relationships ($P<0.05$), higher family conflict ($P<0.01$) and lower levels of parent-reported family cohesion ($P<0.01$), expressiveness ($P<0.05$), and organization ($P<0.01$). In males, repeat episodes were associated with mature defence mechanisms ($P<0.05$) and maternal-reported higher levels of family organisation ($P<0.01$).	Relatively small sample capturing few repeat episodes, described findings as exploratory only Underpowered to detect statistical significance
Everett & Mathioudakis (2019)[33] US	Cross-sectional database review To compare differences in the relationship between psychosocial factors and repeat diabetic ketoacidosis in type 1 diabetes across paediatric and adult populations.	4037 children, young people and adults living with type 1 diabetes Age range: 2-80+ (precise upper limit unspecified) 1931 female, 2106 male	More than one diabetic ketoacidosis readmission across the five-year study period	Females had increased odds of repeat diabetic ketoacidosis in both paediatric and adult groups. Within this, the paediatric group had greater odds of four or more readmissions than the adult group (paediatric OR 2.31, adult OR 1.51, $P_{int}=0.20$). In the paediatric group, odds of repeat diabetic ketoacidosis increased with age, with odds of 11.66 for four or more repeat episodes (95% CI 3.74-36.37). Increasing age was associated with decreased odds of four or more repeat episodes in adults, with a 29% decrease in odds of four or more episodes for each increase in age bracket (OR 0.71, 95% CI 0.66-0.76, $P_{int}=0.01$). (*continued overleaf)*	Estimated area deprivation via postal code which may overlook within-postcode variance in deprivation. However, authors note that the area under study is relatively homogenous with regards to geographical distribution of deprivation Use of pre-recorded data precludes ability to control for potential confounds

Table 1. *Continued*

Authors, year, location	Study design and rationale	Sample	Definition of repeat diabetic ketoacidosis	Findings regarding psychosocial factors and repeat diabetic ketoacidosis	Main limitations
				Concerning area deprivation, there were significant differences between paediatric and adult populations for those with one to three repeat episodes (P_{int}=0.01 for both) and those with four or more episodes (P_{int}=0.1 and P_{int}=0.2, respectively). Compared to the least deprived, moderately deprived individuals in the paediatric group had increased odds of one to three (OR 4.26, 95% CI 1.79-10.12) and four or more episodes (OR 7.87, 95% CI 1.02-60.81). There were no significant differences in these outcomes for adults. When comparing the most deprived individuals to those who are least deprived, there were increased odds for one to three episodes (OR 4.04, 95% CI 1.04-58.11) in the paediatric group. Although there was no association observed in one to three episodes in the adult cohort, there were significantly increased odds of four or more episodes between the most and least deprived adults (OR 2.23, 95% CI 1.16-4.25). When comparing Medicaid insurance with private insurance, there were increased odds of both one to three admissions, and four or more admissions, across both adult and paediatric cohorts (for one to three admissions: adult OR 1.85, 95% CI 1.17-2.90, paediatric OR 1.39, 95% CI 1.11-1.75, P_{int}=0.06; for four or more admissions: adult OR 2.81, 95% CI 1.35-5.87, paediatric OR 1.99, 95% CI 1.32-3.01, P_{int}=0.64).	

Table 1. *Continued*

Authors, year, location	Study design and rationale	Sample	Definition of repeat diabetic ketoacidosis	Findings regarding psychosocial factors and repeat diabetic ketoacidosis	Main limitations
Everett & Mathioudakis (2019)[34] US	Cross-sectional database review To investigate individual and hospital predictors of repeat diabetic ketoacidosis admissions in adults living with type 1 diabetes	181 284 adults living with type 1 diabetes Age range: not reported (lower limit: 18 years, median age: 35 years) 88 104 female, 93 180 male	Any readmission with diabetic ketoacidosis within the same calendar year as the index admission	Increasing age was associated with lower odds of repeat diabetic ketoacidosis, with the largest effect sizes demonstrated in those with higher rates of repeat episodes (*P*<0.001). Female gender was associated with higher odds of repeat episodes, with a 40% increase in odds of four or more readmissions (*P*<0.001) There was a 19% increased risk of one to three repeat episodes, and a 46% increase in the odds of four or more readmissions for those with the lowest income as compared to those with the highest income (*P*<0.001) When compared to those with private insurance, individuals with Medicare insurance had increased odds of both one to three (OR 2.08, 95% CI 1.97-2.19) and four or more (OR 3.33, 95% CI 2.94-4.38) episodes of repeat diabetic ketoacidosis (*P*<0.001). This trend was also observed between users of Medicaid and private insurance (OR of one to three readmissions 1.89, 95% CI 1.82-1.97; OR of four or more admissions 3.33; 95% CI 3.02-3.67, *P*<0.001).	Design of database meant that only readmissions within a calendar year could be followed. Therefore, readmissions of those admitted later in the calendar year may be missed. Use of pre-recorded data precludes ability to control for potential confounds (e.g. race not recorded in the database)

Table 1. *Continued*

Authors, year, location	Study design and rationale	Sample	Definition of repeat diabetic ketoacidosis	Findings regarding psychosocial factors and repeat diabetic ketoacidosis	Main limitations
Flexner et al. (1984)[35] US	Matched control chart review To explore the contributary factors to repeat diabetic ketoacidosis in type 1 diabetes	42 people living with type 1 diabetes Age range: not reported Gender distribution: not reported	Considered repeat diabetic ketoacidosis if an individual was admitted more than once in one year primarily for DKA	People with repeat diabetic ketoacidosis had spent fewer years in education (8.1 years vs. 10.1 years) and were more likely to have a ‘diagnosed neurosis’ (29% vs. 6%) than those with a single episode (*P*≤0.05)	Small sample with large number of outcomes. Analysis not specified and no report of effect size or variance in the data Diagnosed ‘neuroses’ not specified
Fritsch et al. (2011)[36] Germany & Austria	Cross-sectional database review To investigate incidence and risk factors for repeat diabetic ketoacidosis in young people living with type 1 diabetes	28 770 children and young people living with type 1 diabetes Age range: 0-20 years 13 781 female, 14 989 male	Two or more episodes of diabetic ketoacidosis in the most recent year of follow up	Females more likely to experience repeat diabetic ketoacidosis than males (57.4% vs 42.5%, *P*=0.02). People from a ‘migration background’ also more likely to experience repeat diabetic ketoacidosis, with 19.3% of people with a migration background experiencing two or more episodes	‘Migration background’ used as a proxy for ethnic minority status, defined by having at least one parent born outside of the locality. This overlooks migration by those not from an ethnic minority group. Use of pre-recorded data precludes ability to control for potential confounds
Gibb et al. (2016)[9] UK	Retrospective cohort file and database review To investigate the risk factors and mortality associated with repeat diabetic ketoacidosis in type 1 diabetes	298 people living with type 1 diabetes Age range: not specified 134 female, 164 male	More than one admission with diabetic ketoacidosis across the lifespan	No gender differences (*P*=0.186) Higher levels of social deprivation were associated with repeat episodes (*P*=0.005) Antidepressant use more common in those with five of more episodes of repeat diabetic ketoacidosis (47.5%) as compared to those with two to four episodes (27.8%) and those with one episode (12.6%; *P*=0.001). There was no statistically significant association between higher rates of repeat diabetic hospital admission for treatment of psychiatric illness (*P*=0.092)	Estimated area deprivation via postal code which may overlook within-postcode variance in deprivation. Use of pre-recorded data precludes ability to control for potential confounds

Table 1. *Continued*

Authors, year, location	Study design and rationale	Sample	Definition of repeat diabetic ketoacidosis	Findings regarding psychosocial factors and repeat diabetic ketoacidosis	Main limitations
Gill (1992)[37] UK	Cross-sectional study To explore psychosocial factors associated with brittle diabetes in people living with insulin-dependent diabetes	84 people living with insulin-dependent diabetes Age range: not reported 59 female, 25 male	‘Brittle diabetes’ group defined as people for whom 90% or more of admissions were for diabetic ketoacidosis (time frame for admissions not specified)	Psychosocial problems (including “family disturbances”, “personality disturbances” and depression) common in both repeat diabetic ketoacidosis (73%) and ‘other brittle diabetes’ (75%) groups, psychosocial problems more common as compared to the ‘stable diabetes’ group (17%; *P*<0.001). Within the ‘brittle diabetes’ group, those with repeat diabetic ketoacidosis were significantly younger (M= 20.5 years, SD=5.5) than those with ‘other brittle diabetes’ (M= 36.1 years, SD=13.6)	Specific ‘psychosocial problems’ reported across all participants with ‘brittle diabetes’; not stratified by type of ‘brittle diabetes’ Unclear operationalisation of psychosocial factors, leaving room for interpretation regarding the factors being measured. Relatively small sample size
Gill et al. (1996)[38] UK	Questionnaire survey (completed by clinicians) To explore the prevalence, clinical characteristics and causes of brittle diabetes in people living with insulin-dependent diabetes	414 children and adults living with insulin-dependent ‘brittle diabetes’ Age range: 5-85 273 female, 141 male	Not specified, but uses the term ‘recurrent diabetic ketoacidosis’	When comparing individuals with repeat diabetic ketoacidosis with those with ‘mixed brittleness’ and ‘recurrent hypoglycaemia’, the repeat group were younger (mean ages: 22, 28 and 34, respectively) and had the greatest female excess (140%, 90% and 10%, respectively)	Survey response rate of 72%; unclear whether non-responding clinicians had no individuals meeting criteria for ‘brittle diabetes’ on their caseload, or whether there were other reasons for non-response. Authors could not be certain that the sample included only individuals living with type 1 diabetes.
Golden et al. (1985)[39] US	Retrospective chart review Evaluation of an intervention aimed at preventing repeat diabetic ketoacidosis	418 children living with insulin-dependent diabetes Age range: 0.25-7.25 years 186 females, 232 males	Recurrence of diabetic ketoacidosis at any time after initial episode	Observed no significant differences in children with and without repeat diabetic ketoacidosis in terms of age and sex. Children with repeat episodes significantly more likely to be utilising public insurance than children without repeat episodes (36.1% vs. 13.5% respectively, *P*<0.001)	No account of how confounds were considered and ameliorated Outcomes pertinent to this review were not the main aim of this study

Table 1. *Continued*

Authors, year, location	Study design and rationale	Sample	Definition of repeat diabetic ketoacidosis	Findings regarding psychosocial factors and repeat diabetic ketoacidosis	Main limitations
Li et al. (2014)[40] China	Cross-sectional study To assess incidence and risk factors associated with diabetic ketoacidosis and severe hypoglycaemia in people living with type 1 diabetes	611 adults living with type 1 diabetes Age range: 19.5-37.3 years 328 female, 283 male	Two or more episodes of diabetic ketoacidosis in the study period (20 months)	Female gender was associated with increased risk of repeat diabetic ketoacidosis (RR 10.56, coefficient 1.18, 95% CI 1.97-56.72, *P*=0.01). No association was found between level of income and repeat episodes (RR 1.12, coefficient 0.11, 95% CI 0.99-1.27, *P*=0.08)	Data gathered cross-sectionally and via participant self-report Did not measure/control for the impact of potential confounds such as psychological wellbeing
Malik et al. (2016)[41] US	Retrospective cohort medical record review To examine differences in predictors of 365-day admission frequency for diabetic ketoacidosis for children living with type 1 diabetes, across and within hospitals	12 449 children and young people living with type 1 diabetes Age range: 2-18 years 6576 female, 5912 male	Two or more episodes of diabetic ketoacidosis within a 365-day period	When comparing children with zero episodes of repeat diabetic ketoacidosis with those with three or more, there is an increase in the proportion of individuals who are female (50.3% vs 61.8%, *P*< 001), older (especially in the over 12s; 47.4% vs. 58.3%, *P*<0.001), non-Hispanic black (16.1% vs. 46.5%, *P*<0.001), utilising public insurance (27.8% vs. 56.0%, *P*<0.001) and who have a mental health comorbidity (5.1% vs. 8.6%, *P*<0.001)	Use of pre-recorded data precludes ability to control for potential confounds (e.g. glycaemic control) Potential variation in coding practices across research sites may have led to inconsistencies in the data No information provided regarding the nature of 'mental health comorbidities'
Rewers et al. (2002)[42] US	Prospective cohort database design To determine the incidence and predictive risk factors of diabetic ketoacidosis and severe hypoglycaemia for children living with type 1 diabetes	1243 children and young people living with type 1 diabetes Age range: 0-19 years 583 female, 660 male	Two or more episodes of diabetic ketoacidosis. No timeframe specified.	No psychosocial predictors of repeat diabetic ketoacidosis were found for younger children. In older children, repeat episodes were associated with the presence of psychiatric disorders (OR 3.39, 95% CI 2.05-9.40, *P*<0.001) and underinsurance (OR 3.39, 95% CI 1.57-7.34, *P*<0.002)	No information provided regarding which psychiatric disorders individuals had been diagnosed with. Multiple providers involved in data collection process, potential for inconsistencies Based in metropolitan area; may not generalise to rural settings

Table 1. *Continued*

Authors, year, location	Study design and rationale	Sample	Definition of repeat diabetic ketoacidosis	Findings regarding psychosocial factors and repeat diabetic ketoacidosis	Main limitations
Vakharia et al. (2020)[43] US	Retrospective cohort file review study To examine the relationship between family history of diabetes and repeat diabetic ketoacidosis in young people living with type 1 diabetes	131 children and young people living with type 1 diabetes Age range: 0-21 years 62 female, 69 male	Two or more diabetic ketoacidosis admissions during the study period (6 years)	In univariate analyses with non-Hispanic black individuals experienced 80% more admissions than those who were non-Hispanic white (IRR 1.8, 95% CI 1.3-2.5, *P*=0.02). This was not significant in multivariate analysis (*P*=0.2). Individuals aged 15 or older had 60% more repeat episodes than those aged under 15 (IRR 1.6, 95% CI 1.1-2.2, *P*=0.004) Those with public insurance had 50% more repeat episodes than those with private (IRR 1.5, 95% CI 1.2-2.0, *P*=0.002). Those with a family history of diabetes had 50% more episodes of repeat diabetic ketoacidosis than those with no family history (IRR 1.5, 95% CI 1.0-2.3, *P*=0.03). This was not explained by type of family diabetes, how closely related the family members were, nor these family members lived in the same household.	Missing data and possible inaccuracies observed in the charts Use of pre-recorded data precludes ability to control for potential confounds Relatively small sample size
White et al. (1984)[44] US	Retrospective cohort study To examine physical and psychological factors associated with poorly managed insulin-dependent diabetes	30 children and adolescents living with poorly managed insulin-dependent diabetes Age range: 0-17 10 female, 20 male	Two or more hospitalisations or emergency room visits for diabetic ketoacidosis within one year	25 of the families were noted to have poor living conditions and/or limited financial resources In terms of parental functioning, 4 families were rated as 'adequate', whilst 3 were rated as 'over adequate' ('overinvolved with high expectations'), and the remaining 23 were rated as 'inadequate'; 15 of these were due to 'inability' and 8 due to 'disinterest'	Small sample size Psychosocial factors derived from 'psychosocial summaries' in medical records; robustness of this form of measurement not reported. No comparison group No statistical analysis

(*continued overleaf)*

Table 1. *Continued*

Authors, year, location	Study design and rationale	Sample	Definition of repeat diabetic ketoacidosis	Findings regarding psychosocial factors and repeat diabetic ketoacidosis	Main limitations
				In terms of 'family problems', 'unstable composition' was noted in 10 families, 'chronic conflict' in 14, 'conflictual parent-child relationship' in 12, 'child abuse or medical neglect' in 6, 'psychiatric pathology or alcoholism' in 9 and 'illness or death in family or other significant loss' in 6. Behaviour problems were also noted in the children and adolescents: 18 experienced problems at school, in the form of 'truancy and poor performance', 17 demonstrated 'oppositional behaviour' 6 demonstrated 'antisocial behaviour and other psychiatric pathology' and 9 exhibited 'difficulty with peers' Finally, 11 participants were classified as depressed, 14 with decreased self-esteem, 13 with generalised anxiety or fearfulness, 17 were considered to 'internalise feelings' and 7 were described as having 'dependent personality'	
Wright et al. (2009)[45] UK	Retrospective cohort file review study To determine mortality and risk factors associated with repeat admissions for diabetic ketoacidosis in people living with type 1 diabetes	137 people living with type 1 diabetes Age range: 0.92-75 years 86 female, 51 male	Not defined – uses the term 'multiple admissions' across within the study period (9 years)	Female gender ($P<0.005$), the presence of psychological problems ($P<0.05$), younger age ($P<0.005$), and lower social class ($P<0.05$) were associated with increasing frequency of repeat diabetic ketoacidosis.	Use of pre-recorded data precludes ability to control for potential confounds Difficulties accessing records of the deceased 'Psychological problems' not defined Relatively small sample size

Table 1. *Continued*

Authors, year, location	Study design and rationale	Sample	Definition of repeat diabetic ketoacidosis	Findings regarding psychosocial factors and repeat diabetic ketoacidosis	Main limitations
Zhong et al. (2018)[11] UK	Retrospective cohort database study To explore trends in hospital admissions for diabetic ketoacidosis in adults living with type 1 and type 2 diabetes	264 687 adults living with diabetes. Of the 23 246 living with type 1 diabetes: Age range: not reported (lower limit: 18, average age: 44.66 years, SD: 17.67) Gender distribution: Not reported	Two or more admissions for diabetic ketoacidosis within a particular year	Individuals with repeat diabetic ketoacidosis significantly younger than those with single or zero episodes ($P<0.001$)	Multiple comparisons were not corrected for statistically Noted risk of misclassification of diabetes type in the records (sensitivity analysis suggested this was unlikely to significantly impact on results) Use of pre-recorded data precludes ability to control for potential confounds

Abbreviations: CI, confidence interval; OR, odds ratio; RR, risk ratio; IRR, incidence rate ratio; M, mean; SD, standard deviation

3.3 | Study quality and risk of bias

A range of study designs were included, encompassing retrospective (*n*=11),[9,11,28-31,39,41,43-45] prospective (*n*=4),[25,26,32,42] and cross-sectional designs (*n*=7).[33-38,40] The majority of studies utilised pre-existing data sources, including medical files (*n*=9)[28-31,35,39,41,43,45] and databases (*n*=5),[11,33,34,36,42] with one study utilising both of these methods.[9] Outcomes of the quality appraisal are contained in Table 2 (see Appendix B for an illustration of this process). The overall quality of included studies was variable. In general, the most recently conducted studies were of the highest quality. Overall, the included studies were rated highly in terms of the clarity and appropriateness of their objectives, design, participant selection, description of participants, description of results and conclusions being supported by the results. However, seven studies reported on outcomes that were ill-defined and open to misclassification bias.[30,34,35,37,38,44,45] Furthermore, the majority of studies (*n*=17)[9,11,25,26,28,29,31,34,37-45] were considered to have incomplete control of confounding variables which, for the most part, was associated with the use of pre-existing data from medical records or databases. In addition, the small sample size in some studies likely resulted in insufficient power to detect statistical significance.[26,28,30,32,35,43-45]

Table 2. Study quality appraisal ratings on the QualSyst appraisal tool

	Objective	**Design**	**Subject selection**	**Subject characteristics**	**Random allocation**	**Investigator blinding**	**Subject blinding**	**Outcomes**	**Sample size**	**Analytic methods**	**Estimate of variance**	**Confounds**	**Results**	**Conclusions**	**QualSyst score (%)**
Ampt et al. (2019)[25]	Y	Y	Y	Y	N/A	N/A	N/A	Y	Y	Y	Y	P	Y	Y	95
Bryden et al. (2003)[26]	Y	Y	Y	Y	N/A	Y	N/A	Y	P	Y	Y	P	Y	Y	92
Cebeci et al. (2012)[28]	Y	Y	Y	Y	N/A	N/A	N/A	Y	P	P	Y	N	Y	Y	82
Cohn et al. (1997)[29]	Y	Y	Y	Y	N/A	N/A	N/A	Y	Y	Y	Y	P	Y	Y	95
Cooper et al. (2016)[30]	Y	Y	Y	Y	N/A	N/A	N/A	P	P	P	Y	Y	Y	Y	86
Del Degan et al. (2019)[31]	Y	Y	Y	Y	N/A	N/A	N/A	Y	Y	Y	Y	P	Y	Y	95
Dumont et al. (1995)[32]	Y	Y	Y	Y	N/A	N/A	N/A	Y	N	P	N	Y	Y	Y	77
Everett & Mathioudakis (2019)[33]	Y	Y	Y	Y	N/A	N/A	N/A	Y	Y	Y	Y	Y	Y	Y	100
Everett & Mathioudakis (2019)[34]	Y	Y	Y	Y	N/A	N/A	N/A	P	Y	Y	Y	P	Y	Y	91

Table 2. *Continued*

	Objective	**Design**	**Subject selection**	**Subject characteristics**	**Random allocation**	**Investigator blinding**	**Subject blinding**	**Outcomes**	**Sample size**	**Analytic methods**	**Estimate of variance**	**Confounds**	**Results**	**Conclusions**	**QualSyst score (%)**
Flexner et al. (1984)[35]	Y	Y	P	N	N/A	N/A	N/A	P	P	N	N	Y	P	Y	55
Fritsch et al. (2011)[36]	Y	Y	Y	Y	N/A	N/A	N/A	Y	Y	Y	Y	Y	Y	Y	100
Gibb et al. (2016)[9]	Y	Y	Y	Y	N/A	N/A	N/A	Y	Y	Y	Y	P	Y	Y	95
Gill (1992)[37]	P	P	Y	Y	N/A	N/A	N/A	P	Y	P	Y	P	Y	Y	77
Gill et al. (1996)[38]	Y	Y	Y	Y	N/A	N/A	N/A	P	Y	N	Y	N	Y	Y	77
Golden et al. (1985)[39]	Y	Y	Y	Y	N/A	N/A	N/A	Y	Y	P	Y	N	Y	Y	86
Li et al. (2014)[40]	Y	Y	P	Y	N/A	N/A	N/A	Y	Y	Y	Y	P	Y	Y	91
Malik et al. (2016)[41]	Y	Y	Y	Y	N/A	N/A	N/A	Y	Y	Y	Y	P	Y	Y	95
Rewers et al. (2002)[42]	Y	Y	Y	Y	N/A	N/A	N/A	Y	Y	Y	Y	P	Y	Y	95

Table 2. *Continued*

	Objective	**Design**	**Subject selection**	**Subject characteristics**	**Random allocation**	**Investigator blinding**	**Subject blinding**	**Outcomes**	**Sample size**	**Analytic methods**	**Estimate of variance**	**Confounds**	**Results**	**Conclusions**	**QualSyst score (%)**
Vakharia et al. (2020)[43]	Y	Y	Y	Y	N/A	N/A	N/A	Y	P	Y	Y	P	Y	Y	91
White et al. (1984)[44]	Y	Y	P	Y	N/A	N/A	N/A	P	P	P	P	N	Y	Y	68
Wright et al. (2009)[45]	Y	Y	Y	Y	N/A	N/A	N/A	P	Y	Y	N	P	Y	Y	82
Zhong et al. (2018)[11]	Y	Y	Y	Y	N/A	N/A	N/A	Y	Y	P	Y	P	Y	Y	91

Key: Y: Yes (score= 2)
P: Partial (score= 1)
N: No (score= 0)
QualSyst score: (total sum ÷ total possible sum) x 100

3.4 | Synthesis of results

In considering the main findings across studies with regards to the relationship between psychosocial factors and repeat diabetic ketoacidosis, themes were identified around age, gender, ethnicity, socioeconomic status, mental health difficulties, family-related factors, and social and behavioural issues (in children and young people). The main findings pertaining to each theme are synthesised in turn.

3.4.1 | Age

Of the 22 studies, 12 investigated the relationship between age and repeat diabetic ketoacidosis.[11,29,31-34,37-39,41,43,45] A significant association between these two factors was observed in eight studies, with results suggesting that diabetic ketoacidosis generally appears to be most common amongst adolescents and younger adults. Indeed, in their comparison of paediatric and adult populations, Everett and Mathioudakis[33] observed that the odds of repeat diabetic ketoacidosis increased with age for paediatric participants, and decreased with age for adult participants, with a 29% decrease in odds of four or more episodes for each increase in age bracket in adult participants. In studies of mixed-age participants, repeat diabetic ketoacidosis was associated with younger age.[38,45] The same was true of studies concerning only adult populations.[34,11] The inverse was true of studies focusing on children and young people,[41,43] with a recent study suggesting that individuals aged 15 and over had 60% more admissions for repeat diabetic ketoacidosis than those under 15.[43] Furthermore, studies comparing the recurrence of differing diabetes complications in adults found that people who experienced repeat diabetic ketoacidosis were generally younger than those who experience other repeat complications such as recurrent hypoglycaemia.[37,38] However, three studies did not find a significant relationship between age and diabetic ketoacidosis. One of these studies included adult participants only, though this study did not report on the age range of participants,[31] and the remaining two concerned only children and young people. One of these included only a narrow age range of participants (9-16 year olds)[32] and the other concerned only participants aged 7 and under.[39] Interestingly, a large prospective cohort study also found no psychosocial predictors of repeat diabetic ketoacidosis for the youngest participants in their study.[42]

3.4.2 | Gender

Fourteen studies investigated the association between gender and repeat diabetic ketoacidosis.[9,25,28,29,31-34,36,38,39,40,41,45] The majority of studies (*n*=11) found that repeat diabetic ketoacidosis was more common in females than males, and this effect was observed across studies concerning children and young people,[25,28,29,32,36,41] adult populations,[34,40] and mixed-age studies.[33,38,45] Of these studies, two directly discussed the interplay between age and gender in repeat diabetic ketoacidosis. In their study of 1676 children and young people aged 0-18, Cohn et al.[29] observed the largest female excess in repeat diabetic ketoacidosis in adolescents. Furthermore, in their direct comparison of adult and paediatric populations, Everett and Mathioudakis[34] observed that, whilst the odds of repeat diabetic ketoacidosis were 1.51 times higher for female adults, they were 2.31 times greater for female children and young people. Indeed, in those studies reporting on the odds of repeat diabetic ketoacidosis, odds estimates range between 1.47 and 2.31 times greater for female children and young people[25,33] and 1.4 and 1.51 in adult females.[33,34] Conversely, three studies observed no significant relationship between gender and repeat diabetic ketoacidosis. One of these studies focused on children aged 7 years and under,[39] one on just adults aged 18 and over,[31] and one did not report on age of participants.[9]

3.4.3 | Ethnicity

The role of ethnicity in repeat diabetic ketoacidosis was considered in three studies.[36,41,43] These studies included only children and young people, with all participants aged 21 and under. In one study comparing individuals with zero episodes of repeat diabetic ketoacidosis with those who had experienced three or more episodes, a higher proportion of people who were non-Hispanic black were observed in the repeat group (46.5% as compared to 16.1% in the zero episode group).[41] Furthermore, in univariate analysis, Vakharia et al.[43] observed that non-Hispanic black individuals experienced 80% more admissions for repeat diabetic ketoacidosis than non-Hispanic white individuals. However, this association was not significant at multivariate analysis (P=0.2). Finally, Fritsch et al.[36] used ‘migration background’ as a proxy for ethnic minority status and determined that those from a ‘migration background’ were more likely to experience repeat diabetic ketoacidosis, However, ‘migration background’ may be considered a poor proxy for ethnic minority status as it was defined by having at least one parent born outside of the locality – this definition could be critiqued for failing to consider migration by individuals who are not from an ethnic minority background.

3.4.4 | Socioeconomic status

Thirteen studies explored the impact of socioeconomic status on repeat diabetic ketoacidosis.[9,25,33-35,39-45] Socioeconomic status was inferred through a variety of means across studies, including; the neighbourhood participants lived in,[9,25,33] social class,[35,45] income[31,34,40,44,] and, where applicable, insurance status.[33,34,39,41-43] Regardless of how socioeconomic status was estimated, a significant association between low socioeconomic status and repeat diabetic ketoacidosis was observed in 11/13 studies across populations of children/young people and adults. Although most of these studies were based in the US,[33,34,39,41-44] two were UK-based,[9,45] suggesting that this association is not solely a function of healthcare costs. Conversely, no association was found between socioeconomic status and repeat diabetic ketoacidosis in two studies.[32,40] However, one of these studies included only nine participants who experienced repeat diabetic ketoacidosis[32].

3.4.5 | Mental health difficulties

Ten studies investigated the association of mental health difficulties with repeat diabetic ketoacidosis.[9,26,30,31,35,37,41,42,44,45] Of these, the outcomes of eight were supportive of a link between poorer mental health and increased likelihood of repeat diabetic ketoacidosis, across both child/young people and adult populations. Most studies concerned mental health difficulties in a broad sense, thus reporting on general outcomes such as 'psychiatric symptoms or disorders',[26,42] 'diagnosed neuroses',[35] 'mental health comorbidity',[41] or 'psychological problems'.[45] On the other hand, Gibb et al.[9] observed an increase in antidepressant use across participants with one episode of repeat diabetic ketoacidosis (12.6%), those with two to four episodes (27.8%), and those with four or more (47.5%, P=0.001). Two further studies considered more specific mental health difficulties and observed that people who experienced repeat diabetic ketoacidosis may be more likely to experience difficulties with depression, low self-esteem, anxiety and 'personality disturbances'.[37,44] However, those outcomes were observational in nature and thus have limited generalisability. Conversely, two studies reported no significant association between mental health difficulties and repeat diabetic ketoacidosis: in their study of young people and adults, Cooper et al.[30] observed no significant difference between people with single and repeat diabetic ketoacidosis with regards to comorbid psychiatric illness, alcohol or substance abuse. Furthermore, in an adult population, Del Degan et al.[31] observed no differences between individuals with repeat and single episodes with in terms of presence of an eating disorder and, whilst diagnosis of a psychiatric illness and alcohol/illicit drug use were identified as risk factors for repeat diabetic ketoacidosis in bivariate regression, these findings did not retain statistical significance in multivariate analyses.

3.4.6 | Family-related factors

Four studies explored family-related factors and repeat diabetic ketoacidosis.[11,32,37,44] Three of these included only participants under the age of 21[11,32,44] and one did not report participant ages.[37] Three of these studies were of relatively low quality as determined by the QualSyst and qualitative critical appraisal, consisting of small sample sizes and occasional ambiguity with regards to the operationalisation of psychosocial outcomes. They were also amongst the oldest studies in the review, published between 1984 and 1995. Across these studies, repeat diabetic ketoacidosis was associated with higher levels of difficulty on the family-level, including greater conflict and problematic parenting styles.[32,37,44] However, the methodological limitations of these studies are such that the generalisability of these findings is limited. A more recent study by Vakharia et al.[43] found that children and young people with a family history of diabetes experienced 50% more episodes of repeat diabetic ketoacidosis than those with no family history, and noted that this relationship was not explained by type of family diabetes, how closely related the family members were, nor these family members living in the same household.

3.4.7 | Social and behavioural issues in children and young people

Three of the 22 studies considered social and behavioural factors associated with repeat diabetic ketoacidosis.[32,35,44] Two of these concerned children and young people only: White et al.[44] observed what they termed ‘behavioural problems’ in the majority of participants in their study, all of whom were living with ‘poorly managed insulin-dependent diabetes’. These problems included truancy, oppositional or antisocial behaviour, and difficulties getting along with peers. However, these observations were of a descriptive nature only. Similarly, Dumont et al.[32] observed that, in females, there were significant associations between repeat diabetic ketoacidosis and both ‘internalising’ and ‘externalising behaviour problems’, and poorer peer relationships. They also observed that, in male participants, repeat diabetic ketoacidosis was associated with more ‘mature defence mechanisms’ (ways of coping with uncomfortable thoughts or feelings[46]) such as altruism, intellectualisation and suppression.[32] Further, Flexner et al.[35] observed that people who experienced repeat diabetic ketoacidosis had, on average, spent fewer years in education than those with a single episode of diabetic ketoacidosis (8.1 years as compared to 10.1 years). However, compared to other studies within this review, the studies described here are older and of lower methodological quality. Again, methodological limitations limit the generalisations that may be made from these findings.

4 | DISCUSSION

Our systematic search yielded 22 studies investigating the psychosocial factors associated with repeat diabetic ketoacidosis. Considered as a whole, the evidence would seem to suggest that repeat diabetic ketoacidosis is most common amongst individuals who fall into the adolescent or young adult age bracket,[11,33,34,37,38,41,43,45] who are female,[25,28,29,32,33,34,36,38,40,41,45] who have backgrounds of lower socioeconomic status,[9,25,31,33,34,41-45] and whose psychological wellbeing is poorer.[9,26,35,37,41,42,44,45] Indeed, these factors have received the most research attention, and although the methodological quality of the studies from which these findings are derived is variable, the findings are relatively consistent across studies.

Evidence pertaining to the remaining themes identified across studies was less consistent and had received less research attention. Three studies considered the relationship between ethnicity and repeat diabetic ketoacidosis.[36,41,43] Whilst these studies were amongst those with the highest methodological rigour included within the review, and some association was found between being from an ethnic minority background and increased prevalence of repeat diabetic ketoacidosis across each of the studies, this association was not significant at multivariate analysis in one study,[43] and the operationalisation of how ethnic minority status was determined was considered problematic in another.[36] Additionally, a small number of studies suggested that repeat diabetic ketoacidosis in children and young people may be associated with difficulties on the family-level (including greater conflict and problematic parenting styles[32,37,44]) and at the individual-level in terms of social or behavioural difficulties (such as school truancy, antisocial behaviour and difficulties getting on with peers[32,44]). However, these studies were all conducted between 25 and 36 years ago and may therefore not be representative of today's children and young people. Furthermore, they received some of the lowest quality ratings of studies included in the review. Therefore, this review might tentatively surmise that being from an ethnic minority background and, for children and young people, having family and social or behavioural difficulties, may be associated with repeat diabetic ketoacidosis. However, these hypotheses require further investigation via studies with robust methodological rigour before any firm conclusions may be drawn.

This is the first systematic review of the literature pertaining to psychosocial factors and repeat diabetic ketoacidosis in people living with type 1 diabetes. The outcomes of this review are largely consistent with the conclusions drawn by previous non-systematic reviews in this area.[15,16] However, in contrast to previous reviews, the present review considers the outcomes only of studies specifically concerning individuals living with type 1 diabetes and *repeat* diabetic ketoacidosis, and also uses critical appraisals of study quality to determine how much weight to assign to the findings of studies. Consequently, we draw somewhat more tentative conclusions than those of previous reviews with regards to the specific types of mental health difficulty that may be associated with repeat diabetic ketoacidosis. Furthermore, the broad search strategy implemented in the present review has resulted in the inclusion of studies not referenced in previous reviews.[28,29,32,35,36,39-42,44,45]

The outcomes of the present review should be considered in the context of its limitations, both at the review-level and at the level of individual studies. Firstly, although steps were taken to assess inter-rater reliability with regards to the study's inclusion-exclusion criteria, the rigour of this review could have been strengthened by the inclusion of reliability checks at other stages of the review process, such as during data extraction or quality appraisal.[21] Secondly, few of the studies meeting inclusion criteria were prospective in design. As a consequence, there is currently limited evidence as to which, if any, psychosocial factors may predict repeat diabetic ketoacidosis. Thirdly, the outcomes of this review would have been strengthened by using meta-analytic procedures to pool data on each of the psychosocial factors. Meta-analysis would also have enabled risk of publication bias and selective reporting to be assessed for.[47] However, the heterogeneity between studies precluded meta-analysis and also made it difficult to synthesise findings in a concise and meaningful way at narrative review.

To expand on the previous point, considerable differences in the operationalisation of variables across studies were observed. As noted previously, there have been significant changes in the terminology used across diabetes research and clinical practice over the last 40-50 years.[16] To avoid omission of relevant studies due to changes in terminology, a small number of studies using terminology that would now be considered 'dated' ('brittle diabetes', 'insulin-dependent diabetes mellitus') were included in the review, despite these terms not forming part of the search strategy. Furthermore, the inclusion of those terms may have resulted in the data of individuals living with type 2 diabetes being included in the study. The conceptualisation of repeat diabetic ketoacidosis also varied widely across studies. These differences have important implications for comparability across studies; studies considering two episodes of repeat diabetic ketoacidosis across a ten-year study period may be capturing a different phenomenon to studies concerning two episodes within one year. Future studies in this area would benefit from consistency in the operationalisation of repeat diabetic ketoacidosis. One option may be to group participants according to lifetime frequency of diabetic ketoacidosis. For example, Everett and Mathioudakis[33,34] grouped participants in groups of zero repeat episodes, 1-3 repeat episodes, and 4 or more episodes. They based this on the convention of Gibb et al.,[9] citing the stark increases in mortality across these groups as justification for considering them in this way. A final important observation regarding the operationalisation of variables concerns the ways in which psychological distress was measured across studies. The most robust studies typically relied on diagnostic criteria and appear to have been conducted by experts in the field of medicine and physical health. This may mean that the true level of psychological difficulty experienced is underrepresented, as diagnostic labels may not adequately capture the nuances associated with psychological distress.[48] Consequently, future research in this area may benefit from collaboration with mental health professionals.

Despite its limitations, the findings of this review have important implications for clinical practice and future research. Some research implications have already been highlighted, though future researchers may also wish to investigate the ways in which the psychosocial factors associated with repeat diabetic ketoacidosis may interact with one another to exacerbate its recurrence. A further area for consideration might be the role of adverse childhood experiences in repeat diabetic ketoacidosis: A significant association was recently observed between adverse childhood experiences and higher hbA1c scores in children and young people living with type 1 diabetes.[49] Concerning clinical implications, it is worth noting that, despite the considerable medical advances in diabetes management over the period of time covered by the studies in this review,[10,16] the psychosocial factors associated with repeat diabetic ketoacidosis appear to have remained constant. Consequently, diabetes teams may wish to more closely monitor and support individuals who have the following factors present: female gender, adolescent to young adult age range, low socioeconomic status and/or mental health difficulties. Furthermore, interventions targeted at reducing repeat diabetic ketoacidosis in such individuals are implicated, though the content of such interventions would benefit from further research aimed at exploring *why* these factors are associated with repeat diabetic ketoacidosis.[16] Finally, given that mental health is a dynamic factor amenable to intervention, our findings highlight the importance of widening access to mental health support for individuals living with type 1 diabetes.

In conclusion, there is relatively consistent evidence to suggest that repeat diabetic ketoacidosis in type 1 diabetes is associated with female gender, adolescent to young adult age range, lower socioeconomic status, and the presence of psychological difficulties. There is a small body of evidence to suggest that being from ethnic minority heritage and, for children and young people at least, having family and social or behavioural difficulties, may also be associated with repeat diabetic ketoacidosis. However, no firm conclusions can be drawn from these latter findings due to issues around methodological rigour and scant research. Future research would benefit from clear and consistent operationalisation of variables, as well as aiming to investigate more specifically the nature of psychosocial difficulties that may be associated with repeat diabetic ketoacidosis, as well as *why* this may be the case. Nevertheless, the existent evidence base may be used to inform enhanced monitoring of ‘at risk’ groups for repeat diabetic ketoacidosis, as well as to advocate for the importance of mental health professional involvement in type 1 diabetes services.

FUNDING

None. This review was undertaken as part of a doctoral research project.

CONFLICTS OF INTEREST

No potential conflict of interest to declare.

References

1. Umpierrez GE, Kitabchi A. Diabetic ketoacidosis: Risk factors and management strategies. *Treatments in Endocrinology*. 2003;2(2):95-108. https://doi.org/10.2165/00024677-200302020-00003
2. Kitabchi AE, Umpierrez GE, Miles JM, Fisher JN. Hyperglycaemic crises in adult patients with diabetes. *Diabetes Care*. 2009;32(7):1335-1343. https://doi.org/10.2337/dc09-9032
3. Barski L, Nevzorov R, Jotkowitz A, et al. Comparison of diabetic ketoacidosis in patients with type 1 and type 2 diabetes mellitus. *The American Journal of the Medical Sciences*. 2013;345(4):326-330. https://doi.org/10.1097/MAJ.0b013e31827424ab
4. Newton CA, Raskin PR. Diabetic ketoacidosis in type 1 and type 2 diabetes mellitus: Clinical and biochemical differences. *Archives of Internal Medicine*. 2004;164(17):1925-1931. https://doi.org/10.1001/archinte.164.17.1925
5. Dhatariya KK, Glaser NS, Codner E, Umpierrez GE. Diabetic ketoacidosis. *Nature Reviews Disease Primers*. 2020. https://doi.org/10.1038/s41572-020-0165-1
6. Fazeli Farsani S, Brodovics K, Soleymanlou N, Marquard J, Wissinger E, Maiese BA. Incidence and prevalence of diabetic ketoacidosis (DKA) among adults with type 1 diabetes mellitus (T1D): A systematic literature review. *British Medical Journal Open*. 2017. https://doi.org/10.1136/bmjopen-2017-016587
7. Brink SJ. Diabetic ketoacidosis. *Acta Paediatrica*. 1999;88(427):14-24. https://doi.org/10.1111/j.1651-2227.1999.tb14335.x
8. Livingstone SJ, Levin D, Looker HC, et al. Estimated life expectancy in a Scottish cohort with type 1 diabetes, 2008-2010. *Journal of the American Medical Association.* 2015;313(1):37-44. https://doi.org/10.1001/jama.2014.16425
9. Gibb FW, Teoh WL, Graham J, Lockman, KA. Risk of death following admission to a UK hospital with diabetic ketoacidosis. *Diabetologia.* 2016;59:2082-2087. https://doi.org/10.1007/s00125-016-4034-0
10. Evans K. Diabetic ketoacidosis: Update on management. *Clinical Medicine.* 2019;19(5):396-398. https://doi.org/10.7861/clinmed.2019-0284
11. Zhong VW, Juhaeri J, Mayer-Davis, EJ. Trends in hospital admissions for diabetic ketoacidosis in adults with type 1 and type 2 diabetes in England 1998-2013: A retrospective cohort study. *Diabetes care*. 2018;41(9):1870-1877. https://doi.org/10.2337/dc17-1583
12. Skinner TC. Recurrent diabetic ketoacidosis: Causes, prevention and management. *Hormone Research*. 2002;57:78-80. https://doi.org/10.1159/000053320
13. Dhatariya KK, Skedgel C, Fordham R. The cost of treating diabetic ketoacidosis in the UK: a national survey of hospital resource use. *Diabetic Medicine*. 2017;34(10):1361-1366. https://doi.org/10.1111/dme.13427
14. Dhatariya KK, Parsekar K, Skedgel C, Datta V, Hill P, Fordham R. The cost of treating diabetic ketoacidosis in an adolescent population in the UK: a national survey of hospital resource use. *Diabetic Medicine*. 2019;36(8):982-987. https://doi.org/10.1111/dme.13893
15. Brandstaetter E, Bartal C, Jotkowitz I, Barski L. Recurrent diabetic ketoacidosis. *Archives of Endocrinology and Metabolism*. 2019;63(5):531-535. https://doi.org/10.20945/2359-3997000000158
16. Garrett CJ, Choudhary P, Amiel SA, Fonagy P, Ismail K. Recurrent diabetic ketoacidosis and a brief history of brittle diabetes research: Contemporary and past evidence in

diabetic ketoacidosis research including mortality, mental health and prevention. *Diabetic Medicine.* 2019;36(11):1329-1335. https://doi.org/10.1111/dme.14109

17. Ehrmann D, Kulzer B, Roos T, Haak T, Al-Khatib M, Hermanns N. Risk factors and prevention strategies for diabetic ketoacidosis in people with established type 1 diabetes. *Lancet Diabetes Endocrinology.* 2020;8(5):436-446. https://doi.org/10.1016/S2213-8587(20)30042-5
18. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *British Medical Journal.* 2009. https://doi.org/10.1136/bmj.b2535
19. Tattersall R. Brittle diabetes. *Clinics in Endocrinology and Metabolism*. 1977;6(2):403-419. https://doi.org/10.1016/s0300-595x(77)80045-5
20. Gill GV, Walford S, Alberti KGMM. Brittle diabetes – present concepts. *Diabetologia.* 1985;28(8):579-589. https://doi.org/10.1007/BF00281992
21. Belur J, Tompson L, Thornton A, Simon M. Interrater reliability in systematic review methodology: Exploring variation on coder decision-making. *Sociological Methods & Research.* 2018. https://doi.org/10.1177/0049124118799372
22. Kmet LM., Lee RC, Cook LS. *Standard quality assessment criteria for evaluating primary research papers from a variety of fields*. Edmonton, Canada: Alberta Heritage Foundation for Medical Research (AHFMR); 2004.
23. Katrak P, Bialocerkowski AE, Massy-Westropp N, Kumar S, Grimmer KA. A systematic review of the content of critical appraisal tools. *BMC Medical Research Methodology.* 2004. https://doi.org/10.1186/1471-2288-4-22
24. Jüni P, Witschi A, Bloch R, Egger M. The hazards of scoring the quality of clinical trials for meta-analysis. *Journal of the American Medical Association*. 1999;282(11):1054-60. https://doi.org/10.1001/jama.282.11.1054
25. Ampt A, van Gemert T, Craig ME, Donaghue KC, Lain SB, Nassar N. Using population data to understand the epidemiology and risk factors for diabetic ketoacidosis in Australian children with type 1 diabetes. *Pediatric Diabetes*. 2019;20(7):901-908. https://doi.org/10.1111/pedi.12891
26. Bryden KS, Dunger DB, Mayou RA, Peveler RC, Neil HAW. Poor prognosis of young adults with type 1 diabetes: A longitudinal study. *Diabetes Care.* 2003;26(4):1052-1057. https://doi.org/10.2337/diacare.26.4.1052
27. Derogatis LR. *SCL-90-R: Symptom checklist-90-R: Administration, scoring & procedures manual*. 3rd ed. Minneapolis, USA: National Computer Systems; 1994.
28. Cebeci AN, Guven A, Kirmizibekmez H, Yildiz M, Dursun F. Clinical features and management of diabetic ketoacidosis in different age groups of children: Children less than 5 years of age are at higher risk of metabolic decompensation. *Journal of Pediatric Endocrinology & Metabolism*. 2012;25(9-10):917-925. https://doi.org/10.1515/jpem-2012-0110
29. Cohn BA, Cirillo PM, Wingard DL, Austin DE, Roffers SD. Gender differences in hospitalisations for IDDM among adolescents in California, 1991: Implications for prevention. *Diabetes Care*. 1997;20(11):1677-1682. https://doi.org/10.2337/diacare.20.11.1677
30. Cooper H, Tekiteki A, Khanolkar M, Braatvedt G. Risk factors for recurrent admissions with diabetic ketoacidosis: A case-control observational study. *Diabetic Medicine.* 2015;33(4):523-528. https://doi.org/10.1111/dme.13004

31. Del Degan S, Dubé F, Gagnon C, Boulet G. Risk factors for recurrent diabetic ketoacidosis in adults with type 1 diabetes. *Canadian Journal of Diabetes.* 2019;43(7):472-476. https://doi.org/10.1016/j.jcjd.2019.01.008
32. Dumont RH, Jacobson AM, Cole C, et al. Psychosocial predictors of acute complications of diabetes in youth. *Diabetic Medicine*. 1995;12(7):612-618. https://doi.org/10.1111/j.1464-5491.1995.tb00551.x.
33. Everett E, Mathioudakis N. Association of area deprivation and diabetic ketoacidosis readmissions: Comparative risk analysis of adults vs children with type 1 diabetes. *Journal of Clinical Endocrinology and Metabolism*. 2019;104(8):3473-3480. https://doi.org/10.1210/jc.2018-02232
34. Everett E, Mathioudakis N. Association of socioeconomic status and DKA readmission in adults with type 1 diabetes: Analysis of the US National Readmission Database. *BMJ Open Diabetes Research & Care.* 2019. https://doi.org/10.1136/bmjdrc-2018-000621
35. Flexner CW, Weiner JP, Saudek CD, Dans PE. Repeated hospitalisation for diabetic ketoacidosis: The game of "Sartoris". *The American Journal of Medicine.* 1984;76(4):691-695. https://doi.org/10.1016/0002-9343(84)90297-3
36. Fritsch M, Rosenbauer J, Schober E, Neu A, Placzek K, Holl RW. Predictors of diabetic ketoacidosis in children and adolescents with type 1 diabetes: Experience from a large multicentre database. *Pediatric Diabetes*. 2011;12(4):307-312. https://doi.org/10.1111/j.1399-5448.2010.00728.x.
37. Gill GV. The spectrum of brittle diabetes. *Journal of the Royal Society of Medicine*. 1992;85(5):259-261.
38. 38. Gill GV, Lucas S, Kent LA. Prevalence and characteristics of brittle diabetes in Britain. *Quarterly Journal of Medicine*. 1996;89(1):839-843.
39. Golden MP, Herrold AJ, Orr DP. An approach to prevention of recurrent diabetic ketoacidosis in the pediatric population. *The Journal of Pediatrics.* 1985;107(2):195-200. https://doi.org/10.1016/s0022-3476(85)80124-4
40. Li J, Yang D, Yan B, Huang B, Zhang Y, Weng J. Secondary diabetic ketoacidosis and severe hypoglycaemia in patients with established type 1 diabetes in China: A multicentre registration study. *Diabetes Metabolism Research and Reviews*. 2014;30(6):477-504. https://doi.org/10.1002/dmrr.2547
41. Malik FS, Hall M, Mangione-Smith R, et al. Patient characteristics associated with differences in admission frequency for diabetic ketoacidosis in United States children's hospitals. *The Journal of Pediatrics*. 2016;171:104-110. https://doi.org/10.1016/j.jpeds.2015.12.015
42. Rewers A, Chase HP, Mackenzie T, et al. Predictors of acute complications in children with type 1 diabetes. *Journal of the American Medical Association*. 2002;287(19):2511-2518. https://doi.org/10.1001/jama.287.19.2511
43. Vakharia JD, Agrawal S, Molino J. Family history of diabetes is associated with increased risk of recurrent diabetic ketoacidosis in pediatric patients. *Endocrine Practice*. 2020;26(3):305-311. https://doi.org/10.4158/EP-2019-0351
44. White K, Kolman ML, Wexler P, Polin G, Winter RJ. Unstable diabetes and unstable families: A psychosocial evaluation of diabetic children with recurrent ketoacidosis. *Pediatrics*. 1984;73(6):749-755.
45. Wright J, Ruck K, Rabbitts R, et al. Diabetic ketoacidosis (DKA) in Birmingham, UK 2000-2009: An evaluation of risk factors for recurrence and mortality. *The British*

Journal of Diabetes and Vascular Disease. 2009;9(6):278-282. https://doi.org/10.1177/1474651409353248

46. Freud A. *The Ego and the Mechanisms of Defence*. London, England: Hogarth Press; 1937.
47. Borenstein M, Hedges LV, Higgins JPT, Rothstein HR. *Introduction to Meta-Analysis.* Chichester, England: John Wiley & Sons, Ltd; 2009.
48. Johnstone L, Boyle M, Cromby J, et al. *The power threat meaning framework: Towards the identification of patterns in emotional distress, unusual experiences and troubled or troubling behaviour, as an alternative to functional psychiatric diagnosis*. Leicester, England: British Psychological Society; 2018.
49. Iqbal AM, Kumar S, Hansen J, Heyrman M, Spee R, Lteif A. Association of adverse childhood experiences with glycaemic control and lipids in children with type 1 diabetes. *Children*. 2020. https://doi.org/10.3390/children7010008

Chapter 2 – Empirical Study

Understanding how Expert by Experience Activity Empowers Young Adults Living with Type 1 Diabetes: A Grounded Theory Approach

Bethan Allcock[a], Rose Stewart[b]* and Mike Jackson[a]

[a]North Wales Clinical Psychology Programme, School of Psychology, Bangor University, Bangor, UK; [b]Young Adult Diabetes Service, Wrexham Maelor Hospital, Betsi Cadwaladr University Health Board, UK.

*Corresponding author. Email: Rose.Stewart@wales.nhs.uk

This paper has been prepared in accordance with the submission guidelines for *Psychology & Health:*

https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=gpsh20

Understanding how Expert by Experience Activity Empowers Young Adults Living with Type 1 Diabetes: A Grounded Theory Approach

Objective: There are well-recognised service-level benefits associated with the involvement of service users in expert by experience activity. However, little is known about the impact of such involvement on the experts by experience themselves. This study aimed to develop a conceptual model of the personal impact of expert by experience activity for young adults living with type 1 diabetes.

Design: Seven people meeting the study criteria participated in semi-structured interviews. Interviews were analysed using the Grounded Theory Method.

Results: A theory of empowerment through expert by experience activity was developed. It suggested that involvement in expert by experience activity is associated with empowerment in relation to an individual's psychological wellbeing, social relationships, and condition management. Through processes of empowerment across these areas, individuals experience an enhanced sense of autonomy, control, and independence.

Conclusion: Engagement in expert by experience activity may enhance psychological wellbeing and condition management for young adults living with type 1 diabetes. Given the well-established benefits of such involvement on a service-level also, services may wish to consider how they might expand their programme of expert by experience involvement for the benefit of all stakeholders.

Keywords: expert by experience; patient involvement; type 1 diabetes; young adults; empowerment; grounded theory

Introduction

Over the last 50 years, there has been a shift away from conceptualising people with lived experience of mental or physical health difficulties as passive recipients of services, towards recognising that people are actively involved consumers (or users) of services (Andreassen, 2018). There is growing recognition that people who have used such services are 'experts by experience' (EbE), with valuable perspectives that can be used to inform service delivery (Division of Clinical Psychology, 2018). In the UK, EbE involvement is a policy priority and is becoming increasingly incorporated throughout various levels of decision making and service delivery (Department of Health, 2007; Noorani, 2013). Across health and social care services, EbE involvement is most common in areas such as research, service evaluation, service development, staff recruitment, and staff education (Higgins et al., 2011; Simpson & House, 2002; Thornicroft & Tansella, 2005). Whilst the rate of expansion of EbE involvement has been rather slow (Rooke et al., 2014), EbE involvement is generally regarded positively by both healthcare staff and the people who are EbE themselves (Omeni et al., 2014).

Existent research regarding EbE activity is typically concerned with the impact on a service-level, predominantly focusing on the training of staff and research activity. For instance, the delivery of teaching by people who are EbE has been demonstrated as crucial to the learning experiences of healthcare staff (Schreur et al., 2015; Terry, 2012). Indeed, most trainees report personal and professional benefit from EbE involvement in their education, citing that it motivates them to improve their practice and implement more person-centred ways of working (Khoo et al., 2004). Likewise, the involvement of EbE in research activity is experienced positively by most researchers (Thompson et al., 2009). Reported benefits of EbE involvement with research include: greater richness in research findings; enhanced participant recruitment; increased research funding and selection of more meaningful outcome measures (Domecq et al., 2014; Mjøsund et al., 2016).

In 2002, Crawford and colleagues observed a scarcity of research into the personal impact of EbE involvement (Crawford et al., 2002). Almost 20 years later such research remains scant. However, the emerging research base suggests that EbE activity may be associated with positive outcomes for the people who are EbE. Many describe the experience as validating and appreciate the opportunity to share their stories in a supportive environment (Barnes et al., 2006). EbE activity has also been associated with increased self-esteem and confidence (Repper & Breeze, 2007; Simpson et al., 2014), which in turn enhances the psychological wellbeing of people who are EbE (McKeown et al., 2012). Furthermore, some individuals report that talking through their experiences in this way has enabled them to gain new insights and attribute a retrospective sense of meaning to their discomfort or distress (Patterson et al., 2014; Walters et al., 2003). Although some people report that involvement in EbE activity can cause distress (for example, when met with a lack of compassion from those they are teaching), they still generally rate the experience positively overall (Patterson et al., 2014; Walters et al., 2003).

The above findings predominantly concern involvement by people accessing mental health services. There appears to be just one publication directly investigating the personal impact of EbE involvement for people living with physical health conditions. The study concerned individuals accessing cancer services, who reported that EbE involvement evoked a sense of achievement whilst reducing loneliness and low mood (Cotterell et al., 2011). There exists no published research into the personal impact of EbE involvement for people living with type 1 diabetes. Existing research in this area reports only on outcomes for diabetes services and research (e.g. Lindenmeyer et al., 2007; Murad et al., 2011). Living with chronic conditions such as type 1 diabetes is often burdensome, due to both its physical manifestations and its complex management regime (Tran et al., 2015). In the context of such burden, people commonly experience psychological distress (Naylor et al., 2012). This appears particularly pronounced in the young adult population, where the prevalence of mental health issues is much higher than in peers without diabetes (Cooper et al., 2017; Hislop et al., 2008). Further, across all individuals living with diabetes, young adults have by far the highest rates of emergency hospital admissions for serious diabetes complications (National Diabetes Transition Audit, 2019). Indeed, between the ages of 20 and 39, men and women living with diabetes face a mortality risk of 2.54 and 3.76 times higher than men and women without diabetes respectively, with much of this risk carried by those living with type 1 diabetes (Holman, 2008). Thus, while chronic conditions contribute to psychological distress, psychological distress also contributes to poor condition management (Brady et al., 2013). Consequently, services need to take all possible opportunities to boost the psychological wellbeing of young adults living with diabetes. Anecdotal clinical observations by one of the authors (RS) suggest that EbE involvement by young adults living with type 1 diabetes may contribute to reduced distress, improved condition management, and increased self-esteem for the young adults, who often describe the experience as ‘life-changing’.

This investigation aims to explore if – and how - EbE activity by young adults living with type 1 diabetes impacts on psychological wellbeing, self-perception, and condition management. Given the dearth of extant theory and research in this area, a qualitative, theory-building approach was deemed appropriate to explore these issues. This investigation appears particularly timely, given the recent recommendations that qualitative diabetes researchers should focus on “how people with diabetes can make positive psychosocial adaptations to diabetes” (Stuckey & Peyrot, 2020, p. 502).

Methods

Design

A grounded theory design was selected given this study’s aim to go beyond exploration and description of EbE involvement, to develop a theory that might *explain* the processes by which it has a personal impact (if any). Corbin and Strauss’ (2015) grounded theory approach was selected due to the scaffolding it offers the neophyte grounded theory researcher (Polacsek et al., 2018). Furthermore, its epistemological underpinnings align with the world views of the first author (see reflexive statement).

Ethical Considerations

This study was granted ethical approval by the Research Ethics Committees of the local University and NHS and was registered with the local NHS health board’s Research and Development department (Appendices C-F). All participant materials (Appendices G-H) were reviewed by a member of the EbE Panel for the local Clinical Psychology training course. No deception was involved in the study; participants were fully informed of the study aims from the outset and written confirmation of informed consent was obtained. Participants were advised that their participation was entirely voluntary, though they were given a £15 voucher in recompense for their time. Participants were also reassured that they did not have to respond to any questions they did not want to, that they could take breaks if needed, and that they could withdraw their data for any reason until the end of March 2020.

Participant Recruitment

This study sought to recruit young adults living with type 1 diabetes, who were aged between 16 and 35 and who had used their lived experience to inform the work of UK healthcare professionals working in diabetes services (for example, public speaking, staff training, service development). There were no exclusion criteria with regards to duration/frequency of EbE involvement. Two recruitment methods were employed. In the first instance, potential participants accessing local NHS diabetes services were provided with study information by a member of their healthcare team. The study was also advertised via social media, where people with type 1 diabetes have a strong online presence (Hilliard et al., 2015). Participants were required to self-select for the study by contacting the first author for further information.

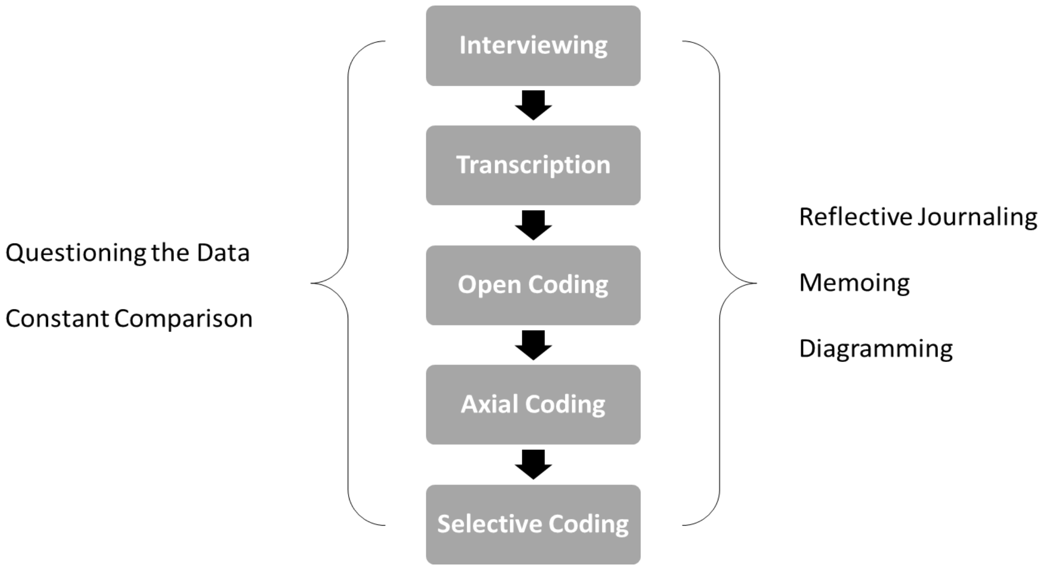
Data Collection

Study data were generated through semi-structured interviews conducted by the first author between December 2019 and March 2020. The interviews lasted between 40 and 90 minutes (*M*=56.43 minutes). Two were face-to-face (one on NHS premises, one at the participant’s home) and five were via video conferencing. The interviews loosely followed an interview guide containing broad topic areas and open questions aimed at generating detailed responses (Appendix I). Participants were asked about their experiences of acting as an EbE, the impact this may have had on them personally, and how this may have impacted on their condition management. Interviews were flexible to follow up on unanticipated areas of enquiry introduced by participants. As the process of grounded theory is iterative in nature, the content of the interview guide was shaped to follow up on the content of preceding interviews and emerging themes within the data. Interviews were audio-recorded and additional observations made during interviews were documented in field notes. In addition, reflections on the research process were recorded in a journal kept by the first author.

Analysis

Interviews were anonymously transcribed, coded and analysed by the first author. In line with the grounded theory method (Corbin & Strauss, 2015), data collection and analysis ran in parallel, and each interview was analysed prior to the next wherever practicable. For pragmatic reasons such as participant availability, it was not always possible to complete analysis between every interview. In such instances, the next interview's guide was nevertheless shaped by observations made in the field notes and reflective journal. Due to the iterative nature of the grounded theory method, data analysis does not progress in a linear fashion (Birks & Mills, 2015); however, the process is described here in stages for ease of reporting, and represented diagrammatically in Figure 1.

Figure 1. The Analytic Process



Transcribed data first underwent open coding. During this process, transcripts were considered on a line-by-line basis and conceptual labels were applied to reflect what appeared to be represented by the data. As noted by Saldaña (2015), this intensive process enables researchers to immerse themselves in the data and become sensitised to its nuances. Through this process, instances in the data concerning similar issues were grouped together and the properties and dimensions of these concepts were explored and expanded. Participant recruitment continued until theoretical saturation appeared to have been achieved. Indeed, the concepts (and their associated properties and dimensions) observed in the final two interviews already appeared to be represented by the existing data. Consequently, it appeared that further data collection would no longer add properties or dimensions to existing concepts (Dey, 2007).

Axial coding was used to code for context and process within the data (for example, identifying which events or circumstances may lead to certain actions or interactions by participants, and the consequences of these). In this way, connections were identified between the concepts identified during open coding. As noted by Corbin and Strauss (2015), the identification of context and process is an essential element in elevating the research findings from the level of description to explanation, a necessary component of theory building. Higher level categories linking lower level concepts were also identified. Over the course of analysis, a core category emerged, representing the main theme of the research. During the final stage of selective coding, the other categories in the data were linked to the core concept via a series of relational statements and interview transcripts were revisited with the core category in mind to ensure that this category was evident across the dataset.

Throughout the processes outlined above, a series of analytic tools as detailed by Corbin and Strauss (2015) were implemented. These tools included ‘questioning the data’ (for example, ‘what is going on here?’) and constant comparison (a process by which instances of data were compared for similarities and differences, with conceptually similar data grouped together under the same conceptual labels). Additionally, the whole analytic process was documented in written memos and diagrams aimed at developing concepts in terms of their properties and dimensions and denoting relationships between concepts (Appendix J).

Author Epistemological and Reflexive Statement

Data collection and analysis were conducted by the first author. This process was approached from the epistemological stance that, whilst an independent reality may exist, there are limitations to the extent to which researchers may be able to accurately capture and convey that reality due to the inevitable influence of researcher subjectivity (Corbin & Strauss, 2015). To position the first author within this research, she is a white, straight, female, trainee clinical psychologist, of a similar age to some of the participants and with no chronic physical health conditions. She entered into the research process with minimal knowledge regarding the physical and psychological implications of living with type 1 diabetes and deliberately abstained from immersing herself in the literature around this to avoid entering the process with pre-existing biases and assumptions regarding how EbE activity may impact on people living with type 1 diabetes. The author highly values co-production and EbE involvement, which is reflected by the choice of grounded theory methodology - she wanted the research findings to be grounded in the words of participants. The author's positioning may have implications for the identification and/or articulation of concepts pertinent to the participants with which she has limited experience. Furthermore, the concepts generated during the coding process may have been influenced by the author's conviction related to the importance and utility of EbE involvement.

Quality Assurance

To promote research quality and integrity, the first author kept a reflective journal during the data collection and analysis process. This journal was used to maintain self-awareness and to monitor for biases and assumptions. Furthermore, the methods of constant comparison and questioning the data are conceptualised as built-in checks and balances designed to ensure consistency in how the data is treated, and that a broad range of possible meanings of data are considered (Corbin & Strauss, 2015); these methods were adhered to throughout the research process. In addition, concepts within the data and the excerpts in which they were grounded were shared with the co-authors for purposes of triangulation and to ensure that aspects of the data were not over-stated. Finally, member-checking was used, whereby a draft of the theory was shared with each participant for validation (Corbin & Strauss, 2015). Participants were advised that provision of feedback was optional and two of the seven responded to this request. Participant feedback was positive, and respondents indicated that the model captured meaningful processes for them. No suggestions for amendments were made by participants.

Results

Participants

Seven participants were recruited into the study: two via their healthcare team and five via social media. There were four females and three males. Participants were aged between 25 and 35 (M=29.43 years) and had been living with type 1 diabetes for between 5 and 29 years (M=15 years). The nature of EbE involvement varied across participants, with some involved in more than one type of activity. Their EbE activities included: public speaking to healthcare professionals (n=4); panel membership (for diabetes services, training programmes and staff interviews, n=4); service improvement projects (n=2); resource development (n=2); establishing peer support groups (n=2); campaigning for healthcare policy change (n=1); and teaching healthcare professionals (n=1). One participant's involvement was on a 'one-off' basis, whilst the others were involved on an ongoing basis (duration of involvement ranged between 8 months and 6 years; M=29.83 months).

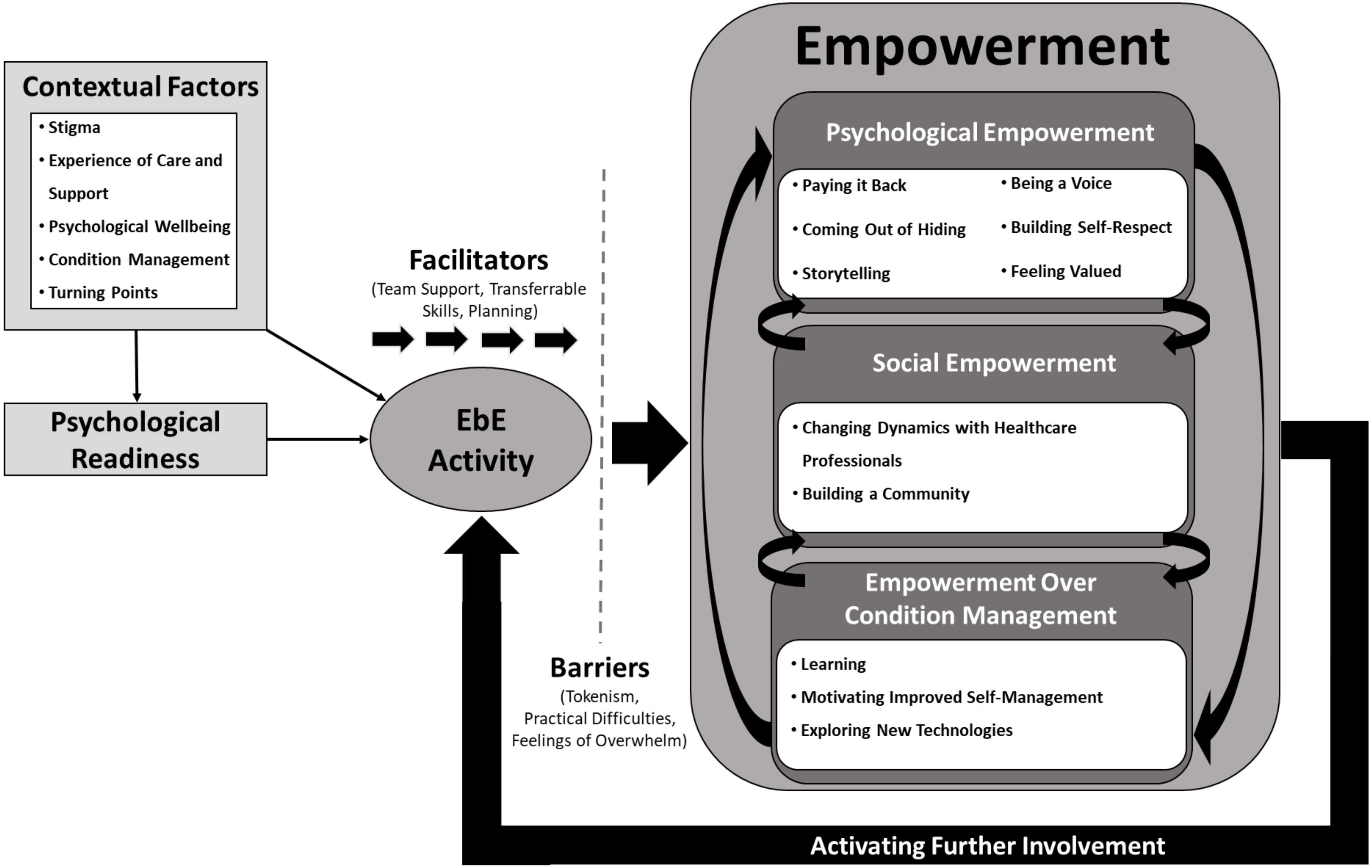
The Core Category - Empowerment

Application of the above described procedures led to the development of a theory of empowerment through EbE activity. The processes involved in this theory are represented in Figure 2. The core category of the theory is *empowerment.* This category of *empowerment* is observed throughout the study and denotes both the processes and the outcomes with regards to how involving young adults living with type 1 diabetes in EbE activity impacts on their self-perception and condition management. In other words, the process through which EbE activity impacts on participants is empowerment, but it is also the end-product. Ultimately, the theory demonstrates that EbE activity may lead to increased confidence, autonomy, and control for young adults, across many different areas of their lives. The core category of *empowerment* is underpinned by three subcategories, each of which represents a different element of empowerment: *psychological empowerment; social empowerment*, and *empowerment over condition management.* Each subcategory is underpinned by different concepts and processes which explain the impact of EbE activity within that subcategory (see Appendix K for illustrative quotations). Although each subcategory represents a distinct element of *empowerment*, they are linked to one another. As processes or changes occur within one subcategory, they also impact on other subcategories. This will be discussed in further detail, but it is first important to address the setting events and processes which lead into EbE activity, thus allowing for *empowerment* to develop.

Contextual Factors

The contextual factors within which EbE activity is initiated, enacted, and experienced play a vital role in shaping the self-perception, experiences, and expectations of young adults prior to EbE activity. The main contextual factors highlighted by participants encompassed: *stigma* (associated with living with type 1 diabetes); *experience of care and support* (from their care team, family and friends); *psychological wellbeing*; *condition management*, and; *turning points* (i.e. the points at which, for a variety of different reasons, people become more engaged with their team and their condition management and/or psychological wellbeing improves). Each of these factors may be viewed as running along a continuum. As such, different people have different experiences prior to engagement with EbE activity.

Figure 2. A Grounded Theory of Empowerment through Expert by Experience Activity



Psychological Readiness

Many participants alluded to *psychological readiness* as a prerequisite for starting EbE involvement:

> *I was in a better place by the time I got to do a talk, uhh, not sure I could have done a talk if I was in a bad place anyway to be honest but yeah, so I was kind of making a bit of a journey there anyway* (Participant 3)

As referenced above, timing is key for *psychological readiness*; it is important that participants are in a 'better place' to be able to do EbE activity. For many, this *psychological readiness* appeared closely linked to *turning points* – being *ready* involves having improved psychological wellbeing (compared to the way things were for them before, it needed not be 'perfect') and greater confidence in their credibility as an EbE, as achieved through improved diabetes management (again, compared to the way things were for them before).

Facilitators

There are important factors which facilitate both engagement *and* empowerment via EbE activity. The main *facilitators* include: t*eam support* (being well supported by the team); *transferrable skills* (having existing skills that can be transferred into EbE activity, such as skills in public speaking), and; *planning* (feeling well prepared for the activity).

Barriers

Participants also identified factors which may serve as *barriers* to engagement and empowerment through EbE activity. The main *barriers* include: *tokenism* (being unable to effect meaningful change, not feeling listened to); *practical difficulties* (being asked difficult questions, feeling anxious), and; *feelings of overwhelm* (feeling overloaded with information, or the volume of work, or the experience of type 1 diabetes becoming 'all-consuming' due to living *and* working with it).

Psychological Empowerment

Psychological empowerment encapsulates the processes, actions, and interactions through which EbE activity impacts on emotional and psychological wellbeing. It comprises the following concepts: *paying it back; coming out of hiding; being a voice; storytelling; building self-respect* and *feeling valued.* Each is outlined in turn:

Paying it Back

Paying it back refers to the sense of contribution experienced through EbE involvement. Participants described that this was derived from two main contexts; as a way of acknowledging or thanking those that have helped them, *or* as a means of changing things so their discomfort or distress is given a sense of meaning:

> *My own team were there as well and uhh there was a bit of like a homage to them a little bit as well, especially my paediatric team… So it was like, it was a big thank you to them at that time* (participant 2)
>
> *It's really made me feel like actually diabetes can be used for a good thing and even though like it's such a negative draining illness that I- I hate more than anything, but actually I can still use it for good and help other people?... I just needed some positive spin on it you know, to get me though it? Umm I found it really empowering… it just makes you feel empowered and like you're helping other people, it's not just for me it kind of makes it a much bigger picture* (participant 5)

This sense of helping others and contributing to the greater good was associated with a sense of pride and achievement. It also contributed to a sense of being part of something that was bigger than the self, all of which was experienced as empowering by participants.

Being a Voice

Being a voice represents the notion of many participants that they are a mouthpiece to represent similar others. Power is an important feature within this concept, and there is a sense that, by being involved in EbE activity, one's voice is given privilege. This is experienced as an important responsibility, as there is a sense that, if they do not get involved in EbE activity, the voices of other young adults (for example, those who have quieter or weaker voices, or who not been given this opportunity) will not be represented:

> *You've just gotta keep going and just be a voice because if you're not a voice, or if you're not someone who can speak out, then who else is going to do it?* (participant 1)

Being a voice also links into the subcategory of *empowerment over condition management* because when they are empowered to use their voice, young adults become more confident. This increased confidence leads to using their voice more often and in different settings, such as the clinic room, in asking more confidently for the treatment they want.

Coming out of Hiding

Coming out of hiding refers to the process by which young adults deal with the stigma related to living with type 1 diabetes. Participants reported that EbE activity can provide a safe space for talking about life with type 1 diabetes, and this experience leads to a powerful sense of acceptance by others. This idea is illustrated in the excerpt below, which was the participant's response to being asked if EbE activity had led to any personal changes in their life:

> *I've probably just got more confidence. It's nice to be known, because hiding diabetes is hiding a huge part of my life… when you feel known and accepted anyway umm it's just a massive relief you know? So yeah, more confident. More me I think* (participant 5)

Participants described a sense of relief resulting from talking about type 1 diabetes through EbE activity, which in turn was associated with participants treating themselves more kindly, feeling more comfortable in their identity as a person living with type 1 diabetes, increasing their confidence, leading them to worrying less about the thoughts of others and experiencing decreased anxiety. All these gains empowered the young adults to longer need to hide their diabetes. This meant they could make better decisions about their diabetes management (as they did not feel the need to delay or conceal management tasks in public), thereby resulting in improved diabetes management. Given the social and condition management implications of *coming out of hiding*, this concept also links into the other two subcategories.

Building Self-Respect

This concept points to how self-respect is built through EbE activity. Self-respect is understood to develop as a consequence of EbE activity fostering awareness and acknowledgement of the following: that life with type 1 diabetes can be really hard; that it is okay not to be okay; that being invited to do EbE activity is an achievement and that one's sense of self can be separated from HbA1c results. (i.e. there is more to someone than their HbA1c number). Participants were also able to share past achievements and recognise that they may be exceeding their own expectations. This increased self-respect also increases self-compassion and confidence. Elements of this process can be observed in the following:

> *It was having the time to think about it and actually go 'wow, in the context of things I'm actually doing okay, I've got my GCSEs, I've got my A Levels on top of, you know, they say type 1 diabetes is a full time job, but its four and a half full time jobs before you've even had a job interview, you know, its relentless…. When you start to say things out loud you listen to yourself and it did give me a lot of confidence for me to realise that actually I do know what I'm talking about… it changed or switched something in the way I view myself* (participant 3)

Storytelling

Storytelling applies to a subset of participants who had the opportunity to 'tell their story' via EbE activity (by speaking fully about their lived experiences at conferences for example). There appears to be an additional benefit to this form of activity, in comparison to types of involvement during which the individual's story is not told (for example, sitting on a panel). According to participants, the process of preparing their story and then speaking it aloud led to numerous psychological benefits. It gave them an opportunity to 'process' their experiences in a way they had not previously been able to, which they likened to therapy:

> S*haring it was like therapy, and it has been a little bit like therapy, umm sharing some of my experiences, sharing some of the challenges, getting it out there* (participant 4)

Furthermore, telling the story was associated with increased ability to talk openly and thereby strengthened connections with significant others in the person's life. Consequently, this concept also feeds into *social empowerment.*

Feeling Valued

Feeling valued refers to the process through which EbE activity causes participants to feel appreciated. Participants identified that being invited become involved as an EbE made them feel valued. This was further enhanced by the subsequent gratitude and recognition of others. This empowers the individual psychologically via a sense of pride and achievement and is also linked with an increase in confidence. Echoes of this are evident in the following excerpt:

> *I feel quite proud. I'm like 'I'm going to the diabetic day' and everyone's like 'what's that' and I'm like 'oh just where we discuss things" [laughs] yeah its nice… It's like nice to feel appreciated isn't it? And like you are wanted... people want to include you and when we go everybody's opinions and values matter and everything's discussed together* (participant 6).

Social Empowerment

This subcategory denotes the ways in which EbE activity affects interpersonal relationships. It comprises: *changing dynamics with healthcare professionals* and b*uilding a community*.

Changing Dynamics with Healthcare Professionals

Changing dynamics with healthcare professionals refers to the notion that the relationship between individuals and their care teams are shaped by EbE involvement. Participants indicated that EbE activity changes the reciprocal understanding and respect between the young adult and their team. It causes a shift in the power dynamic, in the direction of the young adult holding an increasing share of the power:

> *They're your healthcare professionals but they're also sort of your colleagues, but not your colleagues? So you're working alongside of them instead of like [pause] uhh not under them, but like there's a different- like they seem to have an authority over you, like a headteacher or*

> *you know, your teacher at school? But then you're suddenly like colleagues cos you're working together on something* (participant 5)

This empowerment leads to changes in communication and engagement between young adults and their teams. Indeed, many young adults spoke of growing in confidence to be more assertive with their team; to ensure that their concerns were expressed, and their needs met:

> *I've gained a lot of confidence in being able to shift the agenda so I will go in and now I will say how I feel… it gave me confidence to say 'actually no, this is what I want'* (participant 3)

As alluded to above, the change in dynamic often results in improved access to person-centred care and thereby leads to improved diabetes management. Consequently, this concept links into e*mpowerment over condition management.*

Building a Community

Building a community denotes the ways in which EbE involvement can expand an individual's social network, both in person and on social media. Through either format, young adults experience a sense of belonging via the normalisation and validation associated with connecting to similar others:

> *It makes me feel more confident knowing there's others. So like we'd be talking about the same things and you're like, 'oh yeah, people do the same'… it boosts my confidence. It literally is by feeling like, not the only diabetic in the world. It's the acceptance of knowing there's other people around… it's like a sense of belonging* (participant 6)

Participants also learned about diabetes and its management from these peers. This notion is illustrated by the below excerpt, in which the participant is speaking of their experience of the online diabetes community (which they discovered through EbE involvement):

> *I don't know if it sounds silly, but it really keeps me in check because people get in touch with me and they ask me advice. And I ask other people advice. It's just like a whole community where- it's like you've got a whole bunch of friends really, even though you don't know these people, so that also made a big umm big difference for me* (participant 7)

As can be inferred from these excerpts, *building a community* impacts on psychological wellbeing (via reducing loneliness and increasing confidence) and diabetes management. Consequently, this concept feeds into the other two subcategories within the theory.

Empowerment over Condition Management

This final subcategory delineates the ways in which EbE activity impacts on how young adults and their teams manage their health condition. It is underpinned by: l*earning, motivating improved self-management* and *exploring new technologies.*

Learning

Learning denotes the process by which EbE activity may develop the young adult's understanding of diabetes. *Learning* can come about in many ways, including through listening to the contributions of other speakers at EbE events, or through doing research for the content of their own EbE activity. This generally leads to enhanced diabetes management. This may occur through different processes, such as increased confidence to ask for the treatment they want (their increased knowledge increases their confidence to ask about this). Alternatively, it may enhance diabetes management through facilitating an acceptance and respect for the condition. Given that this increased knowledge can empower young adults to engage differently with their team, this concept also maps onto the s*ocial empowerment* subcategory. An example of empowerment via *learning* is demonstrated below:

> *Because you're learning so much about things you constantly pick up things like even from with teaching sessions with [healthcare professional] umm you do kind of pick up some little things, like if [healthcare professional] says something then I'll kind of be like 'oh I've never heard of that' and like yeah we'll talk about it later and stuff like that… I think that's been the biggest thing with me is understanding diabetes more, being able to respect diabetes more cos unfortunately it [sigh] you have to accept it to move on* (participant 2)

Motivating Improved Self-Management

Motivating improved self-management concerns the processes through which EbE activity empowers young adults over their diabetes management, by increasing their motivation to manage their diabetes well. The processes by which this happened varied between participants, but their outcomes were nevertheless similar. For instance, in some participants the increased motivation was triggered by EbE activity putting them in closer contact with their teams. For others, it was exposure to the content of other people's contributions at EbE events (whether professionals or other people living with type 1 diabetes). For example:

> *Once we started I was more in touch with my team at the hospital and that's when the ball started rolling with all of this… It just sort of started the ball rolling with me making better choices and doing better for myself* (participant 7)

There was also variance with regards to how long this motivation boost lasted, the way in which it was experienced (from a 'welcome boost', to 'pressure to be perfect'), and also in rationales for maintaining the motivation (for self/health, to inspire others, to stay involved in EbE activity). Some of these ideas are illustrated below:

> *I think it adds some pressure cos I don't think anybody would listen to me if my HbA1c was 85/90… whether I'm right or wrong I don't know but that's how I perceive it… but the facts are there you know… I've achieved the most with my HbA1c where it sits and if I paint that picture then it's a good picture for others to look at* (participant 4)

Exploring New Technologies

This concept denotes the process by which EbE activity leads to increased openness new technologies (such as insulin pumps, new monitoring technologies). Through EbE activity, people frequently meet similar others who may be using alternative management approaches which they may have previously discounted using for themselves, as illustrated below:

> *I've recently had the freestyle libre as well that, so that is massive for me… its uhh a physical like, diabetes you can't see can ya? And we can like hide it, but this you can see, yeah… Yeah, so on that [EbE event] thing I went to, a lot of people had them, and it was dead comforting, like 'oh wow, you've got one'* (participant 6).

In this way, people may be inspired to consider trying new technologies. Other participants spoke of increased willingness to explore new technologies as a result of *coming out of hiding* (consequently, this concept also feeds into *psychological empowerment*):

> *I would never have worn anything on my arms or done anything like pumps. They're like a constant sign that you're different, having them attached to you is an acceptance that you're different. That was not something I would have done before because I would have been like 'I'm the same as everybody else, I need to be the same as everybody else'* (participant 4).

Activating Further Involvement

Finally, there is also a 'feedback loop' through which EbE involvement and its associated benefits lead to increased willingness to participate in more EbE activity, and in wanting others to be able to share the experience too. In this way, further benefits can be experienced for others and for the self. In addition, the more experience a person gets in doing EbE activity, the more they can put on their CV. This then feeds into career opportunities, whether in the field of type 1 diabetes or in developing skills that can be transferred into other fields:

> *Every time it opened further doors… its really helped me and I can see, from the small experiences I've had with other people that it's helped them as well… If you could just use that to be that turning point for someone, you can see their confidence grow. So that's when, from that they realise that they can give a talk, and that they can get involved in service development, or then they could do whatever it is, then they go on and use that to get a job. Whatever that looks like for somebody, [there] needs to be more chance of that* (participant 3)

Discussion

This study explored the personal impact of EbE activity on young adults living with type 1 diabetes. A theory of empowerment through EbE activity has been developed, grounded in the narratives of study participants. The theory suggests that involvement in EbE activity is associated with empowerment in relation to an individual's psychological wellbeing, social relationships, and condition management. Through processes of empowerment across these areas, individuals experience an enhanced sense of autonomy, control, and independence. These findings mirror those of previous studies concerning EbE activity by individuals accessing mental health services, which have suggested that such activity impacts positively upon an individual's psychological wellbeing, self-esteem, and confidence (McKeown et al., 2012; Repper & Breeze, 2007; Simpson et al., 2014). Furthermore, the concept of *paying it back* echoes the findings of Patterson et al. (2014), who also observed that involvement in EbE activity can help individuals attribute a sense of retrospective meaning to their experiences. In addition, the concept of *building a community* has overlaps with previous findings that EbE activity reduces feelings of loneliness (Cotterell et al., 2011).

This study is the first to consider the personal impact of EbE activity on young adults living with type 1 diabetes. However, the findings must be considered in the context of the study's limitations. Whilst the use of the member-checking method might be considered a strength, only two of the seven participants opted to engage in this process. The reasons for this are unclear, but the request for feedback was made during the early stages of the Covid-19 pandemic. Given the serious health implications of Covid-19 for people living with diabetes (Chen et al., 2020), perhaps the request was overlooked. On the other hand, it is important to consider that non-responding participants may not have recognised their personal experiences in the model and may therefore have not responded due to feeling unheard (Birt et al., 2016). Alternatively, the participants may not have responded because they had no suggestions for amendments. Indeed, participants who did respond reported that the theory resonated with their experiences and suggested no changes. Member checking requests were sent via email. This unobtrusive method was adopted to minimise the potential for researcher bias intruding at this stage (for example, participants acquiescing with the theory to 'please' the researcher). In retrospect it might have been more beneficial in terms of uptake had more support been offered for participants during the member checking process.

The age range of participants may also present limitations. Although the study was open to people aged 16-35 years, the average participant was 29 years old. The youngest participant was aged 25. As such, the perspectives of people at the lower end of the age range may not be represented by this study. Future investigations in this area would therefore benefit from the inclusion of younger participants. Furthermore, participant ages may have other implications for the validity of the study findings. Young adulthood represents a transitional period in an individual's life, both in terms of psychosocial development, and in increasing responsibility for diabetes management (Rasmussen et al., 2011). Consequently, it is not possible to separate out the impact of EbE activity from the processes of maturation associated with the transitional life stage, nor the maturation effects of learning to live with type 1 diabetes. Therefore, future research into the personal impact of EbE activity may benefit from exploring whether EbE is experienced differently across different age groups, as well as between individuals with long-standing versus more recent diagnoses.

Despite these limitations, the study highlights that involvement in EbE activity may be a powerful means of enhancing psychological and physical wellbeing for young adults living with type 1 diabetes. Given the detrimental impact of diabetes distress and burden experienced by this population (Naylor et al., 2012), there may be important implications for promoting increased involvement in EbE activity for young adults living with type 1 diabetes at an early stage, in order to maximise health outcomes. Afterall, EbE involvement is associated with significant benefits for services too (Khoo et al., 2004; Schreur et al., 2015; Terry, 2012). Such moves need not constitute a radical shift in practice; it may be relatively straightforward to invite someone who is an EbE to speak at an existing training day for healthcare professionals. Further, as suggested by the concept of *storytelling*, there appears to be particular benefit associated with having the opportunity to share one's story via EbE activity. Indeed, participants described how the process of preparing and then verbalising their story enabled them to recognise and 'process' their experiences in a way not previously available to them and described deriving therapeutic benefits from this activity. This notion is supported by previous research by Walters et al. (2003), who also noted therapeutic outcomes associated with recounting one's story via EbE activity. They observed how such activity led to individuals developing a coherent narrative around their experiences. This enabled them to develop new insights into their difficulties and the factors that may be maintaining them.

In considering these observations in the context of wider theory around therapeutic processes, parallels may be drawn with different therapeutic approaches. For instance, Narrative Therapy is underpinned by the premise that the telling of experiences can facilitate therapeutic changes via providing the opportunity for the individual to consider their experiences from different perspectives, guided by questioning by the therapist (White & Epston, 1990). In the case of storytelling via EbE activity, the role of guided questioning of Narrative Therapy may be subsumed by the questions of audience members, or by the people who are EbE themselves as they compose their stories. Similarly, a key component of Acceptance and Commitment Therapy involves the individual developing an awareness that they are not the *content* of their thoughts and feelings (which can lead to unhelpful self-labelling, which may lead to self-imposed restrictions), and learning instead that they are the *context* in which those thoughts and feelings arise (Hayes et al., 1999). The process of preparing a cohesive narrative of one's experiences may have helped participants to disentangle themselves from previously held unhelpful or restrictive narratives.

Based on the above, it is recommended that people acting as EbE are offered the opportunity to engage in *storytelling* as part of their involvement. Further practical recommendations for enhancing the quality of EbE involvement may be gleaned from the *facilitators* and *barriers* highlighted in the model generated within this research. Based on participant accounts regarding *facilitator*s, people acting as EbE may benefit from explicit support and encouragement from their healthcare team, being supported to apply the (transferrable) skills they already possess to their EbE activity, and being encouraged and supported to plan their EbE contributions as far as possible. The barriers identified within this study also have important implications for clinical practice. For instance, it is important that, where applicable, individuals are made explicitly aware of the scope for potential change to service provision, to ameliorate against them perceiving that their input is tokenistic. Furthermore, services may wish to consider offering coaching aimed at offsetting the *practical difficulties* associated with EbE (e.g. coaching fielding of questions or teaching strategies for managing anxieties). It is also important that services regularly check-in with people who are EbE to ascertain and, if appropriate, ameliorate, *feelings of overwhelm* (e.g. reducing workload if the individual is finding it too much)

In summary, this study offers a theory of empowerment through EbE activity based on the experiences of seven young adults living with type 1 diabetes. Our findings suggest that engagement in EbE activity empowers young adults psychologically, socially, and in their condition management, and is associated with positive outcomes in each of these domains. Those working with young adults with chronic physical health conditions, such as type 1 diabetes, may wish to consider how further opportunities for EbE activity may be made available as an innovative approach to improving life quality of those who access their services.

Funding Details

None. This research was undertaken as part of a doctoral research project.

Disclosure Statement

No potential conflict of interest to declare

References

Andreassen, T. E. (2018). Service user involvement and repositioning of healthcare professionals: A framework for examining implications of different forms of involvement. *Nordic Welfare Research, 3*(1), 58-69. https://doi.org/10.1826/ISSN.2464-4161-2018-01-06

Barnes M., Davis A., & Rogers, H. (2006). Women's voices, women's choices: Experiences and creativity in consulting women users of mental health services. *Journal of Mental Health, 15*(3), 329–341. https://doi.org/10.1080/09638230600700664

Birks, M., & Mills, J. (2015). *Grounded theory: A practical guide* (2nd ed.). SAGE Publications Ltd. https://doi.org/10.13140/2.1.2982.0484

Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member Checking: A Tool to Enhance Trustworthiness or Merely a Nod to Validation? *Qualitative Health Research*, *26*(13), 1802–1811. https://doi.org/10.1177/1049732316654870

Brady, T. J., Murphy, L., O'Colmain, B. J., Beauchesne, D., Daniels, B., Greenberg, M., House, M., & Chervin, D. (2013). A meta-analysis of health status, health behaviours, and health care utilisation outcomes of the chronic disease self-management program. *Preventing Chronic Disease, 10,* Article e120112. https://doi.org/10.5888/pcd10.120112

Chen, Y., Gong, X., Wang, L., & Guo, J. (2020). *Effects of hypertension, diabetes and coronary heart disease on COVID-19 diseases severity: A systematic review and meta-analysis*. medRxiv. https://doi.org/10.1101/2020.03.25.20043133

Cooper, M. N., Lin, A., Alvares, G. A., de Klerk, N. H., Jones, T. W., & Davis, E. A. (2017). Psychiatric disorders during early adulthood in those with childhood onset type 1 diabetes: Rates and clinical risk factors from population-based follow-up. *Pediatric Diabetes, 18,* 599-606. https://doi.org/10.1111/pedi.12469

Corbin, J. & Strauss, A. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (4th ed.). SAGE Publications Ltd.

Cotterell, P., Harlow, G., Morris, C., Beresford, P., Hanley, B., Sargeant, A., Sitzia, J., & Staley, K. (2011). Service user involvement in cancer care: The impact on service users. *Health Expectations, 14*(2), 159-169. https://doi.org/10.1111/j.1369-7625.2010.00627.x

Crawford, M. J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., & Tyrer, P. (2002). Systematic review of involving patients in the planning and development of health care. *British Medical Journal, 325,* 1263-1267. https://doi.org/10.1136/bmj.325.7375.1263

Department of Health. (2007). *Putting people first: A shared vision and commitment to the transformation of adult social care*. Department of Health: London. https://webarchive.nationalarchives.gov.uk/20130104175839/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118

Dey, I. (2007). Grounding categories. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 167-190). SAGE Publications Ltd. https://doi.org/10.4135/9781848607941

Division of Clinical Psychology. (2018). *Experts by experience position statement and strategy 2018-2019.* The British Psychological Society.

Domecq, J. P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., Brito, J. P., Boehmer, K., Hasan, R., Firwana, B., Erwin, P., Eton, D., Sloan, J., Montori, V., Asi, N., Dabrh, A. M. A., & Murad, M. H. (2014). Patient engagement in research: a systematic review. *BMC Health Services Research, 14,* Article e89. https://doi.org/10.1186/1472-6963-14-89

Hilliard, M. E., Sparling, K. M., Hitchcock, J., Oser, T. M., & Hood, K. K. (2015). The emerging diabetes online community. *Current Diabetes Reviews, 11*(4), 261-272. https://doi.org/10.2174/1573399811666150421123448

Higgins, A., Maguire, G., Watts, M., Rani, S., & Alexander, J. (2011). Service user involvement in mental health practitioner education in Ireland. *Journal of Psychiatric and Mental Health Nursing, 18,* 519-525. https://doi.org/10.1111/j.1365-2850.2011.01698.x

Hislop, A. L., Fegan, P. G., Schlaeppi, M. J., Duck, M., & Yeap, B. B. (2008). Prevalence and associations of psychological distress in young adults with type 1 diabetes. *Diabetic Medicine, 25,* 91-96. https://doi.org/10.1111/j.1464-5491.2007.02310.x

Holman, N. (2008). *Diabetes Attributable Deaths: Estimating the excess deaths among people with diabetes*. Yorkshire and Humber Public Health Authority. http://www.yhpho.org.uk/resource/view.aspx?RID=9909

Khoo, R., McVicar, A., & Brandon, D. (2004). Service user involvement in postgraduate mental health education. Does it benefit practice? *Journal of Mental Health, 13*(5), 481-492. https://doi.org/10.1080/09638230400006742

Lindenmeyer, A., Hearnshaw, H., Sturt, J., Ormerod, R., & Aitchison, G. (2007). Assessment of the benefits of user involvement in health research from the Warwick diabetes care research user group: A qualitative case study. *Health Expectations, 10*(3), 268-277. https://doi.org/10.1111/j.1369-7625.2007.00451.x

McKeown, M., Malihi-Shoja, L., Hogarth, R., Jones, F., Holt, K., Sullivan, P., Lunt, J., Vella, J., Hough, G., Rawcliffe, L., & Mather, M. (2012). The value of involvement from the perspective of service users and careers engaged in practitioner education: Not just a cash nexus. *Nurse Education Today, 32*(2), 178-184. https://doi.org/10.1016/j.nedt.2011.07.012

Mjøsund, N. H., Eriksson, M., Espnes, G. A., Haaland-Øverby, M., Jensen, S. L., Norheim, I., Kjus, S. H. H., Portaasen, I-L., & Vinje, H. F. (2016). Service user involvement enhanced the research quality in a study using interpretative phenomenological analysis – the power of multiple perspectives. *Journal of Advanced Nursing, 73*(1), 265-278. https://doi.org/10.1111/jan.13093

Murad, M. H., Shah, N. D., Van Houten, H. K., Ziegenfuss, J. Y., Deming, J. R., Beebe, T. J., Smith, S. A., Guyatt, G. H., & Montori, V. M. (2011). Individuals with diabetes preferred future trials use patient-important outcomes and provide pragmatic inferences. *Journal of Clinical Epidemiology, 64*(7), 743-748. https://doi.org/10.1016/j.jclinepi.2010.08.005

National Diabetes Transition Audit. (2019). *National Diabetes Transition Audit, 2011-2017.* https://files.digital.nhs.uk/14/B263BB/National%20Diabetes%20Transition%20Audit%20-%202nd%20Report%20v1.0.pdf

Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M., & Galea, A. (2012). *Long-term conditions and mental health: The cost of co-morbidities.* The King's Fund. https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf

Noorani, T. (2013). Service user involvement, authority and the 'expert-by-experience' in mental health. *Journal of Political Power, 6*(1), 49-68. https://doi.org/10.1080/2158379X.2013.774979

Omeni, E., Barnes, M., MacDonald, D., Crawford, M., & Rose, D. (2014). Service user involvement: Impact and participation: A survey of service user and staff perspectives. *BMC Health Services Research, 14,* Article e491. https://doi.org/10.1186/s12913-014-0491-7

Patterson, S., Trite, J., Weaver, T. (2014). Activity and views of service users involved in mental health research: UK survey. *British Journal of Psychiatry, 205,* 68-75. https://doi.org/10.1192/bjp.bp.113.128637

Polacsek, M., Boardman, G., & McCann, T. (2018). Understanding, choosing and applying grounded theory: Part 2. *Nurse Researcher, 26*(3), 43-49. https://doi.org/10.7748/nr.2018.e1593

Rasmussen, B., Ward, G., Jenkins, A., King, S. J., & Dunning, T. (2011). Young adults' management of type 1 diabetes during life transitions. *Journal of Clinical Nursing, 20,* 1981-1992. https://doi.org/10.1111/j.1365-2702.2010.03657.x

Repper, J., & Breeze, J. (2007). A review of the literature on user and carer involvement in the training and education of health professionals. *International Journal of Nursing Studies, 44*(3), 511–519. https://doi.org/10.1016/j.ijnurstu.2006.05.013

Rooke, C., Jones, B., & Thomas, M. (2014). Including service users in delivering alcohol addiction therapy. *Nursing Standard, 28*(42), 44-48. https://doi.org/10.7748/ns.28.42.44.e8437

Saldaña, J. (2015). *The coding manual for qualitative researchers* (3rd ed.). SAGE Publications Ltd.

Schreur, F. K., Lea, L., & Goodbody, L. (2015). Learning from service user and carer involvement in clinical psychology training. *The Journal of Mental Health Training, Education and Practice, 10*(3), 137-149. https://doi.org/10.1108/JMHTEP-02-2015-0009

Simpson, A., Jones, J., Barlow, S., & Cox, L. (2014). Adding SUGAR service user and carer collaboration in mental health nursing research. *Journal of Psychosocial Nursing and Mental Health Services, 52*(1), 22-30. https://doi.org/10.3928/02793695-20131126-04

Simpson, E.L., & House, A.O. (2002). Involving users in the delivery and evaluation of mental health services: Systematic review. *British Medical Journal, 325*, 1265-1268. https://doi.org/10.1136/bmj.325.7375.1265

Stuckey, H., & Peyrot, M. (2020). Living with diabetes: Literature review and secondary analysis of qualitative data. *Diabetic Medicine, 37*(3), 493-503. https://doi.org/10.1111/dme.14255

Terry, J. (2012). Service user involvement in pre-registration mental health nurse education settings: A review of the literature. *Journal of Psychiatric and Mental Health Nursing, 19,* 816-829. https://doi.org/10.1111/j.1365-2850.2011.01858.x

Thompson, J., Barber, R., Ward, P. R., Boote, J. D., Cooper, C. L., & Armitage, C. J. (2009). Health researchers' attitudes towards public involvement in health research. *Health Expectations, 12*(2), 209-220. https://doi.org/10.1111/j.1369-7625.2009.00532.x

Thornicroft, G., & Tansella, M. (2005). Growing recognition of the importance of service user involvement in mental health service planning and evaluation. *Epidemiologia E Psichiatria Sociale, 14*(1), 1-3. https://doi.org/10.1017/S1121189X00001858

Tran, V. T., Barnes, C., Montori, V. M., Falissard, B., & Ravaud, P. (2015). Taxonomy of the burden of treatment: A multi-country web-based qualitative study of patients with chronic conditions. *BMC Med, 14*(13), Article e115. https://doi.org/10.1186/s12916-015-0356-x

Walters, K., Buszewicz, M., Russell, J., & Humphrey, C. (2003). Teaching as therapy: Cross sectional and qualitative evaluation of patients' experiences of undergraduate psychiatric teaching in the community. *British Medical Journal, 326*, 740-746. https://doi.org/10.1136/bmj.326.7392.740

White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. New York: Norton.

Chapter 3 – Contributions to Theory and Clinical Practice

Contributions to Theory and Clinical Practice

This thesis has explored the interplay between psychological, social, and physical health outcomes for people living with type 1 diabetes. The systematic review investigated the association between psychosocial factors and an acute complication of diabetes, repeat diabetic ketoacidosis, in people living with type 1 diabetes. The empirical paper explored the personal impact of expert by experience activity by young adults living with type 1 diabetes. This final paper aims to further discuss the implications emerging from the previous papers with regards to future research, theory development, and clinical practice. This discussion draws on the previous papers on an individual level, and integrates overarching implications emerging across studies. It is important to note that the below suggestions are made tentatively in line with the limitations of the research as discussed within each individual paper. Finally, personal reflections on the research process are also shared.

Implications for Future Research and Theory Development

In this section, implications for future research and theory development arising from each of the papers are discussed in turn.

Systematic Review

As noted in the systematic review, enquiry into the association between psychosocial factors and repeat diabetic ketoacidosis in people living with type 1 diabetes has benefited from predominantly quantitative explorations, particularly 'big data' studies. Such large datasets are associated with numerous advantages, including greater likelihood that samples will be representative of the population under study and large enough sample sizes to have sufficient power to detect statistically significant effects (Adjerid & Kelley, 2018). However, the systematic search did not detect any qualitative explorations of this phenomenon.

Consequently, the evidence base currently tells us little about *how* the cycle of repeat diabetic ketoacidosis is experienced, or made sense of, by those who experience it. Gaining a rich understanding of lived experience and meaning making are amongst the central concerns of qualitative research methodologies (Willig, 2013). Therefore, it is here postulated that theory development in this area would benefit from the use of qualitative enquiry. For example, use of Interpretive Phenomenological Analysis (Smith et al., 2009) may engender a deeper understanding of the lived experiences of those who repeatedly experience diabetic ketoacidosis, or a study using Grounded Theory Method (e.g. Charmaz, 2014; Corbin & Strauss, 2015; Glaser & Strauss, 1967) might be used to produce a theoretical model to account for how psychosocial factors may impact on repeat diabetic ketoacidosis.

Empirical Paper

A number of steps may be taken to further develop the proposed theory of empowerment via expert by experience activity. For instance, Corbin and Strauss (2015) note that sufficiently broad core concepts may have applications beyond the immediate context in which they were derived. Based on this, we might hypothesise that expert by experience activity may also be associated with similar forms of empowerment for people who engage in expert by experience activity outside of the context of type 1 diabetes services. Further research would benefit from the inclusion of individuals from the wider expert by experience community, both within physical and mental health services. In this way, the existing categories in the theory of empowerment via expert by experience activity may be expanded or modified to account for these experiences.

As noted by Morgan (2014), theories generated through qualitative methodologies may be further developed using ‘quantitative extensions’ to research. Indeed, the observation that ‘storytelling’ may be associated with additional benefits for those who engage in this form of expert by experience activity might be formally tested by comparing measures of psychological wellbeing pre and post expert by experience activities for individuals engaged in activities that do and do not involve the formal sharing of one's experiences. Further, future researchers may wish to follow participants on a longitudinal basis to explore which factors may predict more positive outcomes of expert by experience involvement and also to assess the extent to which the benefits of expert by experience activity may be 'dose-dependent'. In addition, the potential effects of maturation highlighted in the limitations section of the paper may be tested or controlled for in studies utilising quantitative methodologies; possibly by comparing the personal impact of expert by experience activity for younger versus older participants. In turn, such findings may have important clinical implications in terms of informing decisions around *who* may benefit most from expert by experience involvement and *how* they may best be supported to achieve this.

Implications for Clinical Practice

In this section, implications for clinical practice spanning the two papers are discussed. Briefly, these implications concern the importance of psychological and emotional support and the use of language and/or labels in diabetes care. Each is discussed in turn below:

The Importance of Psychological and Emotional Support

The psychological and emotional impact of living with type 1 diabetes emerged as a strong theme across both papers. Within the systematic review, an association between repeat diabetic ketoacidosis and poorer mental health was observed. Participants in the empirical paper also recounted the significant diabetes-related distress they had, at times, experienced. This observation may be unsurprising given the well-documented high level of psychological distress within the type 1 diabetes population (e.g. Barnard et al., 2006; Buchberger et al., 2016; Hagger et al., 2016). Consequently, it seems imperative that appropriate support is available for those in need. This is particularly pertinent given that the presence of psychological and emotional difficulties can impact negatively on an individual's ability to self-manage their diabetes (Bernstein et al., 2013). In further support of this, a recent systematic review and meta-analysis concluded that the psychological and emotional wellbeing of people living with diabetes *is* responsive to psychological intervention and, when such interventions are specifically tailored towards diabetes (as opposed to generic interventions), then they are also associated with reductions in Haemoglobin A1C (HbA1c), indicating improved condition management (Schmidt, 2018). Furthermore, such effective therapeutic input is associated with cost savings to the organisation, in terms of decreased costs associated with diabetes complications (Jeeva et al., 2013; NHS South West Clinical Networks, 2018).

In the UK, guidance from the National Institute for Health and Care Excellence (NICE) stipulates that psychologists should be included within multidisciplinary paediatric diabetes teams (NICE, 2015a). In the case of adults living with type 1 diabetes, NICE guidelines recommend that healthcare professionals within diabetes teams should be sufficiently skilled in the detection and basic management of "non-severe psychological disorders" but that referrals out to specialists should be made in the case of 'more significant' difficulties (NICE, 2015b, p.44). Unfortunately, however, Diabetes UK's recent *Too Often Missing* report highlighted that three-quarters of adults living with diabetes report being unable to access such support (Flury & Solomons, 2019). Their subsequent recommendations, as reproduced below, align with the clinical implications of the findings of this thesis:

- For all healthcare professionals providing general diabetes care to be trained in recognising and supporting emotional and psychological wellbeing needs

- For all diabetes services to be supported by a suitably trained and experienced mental health professional, such as a psychologist
- For a care pathway aimed at diabetes and emotional and psychological wellbeing in an integrated way to be developed and implemented in each UK nation (Flury & Solomons, 2019).

The use of Language and Labels

Issues relating to the use of language arose across both papers. Firstly, considerable variance in terminology was observed across studies included within the systematic literature review, which likely reflects a number of developments in the thinking around, and management of, diabetes during the wide time span (36 years) encompassed by the studies (1984-2020). It was observed that, particularly in older studies, study participants were referred to using terms such as ‘brittle’, ‘neurotic’ and ‘diabetic’. This is concerning given that a recent scoping review determined that ‘poor language practices’ (i.e. use of illness-first descriptors and terminology such as ‘uncontrolled’ and ‘non-compliant/adherent’) are associated with increased stigma, decreased engagement with self-management, lower care satisfaction, and poorer clinical outcomes for people living with type 1 diabetes (Lloyd et al., 2018). Given the potentially profound impact of language use on outcomes for people living with type 1 diabetes, it is imperative that healthcare professionals are skilled in sensitive and appropriate communication (Holt & Speight, 2017). Indeed, following the previously described scoping review, NHS England (2018), alongside other relevant stakeholders in the field of diabetes care, published guidance concerning best practice in promoting positive interactions with people living with diabetes (for example, using person-first and non-blaming language) to promote the most positive outcomes.

Secondly, it has long been understood that the terminology used to refer to people who receive, and provide input into, services (for example, ‘service user’, ‘expert by experience’, ‘patient’, ‘client’, and so on) can have connotations of empowerment or disempowerment (Costa et al., 2019), and that the acceptability of these labels has changed over time (McLaughlin, 2009). It was based on these principles that the term ‘expert by experience’ was adopted in the empirical study; our aim was to signal to participants that their experiences and input were highly valued and respected. However, this term was experienced as somewhat problematic by one participant, as demonstrated in the below excerpt from his interview transcript:

> *The word expert doesn’t sit that well with me, I just would say that I’ve got an interesting level of experience and a varied experience… a different varied kind of thing but it doesn’t mean that, I suppose, that my experience is any more valuable than anybody else’s it’s just a different one, which is why I don’t call it expert, it’s just a different way of viewing it* (participant 4)

In a further observation regarding language use across the studies, another of the participants in the empirical paper frequently used the term ‘diabetic’ to describe herself. Indeed, some proponents and people with lived experience argue against the use of person-first language, and many people with lived experience are often surprised to hear that non-person-first language (such as the use of the term ‘diabetic’) is now considered taboo (Collier, 2012).

Taken collectively, these observations have important clinical implications. It is essential to ensure that language use does not inadvertently alienate people from services, and that a balance is struck between respecting individual differences and preferences whilst also adhering to best practice principles.

Reflective Commentary

In reflecting on my experiences of conducting this research, I realise that I have gained a number of valuable insights that I hope to take forward with me as I embark upon my career as a newly qualified clinical psychologist. Prior to commencing clinical training, I had developed a passion for expert by experience involvement in service development and delivery, having been involved in supporting people to become involved with service development and staff interview panels, as well as in cofacilitating groups, and in developing resources to help fellow service users. During this time, I was witness to the numerous benefits of such involvement for the service, but I did not give much consideration to the personal benefits or costs for the people involved in the expert by experience role, other than those directly related to improvements in service delivery. I am therefore encouraged by the personal benefits the participants in the empirical study shared and am inspired to continue to champion expert by experience involvement for those interested in getting involved. I would also be most eager to continue to be research active in this field, to continue to investigate the most appropriate and beneficial ways of supporting expert by experience involvement.

Prior to commencing work on this thesis, I had only a cursory understanding of what it might be like to live with a chronic physical health condition such as type 1 diabetes. Although I believed I had a good understanding of the interplay between physical and psychological wellbeing, it was not until I immersed myself in the research that I really became aware of the pervasiveness of type 1 diabetes and the burden it can cause for those who live with it. Since commencing this work, I have become acutely aware that, over the course of my training thus far, I have possibly neglected to fully appreciate, or enquire about, long term conditions unless they were immediately obvious or highlighted to me by service users. I therefore aim to be more mindful of this in my clinical work going forward. This may be particularly pertinent given that my first qualified post will be based in a Community

Learning Disability Team; there is currently tentative evidence to suggest that there may be a greater prevalence of type 1 and 2 diabetes in people with Intellectual Disabilities, with self-management presenting a particular challenge for many people with Intellectual Disabilities (MacRae et al., 2015; McVilly et al., 2014).

This was my first experience of conducting qualitative interviews and I believe I have gleaned some valuable – and transferrable – insights from the process. Initially, I was worried that I might ‘drop into’ some sort of ‘therapy mode’, and thus risk steering the interviews away from the direction in which participants may have led them. However, I was able to retain a mindful awareness of the unique nature of research interviews and refrain from, for example, exploring with participants whether there might be alternative ways of conceptualising or responding to particular thoughts or emotions. In doing so, I noticed that I felt more present and more able to follow the agenda of participants. This experience led me to reflect on my sense of presence during clinical encounters. I was reminded that the times at which I feel less connected with my clients are the times during which I am mentally ‘jumping ahead’ and planning what to say next. This observation has enabled me to recognise the importance of holding on to my own agenda less firmly in sessions. In this way, I am better able to ‘hear’ what people are telling me and thereby respond in a more authentic way.

The act of typing up the interview transcripts provided me with a unique opportunity to reflect on, and develop, my own communication skills. Early on in the process, I noticed that I have a tendency towards posing questions that are wordy or comprised of multiple parts (and sometimes both!); something that I had not recognised in myself previously. Following this observation, I was able to make changes to my interview technique for subsequent interviews. I have also endeavoured to take this learning forward with me into my clinical interactions. Moreover, the process of analysing the interviews also gave me pause for thought on how much is left *unsaid* and assumed during conversations. I typically came away from the interviews mostly believing that I had understood what was being communicated with me. However, there were a few occasions during the analytic process where I noted numerous potential ways of interpreting what was being said. In this way, I realised that I may not have understood participants as accurately as I initially thought. This realisation has emphasised to me the importance of checking in on my understanding with the people I work with. This observation has served as a timely and poignant reminder of one of the first lessons I was taught during my very first training placement; that one of the most important jobs in delivering psychological therapy is to support and encourage those we work with to understand themselves with love, care and *precision* (ten Have-de Labije & Neborsky, 2012).

References

Adjerid, I., & Kelley, K. (2018). Big data in psychology: A framework for research advancement. *The American Psychologist*, *73*(7), 899-917. https://doi.org/10.1037/amp0000190

Barnard, K. D., Skinner, T. C., & Peveler, R. (2006). The prevalence of co-morbid depression in adults with type 1 diabetes: Systematic literature review. *Diabetic Medicine, 23*(4), 445-448. https://doi.org/10.1111/j.1464-5491.2006.01814.x

Bernstein, C. M., Stockwell, M. S., Gallagher, M. P., Rosenthal, S. L., & Soren, K. (2013). Mental health issues in adolescents and young adults with type 1 diabetes: Prevalence and impact on glycaemic control. *Clinical Paediatrics, 52*(1), 10-15. https://doi.org/10.1177/0009922812459950

Buchberger, B., Huppertz, H., Krabbe, L., Lux, B., Mattivi, J. T., & Siafarikas, A. (2016). Symptoms of depression and anxiety in youth with type 1 diabetes: A Systematic review and meta-analysis. *Psychoneuroendocrinology, 70,* 70-84. https://doi.org/10.1016/j.psyneuen.2016.04.019

Charmaz, K. (2014). *Constructing Grounded Theory* (2nd ed.). SAGE Publications Ltd.

Collier, R. (2012). Person-first language: Laudable cause, horrible prose. *Canadian Medical Association Journal, 184*(18), E939-E940. https://doi.org/10.1503/cmaj.109-4338

Corbin, J. & Strauss, A. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (4th ed.). SAGE Publications Ltd.

Costa, D. S. J., Mercieca-Bebber, R., Tesson, S., Seidler, Z., & Lopez, A-L. (2019). Patient, client, consumer, survivor or other alternatives? A scoping review of preferred terms for labelling individuals who access healthcare across settings. *British Medical Journal Open*, *9*(3), Article e025166. https://doi.org/10.1136/bmjopen-2018-025166

Flury, R., & Solomons, L. (2019). *Too often missing: Making emotional and psychological support routine in diabetes care.* Diabetes UK. https://www.diabetes.org.uk/resources-s3/2019-05/Full%20Report_Too%20Often%20Missing_Diabetes%20UK_May%202019.pdf

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory.* Aldine.

Hagger, V., Hendrieckx, C., Sturt, J., Skinner, T. C., & Speight, J. (2016). Diabetes distress among adolescents with type 1 diabetes: A systematic review. *Current Diabetes Reports, 16*(9), 1-14. https://doi.org/10.1007/s11892-015-0694-2

Holt, R. I. G., & Speight, J. (2017). The language of diabetes: The good, the bad and the ugly. *Diabetic Medicine, 34*(11), 1495-1497. https://doi.org/10.1111/dme.13520

Jeeva, F., Dickens, C., Coventry, P., Bundy, C., & Davies, L. (2013). Is treatment of depression cost-effective in people with diabetes? A systematic review of the economic evidence. *International Journal of Technology Assessment in Health Care, 29*(4), 384-391. https://doi.org/10.1017/S0266462313000445

Lloyd, C. E., Wilson, A., Holt, R. I. G., Whicher, C., & Kar, P. (2018). Language matters: A UK perspective. *Diabetic Medicine, 35*(12), 1635-1641. https://doi.org/10.1111/dme.13801

MacRae, S., Brown, M., Karatzias, T., Taggart, L., Truesdale-Kennedy, M., Walley, R., Sierka, A., Northway, R., Carey, M., & Davies, M. (2015). Diabetes in people with Intellectual Disabilities: A systematic review of the literature. *Research in Developmental Disabilities, 47*, 352-374. https://doi.org/10.1016/j.ridd.2015.10.003

McLaughlin, H. (2009). What’s in a name: ‘Client’, ‘patient’, ‘customer’, ‘consumer’, ‘expert by experience’, ‘service user’ – what’s next? *British Journal of Social Work, 39*(6), 1101-1117. https://doi.org/10.1093/bjsw/bcm155

McVilly, K., McGillivray, J., Curtis, A., Lehmann, J., Morrish, L., & Speight, J. (2014). Diabetes in people with an intellectual disability: A systematic review of prevalence, incidence and impact. *Diabetic Medicine, 31*(8), 897-904. https://doi.org/10.1111/dme.12494

Morgan, D. L. (2014). *Integrating qualitative and quantitative methods: A pragmatic approach.* SAGE Publications Ltd. https://doi.org/10.4135/9781544304533

National Institute for Health and Care Excellence. (2015a). Diabetes (type 1 and type 2) in children and young people: diagnosis and management (NICE Guideline NG18). https://www.nice.org.uk/guidance/ng18

National Institute for Health and Care Excellence. (2015b). Type 1 diabetes in adults: diagnosis and management (NICE Guideline NG17). https://www.nice.org.uk/guidance/ng17

NHS England. (2018). *Language matters: Language and diabetes.* https://www.england.nhs.uk/publication/language-matters-language-and-diabetes/

NHS South West Clinical Networks. (2018). *Improving Access to Psychological therapies for patients with Diabetes – examples of developments Nationally and across the South West.* https://www.england.nhs.uk/south/wpcontent/uploads/sites/6/2018/10/psychological-therapies-factsheet.pdf

Schmidt, C. B., van Loon, B. J. P., Vergouwen, A. C. M., Snoek, F. J., & Honig, A. (2018). Systematic review and meta-analysis of psychological interventions in people with diabetes and elevated diabetes-distress. *Diabetic Medicine, 35*(9), 1157-1172. https://doi.org/10.1111/dme.13709

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, method and research.* SAGE Publications Ltd.

ten Have-de Labije, J., & Neborsky, R. J. (2012). *Mastering intensive short-term dynamic psychotherapy: A roadmap to the unconscious*. Karnac Books

Willig, C. (2013). *Introducing qualitative research in psychology* (3rd ed.). Open University Press.

Appendices

Appendix A: PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	8
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	10
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	11-12
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	12
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	13
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	13-14
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	14
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	14
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	15
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	15

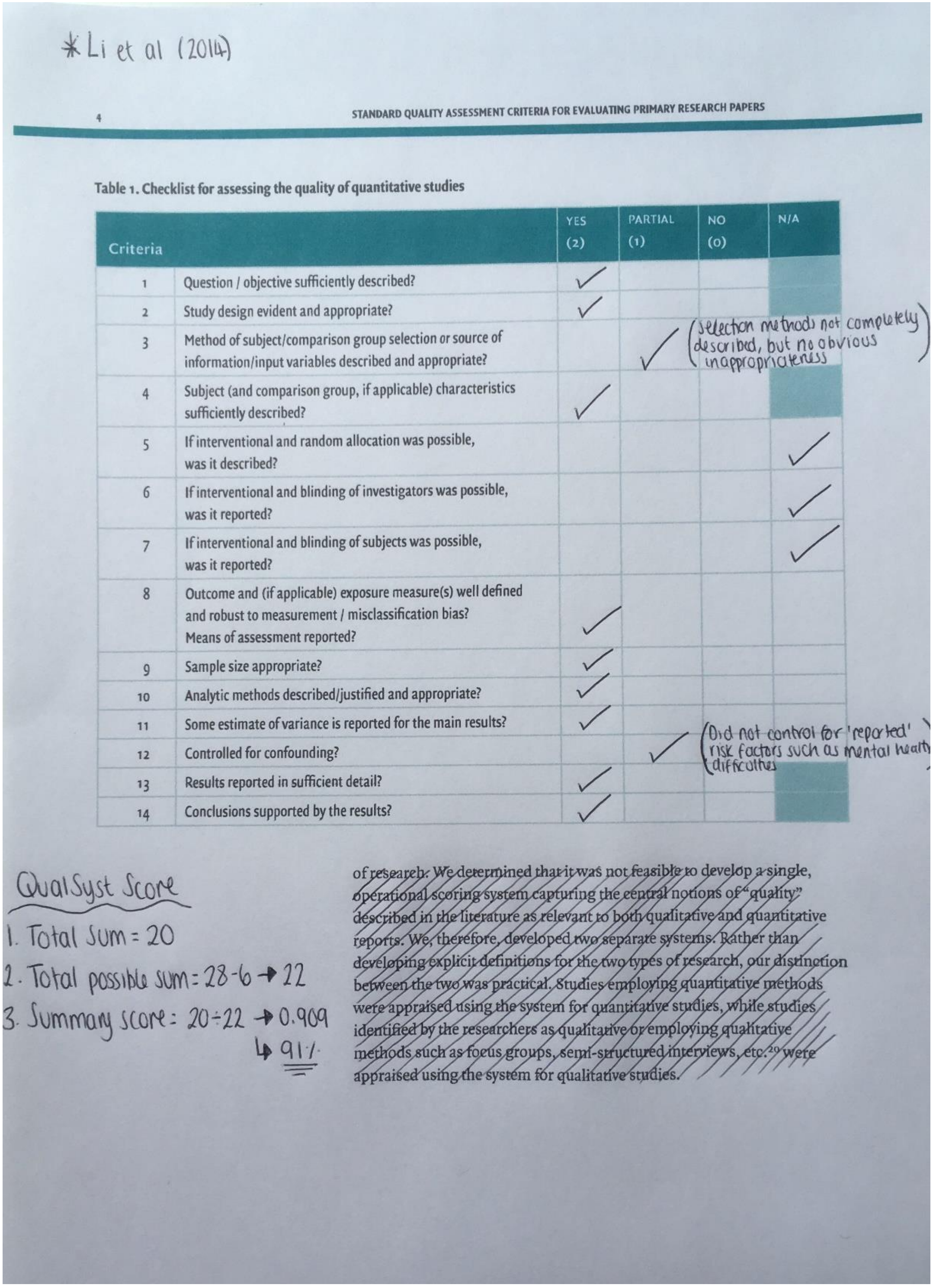
Section/topic	#	Checklist item	Reported on page #
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	15
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	15
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	15
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	16
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	18
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	30
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	34-39
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A

Section/topic	#	Checklist item	Reported on page #
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	39-40
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	41-42
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	42-43
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	44

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

Appendix B: Example of Quality Assessment Procedure



*Li et al (2014)

Table 1. Checklist for assessing the quality of quantitative studies

Criteria		YES (2)	PARTIAL (1)	NO (0)	N/A
1	Question / objective sufficiently described?	✓			
2	Study design evident and appropriate?	✓			
3	Method of subject/comparison group selection or source of information/input variables described and appropriate?		✓ (selection methods not completely described, but no obvious inappropriateness)		
4	Subject (and comparison group, if applicable) characteristics sufficiently described?	✓			
5	If interventional and random allocation was possible, was it described?				✓
6	If interventional and blinding of investigators was possible, was it reported?				✓
7	If interventional and blinding of subjects was possible, was it reported?				✓
8	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?	✓			
9	Sample size appropriate?	✓			
10	Analytic methods described/justified and appropriate?	✓			
11	Some estimate of variance is reported for the main results?	✓			
12	Controlled for confounding?		✓ (Did not control for 'reported' risk factors such as mental healt difficulties		
13	Results reported in sufficient detail?	✓			
14	Conclusions supported by the results?	✓			

QualSyst Score

1. Total Sum = 20
2. Total possible sum = 28-6 → 22
3. Summary score: 20÷22 → 0.909 → 91%

~~of research. We determined that it was not feasible to develop a single, operational scoring system capturing the central notions of "quality" described in the literature as relevant to both qualitative and quantitative reports. We, therefore, developed two separate systems. Rather than developing explicit definitions for the two types of research, our distinction between the two was practical. Studies employing quantitative methods were appraised using the system for quantitative studies, while studies identified by the researchers as qualitative or employing qualitative methods such as focus groups, semi-structured interviews, etc.[20] were appraised using the system for qualitative studies.~~

Table from:

Kmet, L. M., Lee, R. C., & Cook, L. S. (2004). *Standard quality assessment criteria for evaluating primary research papers from a variety of fields.* Alberta Heritage Foundation for Medical Research. http://www.ihe.ca/advanced-search/standard-quality-assessment-criteria-for-evaluating-primary-research-papers-from-a-variety-of-fields

Appendix C: Research Protocol

1. Project title

The Impact of Involving Young People with Chronic Health Conditions as Experts by Experience: An Exploration.

2. Supervision

The Principal Investigator is Bethan Allcock, a Trainee Clinical Psychologist at the North Wales Clinical Psychology Programme at Bangor University. The proposed study comprises partial fulfilment of the requirements of a Doctorate in Clinical Psychology (DClinPsy). Dr Rose Stewart will be the primary research supervisor and will provide supervision for all aspects of the project. She will act as Chief Investigator. Additional supervision and support around research methodology will be provided by the academic supervisor, Dr Mike Jackson.

3. Background

There has been a move away from the conceptualisation of people with lived experience of mental or physical health difficulties as passive recipients of services, and towards recognising them as actively involved consumers or users of services (Andreassen, 2018). There is growing acknowledgement of the unique perspectives offered by people who have received services as 'experts by experience' (EBE; Division of Clinical Psychology, 2018). Indeed, involving EBE with services has become a policy priority (Department of Health, 2007) and is a mandatory requirement of training programmes approved by the Health Care Professional Council (2013). EBE are most commonly invited to become involved in areas such as research, service evaluation, service development, staff recruitment, education and training, and curriculum development, (Simpson & House, 2002; Thornicroft & Tansella, 2005; Higgins, Maguire, Watts, Rani & Alexander, 2011). Although the rate of progress for involving EBE has been rather slow (Rooke, Jones & Thomas, 2014), such involvement is generally viewed positively by EBE and staff (Omeni, Barnes, MacDonald, Crawford & Rose, 2014).

It appears that the main focus of research into the benefits of EBE involvement for services has centred around staff education and research. For instance, it has been demonstrated that being taught by EBE is crucial to the learning experience in the training/education of staff (Rush, 2008; Terry, 2012; Schreur, Lea & Goodbody, 2015). Most mental health trainees report personal and professional benefit from receiving education/training from EBE; it motivates them to improve their practice and implement more person-centred ways of working (Khoo, McVicar & Brandon, 2004). Similarly, the involvement of EBE in research is also viewed positively by most researchers (Thompson et al., 2009). Such research involvement is associated with greater likelihood of measuring outcomes pertinent to the experiences and priorities of the client group, as well as greater insight and richness in research findings (Mjøsund et al., 2016). It is also associated with better recruitment of research participants and increased chances of securing research funding (Domecq et al., 2014; Mjøsund et al., 2016).

As observed by Crawford et al. (2002), research in this field generally focuses on the benefits of EBE activity for services - much less emphasis is placed on outcomes for EBE themselves. Nevertheless, there is emerging research into the benefits of EBE activity for EBEs, particularly for those with lived experience of mental health difficulties. It has been found that EBE can find the experience validating; it is a positive experience to be able to share their stories in environments where their experiences are recognised and valued (Barnes, Davis & Rogers, 2006). For many EBE, involvement is associated with increased self-esteem and confidence (Repper & Breeze, 2007; Simpson, Jones, Barlow & Cox, 2014). It has been observed that these changes in esteem and confidence then contribute to positive improvement of the mental wellbeing of EBE (McKeown et al., 2012). Further, EBE have reported that talking through their experiences has enabled them to gain new insights as well as giving a sense of meaning to their suffering (Walters et al., 2003; Paterson, Trite & Weaver, 2014). However, it must be noted that for a small number of EBE, the experience can be distressing, for example, when faced with the pressures associated with research (Patterson et al., 2014) or when met with a seeming lack of compassion from those they are teaching (Walters, 2003). Even in these circumstances however, EBE generally still rate the experience as positive overall (Patterson et al., 2014).

The above research findings predominantly concern EBE with experience of ‘primary’ mental health difficulties. There appears to be a scarcity of research regarding the involvement of EBE living with chronic physical health conditions. There does exist some literature around involvement of EBE living with diabetes, but, in line with research findings into primary mental health conditions, this research has primarily focused on the benefits of EBE involvement for furthering diabetes research, as well as in garnering EBE views as to how research can be enhanced and services can be improved (Dovey-Pearce, Hurrell, May, Walker & Doherty, 2005; Lindenmeyer, Hearnshaw, Sturt, Omerod & Aitchison, 2007; Murad et al., 2011). Further, the experiences of those living with Type 2 diabetes appear to be represented more in these studies than the experiences of those living with Type 1 diabetes.

There does not appear to be any research into the personal impact of acting as an EBE for individuals with chronic physical health conditions such as Type 1 diabetes. Anecdotally, it appears that being involved as an EBE may be associated with reduced distress, improved condition management and increased self-esteem for young people living with Type 1 diabetes. This may be a particularly pertinent observation given that the management of chronic conditions is often burdensome for the individual living with that condition; not only do they have to contend with physical manifestations of the condition, but its management can be complex too (Tran, Barnes, Monotori, Falissard & Ravaud, 2015). In the context of such burden, people commonly experience psychological distress (Polonsky et al., 2005; Naylor et al., 2012). Thus, while chronic conditions such as Type 1 diabetes contribute to psychological distress, psychological distress may also contribute to poor condition management (Brady et al., 2013; Willis, 2014).

The proposed research therefore seeks to address some of the gaps in the literature by investigating the individual impact of acting as an EBE for young adults living with chronic health conditions such as Type 1 diabetes. The researchers are particularly interested in exploring the experiences of young adults living with Type 1 diabetes given that the significant burden of living with diabetes means that the prevalence of mental health issues in young people with diabetes is much higher than in their non-diabetic peers (Hislop, Fegan, Schlaeppi, Duch & Yeap, 2008; Cooper et al., 2017) Further, young people living with diabetes have higher rates of emergency hospital admissions for diabetic ketoacidosis, a serious complication of diabetes that is associated with poor diabetes control (National Diabetes Transition Audit, 2019). Indeed, between the ages of 20 and 39, men and women living with diabetes face a mortality risk of 2.54 and 3.76 times higher than men and women without diabetes respectively, with much of this risk being carried by those living with Type 1 diabetes (Crowley & Matthias, 2017). As a result, it appears pertinent to formally explore the anecdotal observations that EBE activity may be associated with improvements in condition management and distress for this client group. If this is indeed the case, there would be important implications for promoting increased involvement in EBE activity for young adults living with Type 1 diabetes at an early stage in order to maximise health outcomes.

4. Research question

How does involving young people with chronic health conditions in expert by experience activity (e.g. public speaking, staff training or service development) within their services impact on their self-perception and management of their condition?

5. Method

5a. Participants and recruitment

The proposed study seeks to recruit young people, aged between 16 and 35, who have chronic health conditions and who have been involved as experts by experience, either through public speaking about their condition to service staff, in staff teaching or in service development. The study seeks to recruit between six and ten participants. Young people with Type 1 diabetes meeting the above inclusion criteria will be approached for recruitment in the first instance. This approach will be made via a member of the potential participant's clinical care team – the research team will first make the Young Adult Diabetes Service in BCUHB aware of the research and inclusion criteria, along with the adult diabetes services in central and West BCUHB (there is currently only a Young Adult Diabetes service in East BCUHB). The services will then be asked to consider whether they can identify any individuals who fit these criteria who may be interested in research participation. A member of the clinical care team would then present potential participants with a 'Participant Information Sheet' detailing the purpose of the study and what participation involves. It should be noted that the Chief Investigator works within the Young Adult Diabetes Service – to safeguard against any potential conflict of interest, the Chief Investigator will not be involved in approaching potential research participants under her service. Those interested in participating with the research will be asked to complete and return the 'Initial Contact Form'. The Principal Investigator will then contact the potential participants to answer any queries they may have and to make interview arrangements should the individual decide they did want to participate. In the event that insufficient participant numbers are recruited in this way, the study will be advertised on Twitter to UK based participants meeting inclusion criteria - young people with chronic health conditions currently have a strong online presence on such platforms and there is a particularly active Diabetes online community on Twitter. Potential participants who respond to the Twitter advertisement will be provided with an electronic participant information sheet and initial contact form. The Principal Investigator will make contact with potential participants recruited in this way only upon receipt of a completed initial contact form, or if the potential participant makes contact with any queries. Should insufficient participants be available for recruitment from the diabetes population it is proposed that further participants may be recruited from the Young Adult Renal Service in BCUHB, along with the adult renal services in central and West BCUHB (there is currently only a Young Adult Renal Service in East BCUHB), following the same recruitment procedures outlined above. Prior to any interview, the interviewer will confirm informed consent with the participant and the participant will be asked to sign a 'Participant Consent Form' as a formal record of written consent. Parental consent will routinely be sought for any participants under the care of paediatric services.

During the consent gathering process, participants will also be asked if they would like to review a draft of the theory once data collection is complete. They will be advised that this is an optional additional element to the study and that they can opt out at any point.

5b. Measures

The study proposes to implement a qualitative design whereby data will be gathered via semi-structured interview. Broad interview topics and some potential questions are outlined in an Interview Guide document. The interview will be structured loosely around this topic guide, following unanticipated areas of inquiry as identified by research participants. In line with

Grounded Theory principals, the content of the interview guide is subject to some degree of amendment, as determined by themes that emerge from preceding participant interviews. In addition, the following demographic information would be requested from participants: Age, gender, chronic health condition, length of time since condition diagnosis and type of expert by experience involvement (e.g. public speaking, staff training, service development).

5c. Design and Procedures

Interviews would be conducted by the Principal Investigator. In most instances, the interviews would take place in the North Wales Clinical Research Centre in Wrexham. If this were not feasible, participants could be seen at an NHS location convenient for them (e.g. GP surgeries or local diabetes centres), or home visits could be offered subject to risk assessment. Alternatively, interviews could be conducted over the telephone or via a video call if that were the preference of the participant.

At interview, a semi-structured approach will be taken to ask participants about their experiences of being involved as experts by experience and how this may have impacted on their sense of identity as a person with a chronic condition, as well as how it may have impacted on how they manage their health condition. Interviews aim to be conversational in nature and their content will be led by an interview guide comprised of broad topic areas and example open-ended questions aimed at obtaining detailed responses. Interviews will be flexible to follow up on anticipated areas of inquiry introduced by participants. It is proposed that the qualitative data gathered via interview will be analysed in line with grounded theory principles (Corbin & Strauss, 2015). Grounded theory seeks to develop explanatory theories of social processes (Starks & Trinidad, 2007). It is the proposed method for this study given that at present the personal impact of involvement as an expert by experience has received relatively little research attention. Within the grounded theory approach, data is collected and analysed simultaneously (Charmaz, 2005). In this way, the interview guide will be a flexible tool that may be modified between interviews so as to reflect the emerging theory. Further, within this approach, there are no ‘set’ criteria regarding participant numbers, rather it is recommended that participant recruitment should continue until saturation – that is, when no new themes emerge from interviews (Corbin & Strauss, 2015). However, depending on the information/themes contained within the interviews, it may not be possible to attain saturation within the time constraints of a DClinPsy project. The proposed sample size of between six and ten participants is ordinarily considered ample for qualitative DClinPsy thesis projects. Once a theory has been drafted, participants who have opted to do so will be sent a copy of the theory and asked if they would like to provide comments/feedback. This feedback will then be used to further shape the theory/inform the write up of the study.

6. Data management and storage

Interviews will be audio recorded using an MP3 recorder. As soon as practicable following each interview, the audio recording will be transferred onto an encrypted USB device and deleted from the Dictaphone. Interviews will be transcribed anonymously, with identifying information redacted from the transcripts. These transcripts will be stored securely on an encrypted USB device and backed up onto NHS or Bangor University servers. All data will be kept in accordance with BCUHB’s data protection policy. The encrypted audio recordings will be destroyed upon the Principal Investigator’s completion of the doctorate. It is hoped that the thesis will be published. Consequently, upon completion of the thesis project, the electronic transcript data will be retained and stored securely at the Gladstone Centre, Wrexham Maelor Hospital for up to five years, where it will be available for scrutiny should this information be requested post-publication. After this time, all electronic data will be destroyed.

7. Feedback

Participants will be given the opportunity to provide feedback on the initial theory generated by the study. This feedback will be used to further shape the theory and/or inform the write up of the study. Participants will be offered an accessible report at the end of the study which explains the overall results. Participants will also be made aware that a full-text copy of the thesis will be available at Bangor University Library, and that they can receive an electronic copy via email if they wish.

8. Risk Assessment

As noted previously, it is proposed that most interviews would be conducted at the North Wales Clinical Research Centre, but that home visits could be conducted as necessary. If home visits were needed, then there may be an element of risk associated with this. If home visits are utilised, the Principal Investigator will adhere to the BCUHB lone worker policy. Should any participants become significantly distressed during the research process, they will be encouraged to contact their GP and/or a member of staff from the team they were recruited through. If at any point during the research process, a participant discloses serious risk of harm to themselves or others, then confidentiality will need to be broken in line with BCUHB's safeguarding policies.

9. References

Andreassen, T. E. (2018). Service user involvement and repositioning of healthcare professionals: A framework for examining implications of different forms of involvement. *Nordic Welfare Research, 3*(1), 58-69. https://doi.org/10.1826/ISSN.2464-4161-2018-01-06

Barnes M., Davis A. & Rogers H. (2006). Women's voices, women's choices: Experiences and creativity in consulting women users of mental health services. *Journal of Mental Health 15*(3), 329–341. https://doi.org/10.1080/09638230600700664

Brady, T. J., Murphy, L., O'colmain, B. J., Beauchesne, D., Daniels, B., Greenberg, M., . . . Chervin, D. (2013). A meta-analysis of health status, health behaviours, and health care utilisation outcomes of the chronic disease self-management program. *Preventing Chronic Disease, 10*. https://doi.org/10.5888/pcd10.120112

Charmaz, K. (2005). Grounded theory in the 21st century: A qualitative method for advancing social justice research. In N. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research (3rd ed.,* pp. 507-535). Thousand Oaks: SAGE.

Cooper, M. N., Lin, A., Alvares, G. A., de Klerk, N. H., Jones, T. W., & Davis, E. A. (2017). Psychiatric disorders during early adulthood in those with childhood onset type 1 diabetes: Rates and clinical risk factors from population-based follow-up. *Pediatric Diabetes, 18,* 599-606. https://doi.org/10.1111/pedi.12469

Corbin, J. & Strauss, A. (2015). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (4th ed.). London: SAGE

Crawford, M. J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., & Tyrer, P. (2002). Systematic review of involving patients in the planning and development of health care. *British Medical Journal, 325,* 1263-1267. https://doi.org/10.1136/bmj.325.7375.1263

Crowley, S., & Matthias, J. (2017). *All-Wales standard for people with diabetes moving paediatric to adult services within NHS wales.* Retrieved from http://www.cypdiabetesnetwork.nhs.uk/files/4015/2631/0959/Transition_Standard_ReportV8.pdf

Department of Health. (2007). *Putting people first: A shared vision and commitment to the transformation of adult social care*. Department of Health: London.

Division of Clinical Psychology. (2018). *Experts by experience position statement and strategy 2018-2019.* Retrieved from https://www1.bps.org.uk/system/files/user-files/Division%20of%20Clinical%20Psychology/public/Experts%20by%20Experience%20Strategy%202018%202019.pdf

Domecq, J.P., Prutsky, G., Elraiyah, T., Wang, Z., Nabhan, M., Shippee, N., . . . Murad, M. H. (2014). Patient engagement in research: a systematic review. *BMC Health Services Research, 14,* 89. https://doi.org/10.1186/1472-6963-14-89

Dovey-Pearce, G., Hurrell, R., May, C., Walker, C., & Doherty, Y. (2005). Young adults' (16-25 years) suggestions for providing developmentally appropriate diabetes services: A qualitative study. *Health and Social Care in the Community, 13*(5), 409-419. https://doi.org/10.1111/j.1365-2524.2005.00577.x

Health Care Professional Council. (2018). *Service user and carer involvement.* Retrieved from https://www.hcpc-uk.org/education/resources/education-standards/service-user-and-carer-involvement/

Higgins, A., Maguire, G., Watts, M., Rani, S., & Alexander, J. (2011). Service user involvement in mental health practitioner education in Ireland. *Journal of Psychiatric and Mental Health Nursing, 18,* 519-525. https://doi.org/10.1111/j.1365-2850.2011.01698.x

Hislop, A. L., Fegan, P. G., Schlaeppi, M. J., Duck, M., & Yeap, B. B. (2008). Prevalence and associations of psychological distress in young adults with Type 1 diabetes. *Diabetic Medicine, 25,* 91-96. https://doi.org/10.1111/j.1464-5491.2007.02310.x

Khoo, R., McVicar, A., & Brandon, D. (2004). Service user involvement in postgraduate mental health education. Does it benefit practice? *Journal of Mental Health, 13*(5), 481-492. https://doi.org/10.1080/09638230400006742

Lindenmeyer, A., Hearnshaw, H., Sturt, J., Ormerod, R., Aitchison, G. (2007). Assessment of the benefits of user involvement in health research from the Warwick diabetes care research user group: A qualitative case study. *Health Expectations, 10*(3), 268-277. https://doi.org/10.1111/j.1369-7625.2007.00451.x

McKeown, M., Malihi-Shoja, L., Hogarth, R., Jones, F., Holt, K., Sullivan, P. . . . Mather, M. (2012). The value of involvement from the perspective of service users and careers engaged in practitioner education: Not just a cash nexus. *Nurse Education Today, 32*(2), 178-184. https://doi.org/10.1016/j.nedt.2011.07.012

Mjøsund, N. H., Eriksson, M., Espnes, G. A., Haaland-Øverby, M., Jensen, S. L., Norheim, I., . . . Vinje, H. F. (2016). Service user involvement enhanced the research quality in a study using interpretative phenomenological analysis – the power of multiple perspectives. *Journal of Advanced Nursing, 73*91), 265-278. https://doi.org/10.1111/jan.13093

Murad, M. H., Shah, N. D., Van Houten, H. K., Ziegenfuss, J. Y., Deming, J. R., Beebe, T. J., . . . Montori, V. M. (2011). Individuals with diabetes preferred future trials use patient-important outcomes and provide pragmatic inferences. *Journal of Clinical Epidemiology, 64*(7), 743-748. https://doi.org/10.1016/j.jclinepi.2010.08.005

National Diabetes Transition Audit. (2019). *National Diabetes Transition Audit, 2011-2017.* Retrieved from https://files.digital.nhs.uk/14/B263BB/National%20Diabetes%20Transition%20Audit%20-%202nd%20Report%20v1.0.pdf

Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M., & Galea, A. (2012). *Long-term conditions and mental health: The cost of co-morbidities.* Retrieved from https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf

Omeni, E., Barnes, M., MacDonald, D., Crawford, M., & Rose, D. (2014). Service user involvement: Impact and participation: A survey of service user and staff perspectives. *BMC Health Services Research, 14*, 491. https://doi.org/10.1186/s12913-014-0491-7

Patterson, S., Trite, J., Weaver, T. (2014). Activity and views of service users involved in mental health research: UK survey. *British Journal of Psychiatry, 205*, 68-75. https://doi.org/10.1192/bjp.bp.113.128637

Polonsky, W. H., Fisher, L., Earles, J., Dudl, R. J., Lees, J., Mullan, J., & Jackson, R. A. (2005). Assessing psychosocial distress in diabetes: Development of the diabetes distress scale. *Diabetes Care, 28*(3), 626-631. https://dx.doi.org/ 10.2337/diacare.28.3.626

Repper J. & Breeze J. (2007). A review of the literature on user and carer involvement in the training and education of health professionals. *International Journal of Nursing Studies, 44*(3), 511–519. https://dx.doi.org/ 10.1016/j.ijnurstu.2006.05.013

Rooke, C., Jones, B., & Thomas, M. (2014). Including service users in delivering alcohol addiction therapy. *Nursing Standard, 28*(42), 44-48. https://doi.org/10.7748/ns.28.42.44.e8437

Rush, B. (2008). Mental health service user involvement in nurse education: A catalyst for transformative learning. *Journal of Mental Health, 17*(5), 531-542. https://doi.org/10.1080/09638230802053383

Schreur, F. K., Lea, L., & Goodbody, L. (2015). Learning from service user and carer involvement in clinical psychology training. *The Journal of Mental Health Training, Education and Practice, 10*(3), 137-149. https://doi.org/10.1108/JMHTEP-02-2015-0009

Simpson, A., Jones, J., Barlow, S., Cox, L. (2014). Adding SUGAR service user and carer collaboration in mental health nursing research. *Journal of Psychosocial Nursing and Mental Health Services, 52*(1), 22-30. https://doi.org/10.3928/02793695-20131126-04

Simpson, E.L., & House, A.O. (2002). Involving users in the delivery and evaluation of mental health services: Systematic review. British Medical Journal, 325(7375), 1265-1268. https://doi.org/10.1136/bmj.325.7375.1265

Starks, H., & Trinidad, S. B. (2007). Choose your method: A comparison of phenomenology, discourse analysis and grounded theory. *Qualitative Health Research, 17*(10), 1372-1380. https://dx.doi.org/10.1177/1049732307307031

Terry, J. (2012). Service user involvement in pre-registration mental health nurse education settings: A review of the literature. *Journal of Psychiatric and Mental Health Nursing, 19,* 816-829. https://doi.org/10.1111/j.1365-2850.2011.01858.x

Thompson, J., Barber, R., Ward, P. R., Boote, J. D., Cooper, C. L., & Armitage, C. J. (2009). Health researchers' attitudes towards public involvement in health research. *Health Expectations, 12*(2), 209-220. https://doi.org/10.1111/j.1369-7625.2009.00532.x

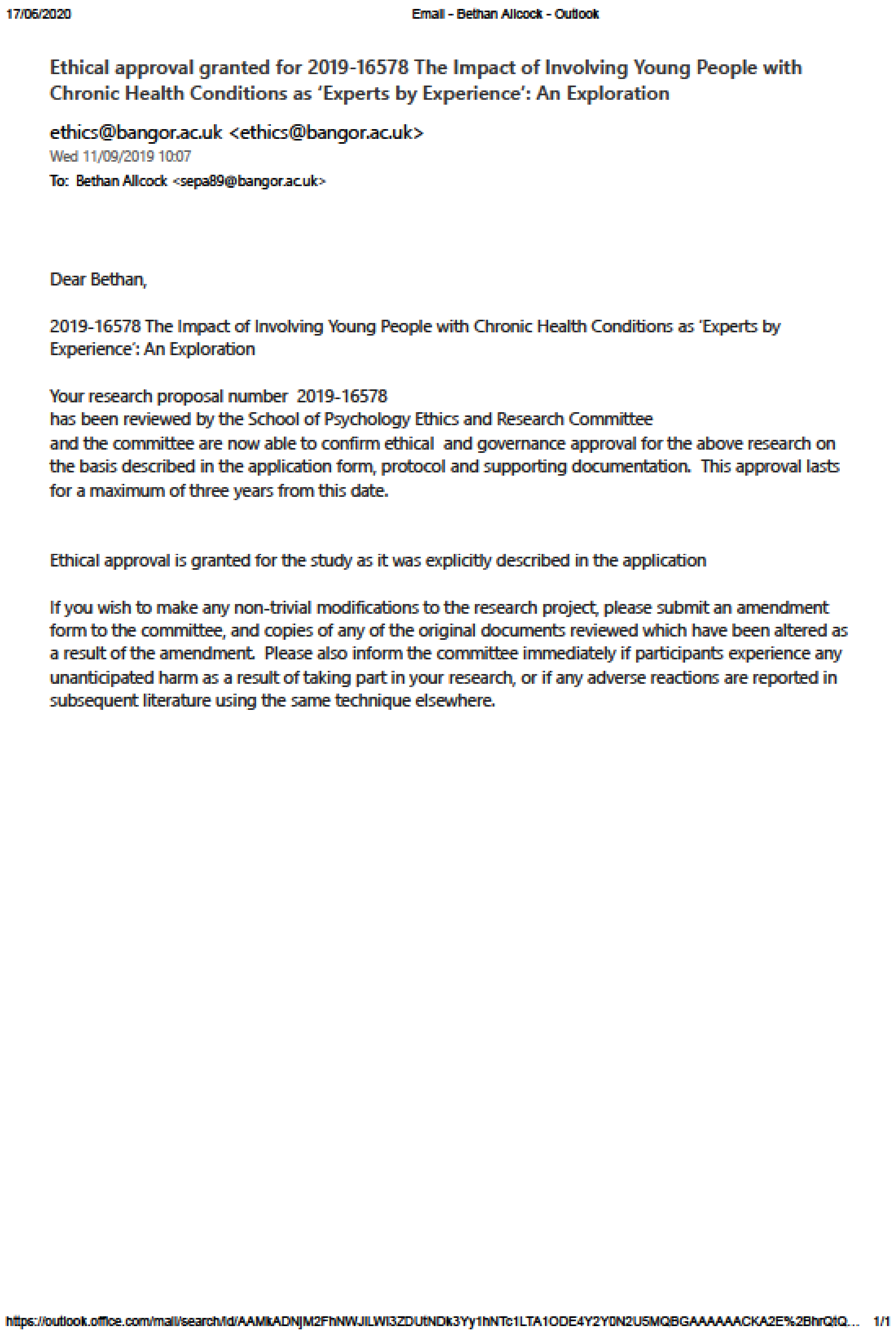
Thornicroft, G. & Tansella, M. (2005). Growing recognition of the importance of service user involvement in mental health service planning and evaluation. Epidemiologia E Psichiatria Sociale, 14(1), 1-3. https://doi.org/10.1017/S1121189X00001858

Tran, V. T., Barnes, C., Montori, V. M., Falissard, B., & Ravaud, P. (2015). Taxonomy of the burden of treatment: A multi-country web-based qualitative study of patients with chronic conditions. *BMC Med, 14*(13), 115. https://doi.org/10.1186/s12916-015-0357-x

Walters, K., Buszewicz, M., Russell, J., & Humphrey, C. (2003). Teaching as therapy: Cross sectional and qualitative evaluation of patients' experiences of undergraduate psychiatric teaching in the community. *British Medical Journal 326*(7392), 740. https://doi.org/10.1136/bmj.326.7392.740

Willis, E. (2014). The making of expert patients: The role of online health communities in arthritis self-management. *Journal of Health Psychology, 19*(12), 1613-1625. https://doi.org/10.1177/1359105313496446

Appendix D: Confirmation of Ethical Approval by Bangor University School of Psychology



17/06/2020 Email - Bethan Allcock - Outlook

Ethical approval granted for 2019-16578 The Impact of Involving Young People with Chronic Health Conditions as 'Experts by Experience': An Exploration

ethics@bangor.ac.uk <ethics@bangor.ac.uk>
Wed 11/09/2019 10:07
To: Bethan Allcock <sepa89@bangor.ac.uk>

Dear Bethan,

2019-16578 The Impact of Involving Young People with Chronic Health Conditions as 'Experts by Experience': An Exploration

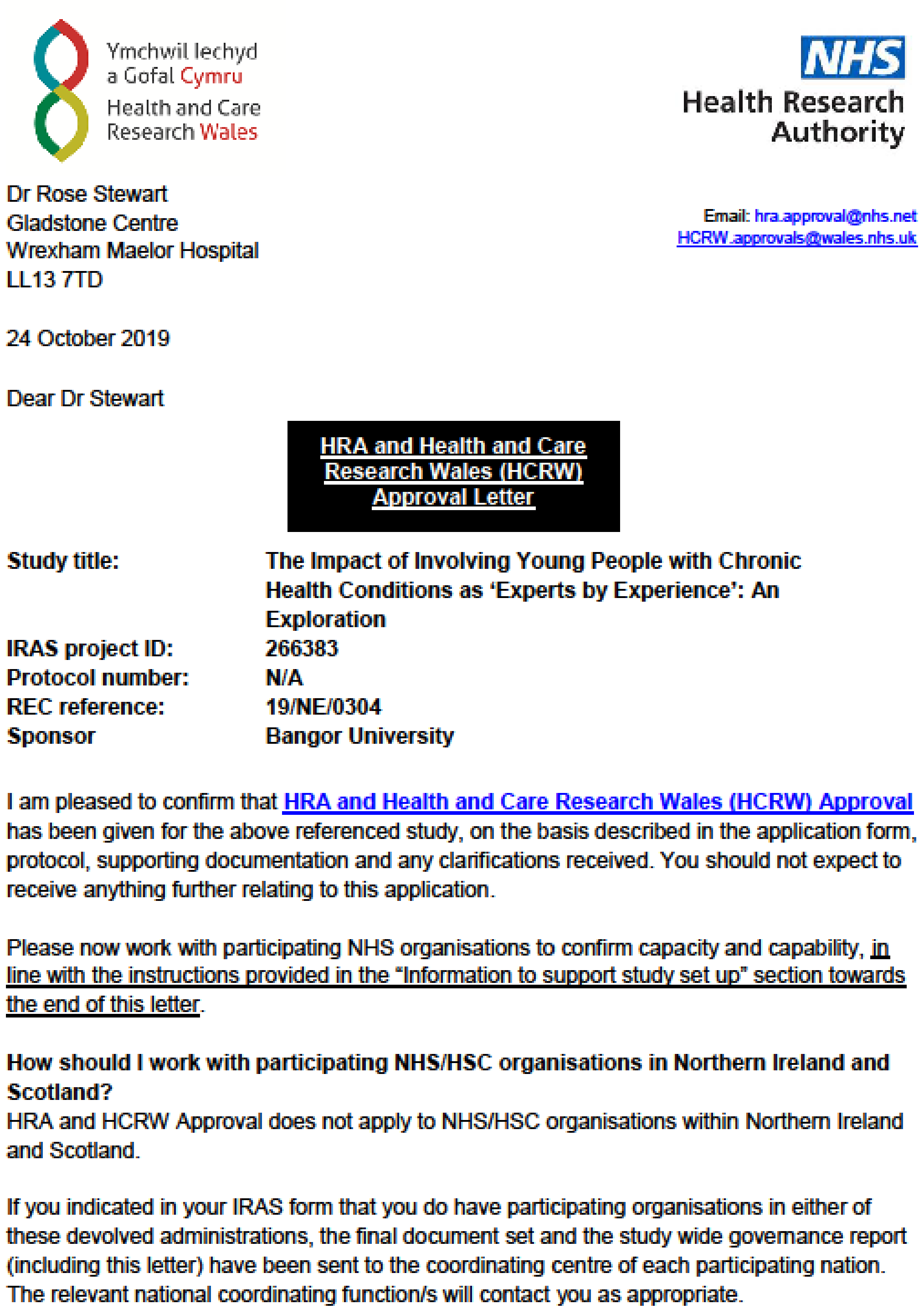
Your research proposal number 2019-16578
has been reviewed by the School of Psychology Ethics and Research Committee
and the committee are now able to confirm ethical and governance approval for the above research on the basis described in the application form, protocol and supporting documentation. This approval lasts for a maximum of three years from this date.

Ethical approval is granted for the study as it was explicitly described in the application

If you wish to make any non-trivial modifications to the research project, please submit an amendment form to the committee, and copies of any of the original documents reviewed which have been altered as a result of the amendment. Please also inform the committee immediately if participants experience any unanticipated harm as a result of taking part in your research, or if any adverse reactions are reported in subsequent literature using the same technique elsewhere.

https://outlook.office.com/mail/search/id/AAMkADNjM2FhNWJlLWI3ZDUtNDk3Yy1hNTc1LTA1ODE4Y2Y0N2U5MQBGAAAAAACKA2E%2BhrQtQ… 1/1

Appendix E: Confirmation of HRA and Health and Care Research Wales (HCRW) Approval



Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Email: hra.approval@nhs.net
HCRW.approvals@wales.nhs.uk

Dr Rose Stewart
Gladstone Centre
Wrexham Maelor Hospital
LL13 7TD

24 October 2019

Dear Dr Stewart

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**The Impact of Involving Young People with Chronic Health Conditions as 'Experts by Experience': An Exploration**
IRAS project ID:	**266383**
Protocol number:	**N/A**
REC reference:	**19/NE/0304**
Sponsor	**Bangor University**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions **document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting** expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

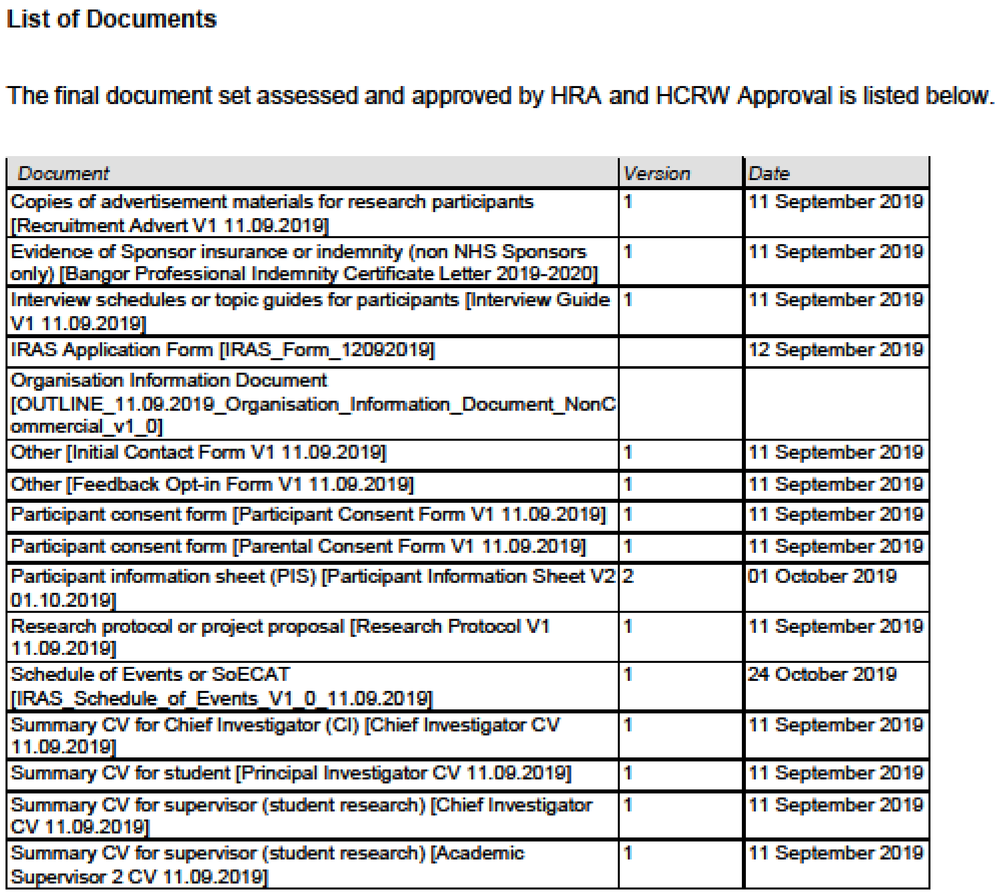
Your IRAS project ID is **266383**. Please quote this on all correspondence.

Yours sincerely,
Steph Blacklock

Approvals Manager

Email: hra.approval@nhs.net

Copy to: *Mr Huw Ellis*



List of Documents

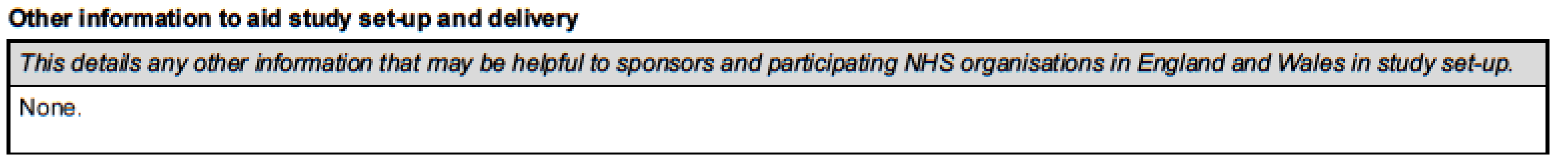
The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Recruitment Advert V1 11.09.2019]	1	11 September 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Bangor Professional Indemnity Certificate Letter 2019-2020]	1	11 September 2019
Interview schedules or topic guides for participants [Interview Guide V1 11.09.2019]	1	11 September 2019
IRAS Application Form [IRAS_Form_12092019]		12 September 2019
Organisation Information Document [OUTLINE_11.09.2019_Organisation_Information_Document_NonCommercial_v1_0]		
Other [Initial Contact Form V1 11.09.2019]	1	11 September 2019
Other [Feedback Opt-in Form V1 11.09.2019]	1	11 September 2019
Participant consent form [Participant Consent Form V1 11.09.2019]	1	11 September 2019
Participant consent form [Parental Consent Form V1 11.09.2019]	1	11 September 2019
Participant information sheet (PIS) [Participant Information Sheet V2 01.10.2019]	2	01 October 2019
Research protocol or project proposal [Research Protocol V1 11.09.2019]	1	11 September 2019
Schedule of Events or SoECAT [IRAS_Schedule_of_Events_V1_0_11.09.2019]	1	24 October 2019
Summary CV for Chief Investigator (CI) [Chief Investigator CV 11.09.2019]	1	11 September 2019
Summary CV for student [Principal Investigator CV 11.09.2019]	1	11 September 2019
Summary CV for supervisor (student research) [Chief Investigator CV 11.09.2019]	1	11 September 2019
Summary CV for supervisor (student research) [Academic Supervisor 2 CV 11.09.2019]	1	11 September 2019

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
All sites will perform the same research activities therefore there is only one site type.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used	No study funding will be provided to sites as per the Organisational Information Document	A Principal Investigator should be appointed at study sites of this type	No Honorary Research Contracts, Letters of Access or pre-engagement checks are expected for local staff employed by the participating NHS organisations. Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on enhanced DBS checks, including appropriate barred list checks and occupational health clearance.



Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
None.

Appendix F: Confirmation of Capacity and Capability at Betsi Cadwaladr University Health Board

17/06/2020 Email - Bethan Allcock - Outlook

IRAS 266383. Confirmation of Capacity and Capability at BCUHB NHS Organisation.

Kelly Andrews (BCUHB - Research & Development) <Kelly.Andrews@wales.nhs.uk>

Thu 12/12/2019 13:39

To: Rose Stewart (BCUHB - Mental Health & Learning Disabilities) <Rose.Stewart@wales.nhs.uk>
Cc: Bethan Allcock <[illegible]@bangor.ac.uk>; Mike Jackson <mike.jackson@bangor.ac.uk>; Huw Ellis <huw.ellis@bangor.ac.uk>; Laura Longshaw (BCUHB - Research & Development) <Laura.Longshaw@wales.nhs.uk>

1 attachments (165 KB)
LOCAL1_1 OID.docx;

Dear Dr Stewart,

Re: IRAS 266383. Confirmation of Capacity and Capability at BCUHB NHS Organisation.

Full study title: The Impact of Involving Young People with Chronic Health Conditions as Experts by Experience: An Exploration.

This email confirms that Betsi Cadwaladr University Health Board (BCUHB) has the capacity and capability to deliver the above referenced study, documents reviewed are those as listed in the HRA/HCRW approved list. **The Organisation Information Document has been attached.**

We agree to start this study on the date you, as Sponsor, provide as the "Green light".

If you wish to discuss further, please do not hesitate to contact me.

N.B. Future submission of amendments, should be sent to our R&D generic inbox: BCU.ResearchApplications@wales.nhs.uk

Cofion, Regards
Kelly

Kelly Andrews
Hwylusydd Ymchwil • Research Facilitator

Bwrdd Iechyd Prifysgol Cymru - Betsi Cadwaladr University Health Board
Ymchwil a datblygiad - Research & Development
Holywell Community Hospital
Halkyn Road
Holywell
CH8 7TZ

E-Bost / Email: Kelly.Andrews@wales.nhs.uk

Ffôn / Tel. External to BCUHB 03000 856767 – Internal to BCUHB WHTN DDI: 856767

Dilynwch ni ar Twitter/Follow us on Twitter: **@BetsiResearch**

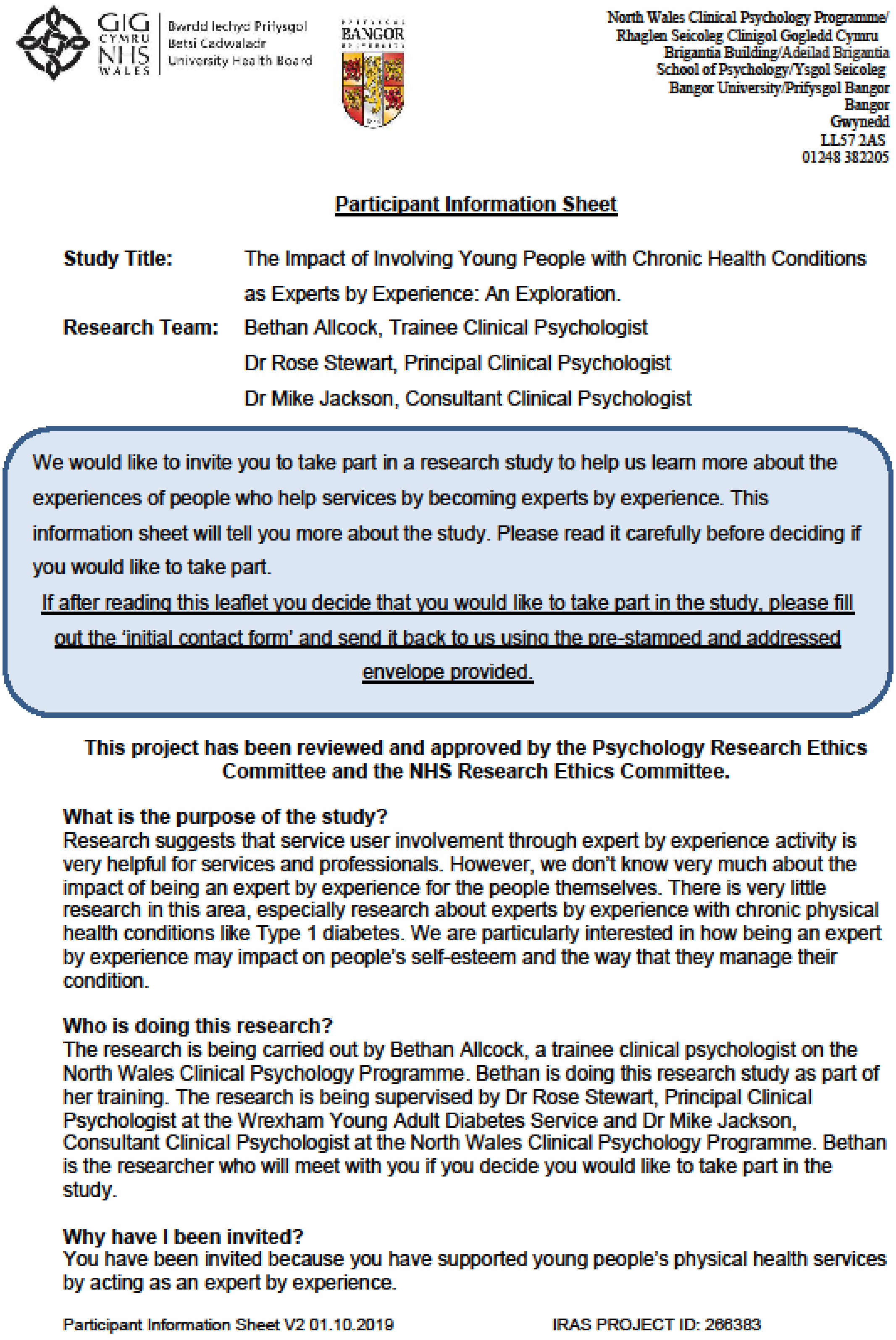
Cymraeg
Rhybudd Ebost (2018) - Bwrdd Iechyd Prifysgol Betsi Cadwaladr
[illegible]
http://www.wales.nhs.uk/sitesplus/861/tudalen/47230

English
Betsi Cadwaladr University Health Board - Email Notice (2018)
[illegible]
http://www.wales.nhs.uk/sitesplus/861/page/47229

Betsi Cadwaladr University Health Board is the operational name of Betsi Cadwaladr University Local Health Board

https://outlook.office.com/mail/search/id/AAMkADNjM2FhNWJlLWI3ZDUtNDk3Yy1hNTc1LTA1ODE4Y2Y0N2U5MQBGAAAAAACKA2E%2BhrQtQ... 1/1

Appendix G: Participant Information Sheet



GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Betsi Cadwaladr University Health Board
BANGOR

North Wales Clinical Psychology Programme/
Rhaglen Seicoleg Clinigol Gogledd Cymru
Brigantia Building/Adeilad Brigantia
School of Psychology/Ysgol Seicoleg
Bangor University/Prifysgol Bangor
Bangor
Gwynedd
LL57 2AS
01248 382205

Participant Information Sheet

Study Title:	The Impact of Involving Young People with Chronic Health Conditions as Experts by Experience: An Exploration.
Research Team:	Bethan Allcock, Trainee Clinical Psychologist Dr Rose Stewart, Principal Clinical Psychologist Dr Mike Jackson, Consultant Clinical Psychologist

We would like to invite you to take part in a research study to help us learn more about the experiences of people who help services by becoming experts by experience. This information sheet will tell you more about the study. Please read it carefully before deciding if you would like to take part.

If after reading this leaflet you decide that you would like to take part in the study, please fill out the 'initial contact form' and send it back to us using the pre-stamped and addressed envelope provided.

This project has been reviewed and approved by the Psychology Research Ethics Committee and the NHS Research Ethics Committee.

What is the purpose of the study?

Research suggests that service user involvement through expert by experience activity is very helpful for services and professionals. However, we don't know very much about the impact of being an expert by experience for the people themselves. There is very little research in this area, especially research about experts by experience with chronic physical health conditions like Type 1 diabetes. We are particularly interested in how being an expert by experience may impact on people's self-esteem and the way that they manage their condition.

Who is doing this research?

The research is being carried out by Bethan Allcock, a trainee clinical psychologist on the North Wales Clinical Psychology Programme. Bethan is doing this research study as part of her training. The research is being supervised by Dr Rose Stewart, Principal Clinical Psychologist at the Wrexham Young Adult Diabetes Service and Dr Mike Jackson, Consultant Clinical Psychologist at the North Wales Clinical Psychology Programme. Bethan is the researcher who will meet with you if you decide you would like to take part in the study.

Why have I been invited?

You have been invited because you have supported young people's physical health services by acting as an expert by experience.

Do I have to take part?
No. Taking part is completely voluntary. We ask that you read this information sheet carefully before you decide. Please contact Bethan if you would like more information or if there is anything you are unsure of (contact details are at the end of this information sheet). If you decide not to take part, **you do not need to give a reason; choosing not to take part will not affect any services you receive in any way.**

Will my treatment or services be affected if I do take part?
No, you will continue to receive the same services or treatment.

What will happen if I do take part?
If you do decide to take part, Bethan will contact you to arrange what happens next. You will be asked to take part in an interview about your experiences as an expert by experience. The int**erview will be 'semi-structured'. This means that Bethan will have some questions** she asks everyone taking part, but you are also free to talk about what matters to you. You do not have to answer any questions that you are uncomfortable with. The interview will be recorded using a Dictaphone. You will also be asked if you would like to review the early findings of the study. Any feedback you provide may be used to shape the study and its write-up. This would be completely optional, and you would be able to opt out at any point.

How long will the interview take?
The interview itself is expected to last around 60 minutes. Some extra time will also be needed to check that you are still happy to be involved in the study, and to answer any questions you may have either before or after the interview. You will be able to take a short break if you want to.

Where will the interview be?
Ideally, the interview would take place at the North Wales Clinical Research Centre in Wrexham. If this was not convenient, you could be seen at an NHS location somewhere better suited to you, such as your local GP surgery or diabetes centre. Alternatively, it may be possible for Bethan to visit you at your home, or the interview could be conducted over the telephone or through a video call if that is better for you. Bethan will contact you to arrange this with you if you do decide to take part in the research.

Are there possible benefits to taking part?
You would be helping us to build our understanding of what it is like to be an expert by experience. Your involvement would help us begin to understand how such activity may impact on the self-esteem and condition management of experts by experience. This may help us to evidence why services should be encouraging more people to become involved as experts by experience. In turn, this means that services could benefit even more from increased support from experts by experience.
You will also receive a gift voucher for £15 at the start of the interview as a thank you for contributing your time and taking part. If at any point you decide that you want to stop the interview or to withdraw from the study, you will not be asked to return the gift voucher.

Are there possible downsides to taking part?
During the interview you will be asked about how your work as an expert by experience may have impacted on your self-esteem and condition management. This may touch on parts of your life that you may have found distressing. You do not have to talk about anything that makes you feel uncomfortable, or that you do not want to talk about. However, it is possible that being reminded of difficult times could cause you to feel upset. If the research team become concerned about your wellbeing, you will be encouraged to contact your GP and/or a member of staff from your health team.

Will my information be kept confidential?
Yes. Any information about you will be kept strictly confidential. At the beginning of the research, you will be assigned a random number, which will be your unique identification number throughout the study. Information about you can only be identified by this unique number, which will be known only to the researchers. Your research data (i.e. your interview and its transcript) will be collected by the researcher. This data will not be linked in any way to your personal details (e.g. name, contact details, etc), which will be stored separately. If, at any time during the study, you disclose any incidents where professionals have acted in an unethical or abusive way towards you, or disclose that either yourself or others may be at risk of serious harm, the researcher has a ***statutory (i.e. legal) requirement*** to breach confidentiality. This means that the researcher cannot keep this information confidential and is required to report this information to the appropriate responsible person or authority. Wherever possible, the researcher will inform you that they will be breaching confidentiality and sharing the information you have provided. The researcher can share this information without your consent if it is felt to be in your best interests, or the best interests of the public to do so.

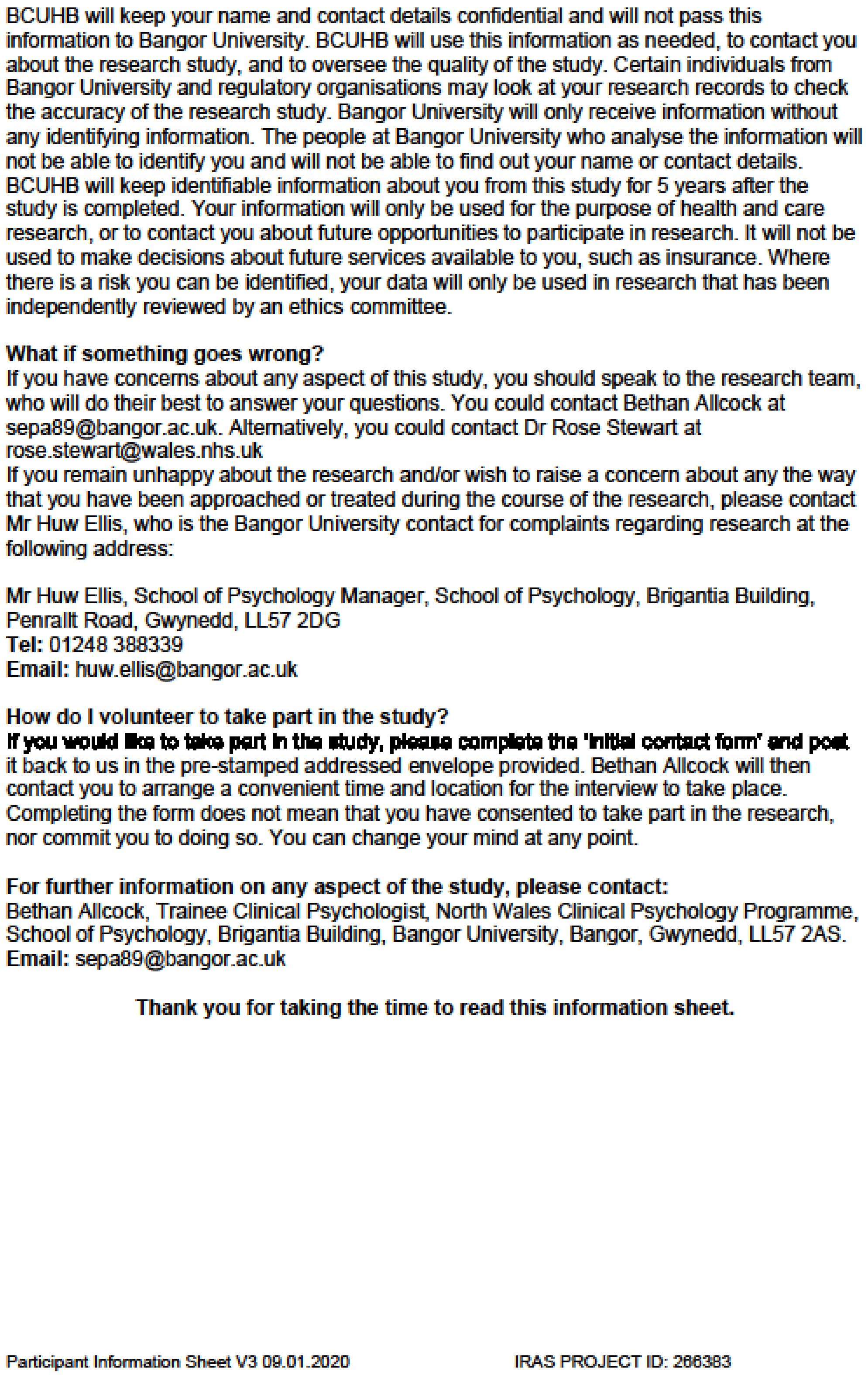
Who will have access to information about me?
Your personal details will be kept strictly confidential. Your name is recorded only for consent purposes and so that the research team can contact you (e.g. with the results of the research). Your personal information will be stored separately from your research data (i.e. your interview). Additional safeguards will be in place, including keeping any data you have supplied, such as your consent form, in a locked filing cabinet. Any electronic data will be stored securely on a password-protected NHS or Bangor University computer. Audio-recordings of interviews will be destroyed upon Bethan being awarded her doctorate. All other data will be retained by the research team for a minimum of 5 years, after which they will be safely and securely disposed of, in line with NHS policies.

What will happen to the results of the study?
The information collected will be written up in the form of a doctoral thesis, a copy of which will be available from Bangor University Library. The study may also be published in academic research articles and conference presentations. It will not be possible to identify any participant individually in any of these publications. The data collected will be combined into 'themes' that may have emerged across all the interviews. There may be some direct quotations, but the research team will ensure there is nothing that makes people identifiable in these. If you decide to take part in the research study, you will receive a letter at the end of the study explaining the overall results, if you want one.

What if I want to withdraw from the study?
You can withdraw from the study at any time before the research is written up in March 2020, and you do not need to explain why. If you choose to withdraw from the study, all your data will be securely destroyed.

Who is funding and organising the study?
The research is organised and funded by the North Wales Clinical Psychology Programme, at Bangor University.

General Data Protection Regulation (GDPR)
Bangor University is the sponsor for this study. The research team will be using information from you in order to undertake this study and we will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Bangor University will keep information for the purpose of this study for 5 years after the study is completed. This information will be held by Bangor University and Betsi Cadwaladr University Health Board (BCUHB).



BCUHB will keep your name and contact details confidential and will not pass this information to Bangor University. BCUHB will use this information as needed, to contact you about the research study, and to oversee the quality of the study. Certain individuals from Bangor University and regulatory organisations may look at your research records to check the accuracy of the research study. Bangor University will only receive information without any identifying information. The people at Bangor University who analyse the information will not be able to identify you and will not be able to find out your name or contact details. BCUHB will keep identifiable information about you from this study for 5 years after the study is completed. Your information will only be used for the purpose of health and care research, or to contact you about future opportunities to participate in research. It will not be used to make decisions about future services available to you, such as insurance. Where there is a risk you can be identified, your data will only be used in research that has been independently reviewed by an ethics committee.

What if something goes wrong?
If you have concerns about any aspect of this study, you should speak to the research team, who will do their best to answer your questions. You could contact Bethan Allcock at sepa89@bangor.ac.uk. Alternatively, you could contact Dr Rose Stewart at rose.stewart@wales.nhs.uk
If you remain unhappy about the research and/or wish to raise a concern about any the way that you have been approached or treated during the course of the research, please contact Mr Huw Ellis, who is the Bangor University contact for complaints regarding research at the following address:

Mr Huw Ellis, School of Psychology Manager, School of Psychology, Brigantia Building,
Penrallt Road, Gwynedd, LL57 2DG
Tel: 01248 388339
Email: huw.ellis@bangor.ac.uk

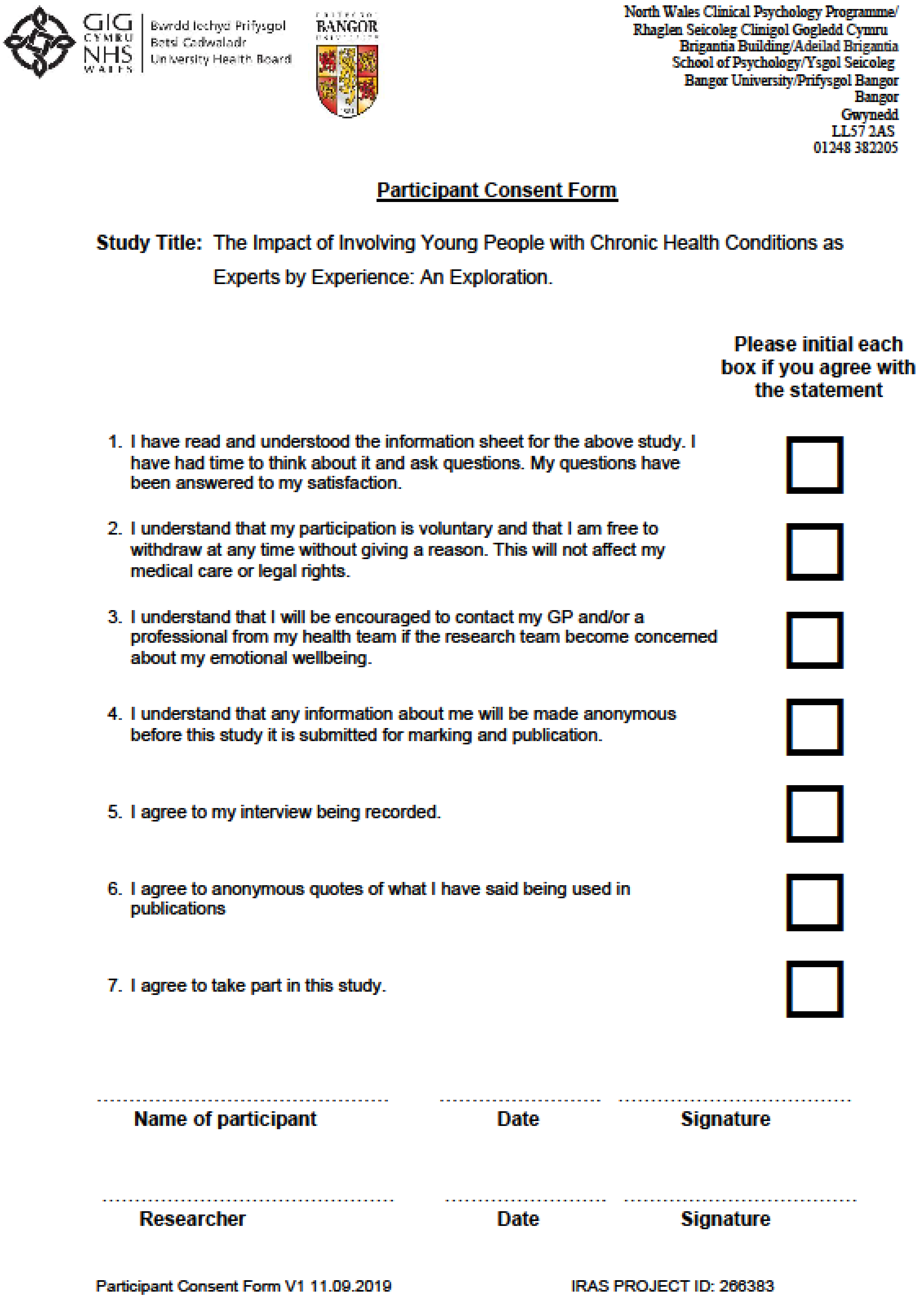
How do I volunteer to take part in the study?
If you would like to take part in the study, please complete the 'initial contact form' and post it back to us in the pre-stamped addressed envelope provided. Bethan Allcock will then contact you to arrange a convenient time and location for the interview to take place. Completing the form does not mean that you have consented to take part in the research, nor commit you to doing so. You can change your mind at any point.

For further information on any aspect of the study, please contact:
Bethan Allcock, Trainee Clinical Psychologist, North Wales Clinical Psychology Programme,
School of Psychology, Brigantia Building, Bangor University, Bangor, Gwynedd, LL57 2AS.
Email: sepa89@bangor.ac.uk

Thank you for taking the time to read this information sheet.

Participant Information Sheet V3 09.01.2020 IRAS PROJECT ID: 266383

Appendix H: Participant Consent Form



GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol
Betsi Cadwaladr
University Health Board

BANGOR

North Wales Clinical Psychology Programme/
Rhaglen Seicoleg Clinigol Gogledd Cymru
Brigantia Building/Adeilad Brigantia
School of Psychology/Ysgol Seicoleg
Bangor University/Prifysgol Bangor
Bangor
Gwynedd
LL57 2AS
01248 382205

Participant Consent Form

Study Title: The Impact of Involving Young People with Chronic Health Conditions as Experts by Experience: An Exploration.

Please initial each box if you agree with the statement

1. I have read and understood the information sheet for the above study. I have had time to think about it and ask questions. My questions have been answered to my satisfaction. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. This will not affect my medical care or legal rights. ☐
3. I understand that I will be encouraged to contact my GP and/or a professional from my health team if the research team become concerned about my emotional wellbeing. ☐
4. I understand that any information about me will be made anonymous before this study it is submitted for marking and publication. ☐
5. I agree to my interview being recorded. ☐
6. I agree to anonymous quotes of what I have said being used in publications ☐
7. I agree to take part in this study. ☐

....	....	....
Name of participant	**Date**	**Signature**
....	....	....
Researcher	**Date**	**Signature**

Participant Consent Form V1 11.09.2019 IRAS PROJECT ID: 266383

Appendix I: Interview Guide

Interview Guide

Demographics

Age:

Gender:

Chronic health condition:

Length of time since condition diagnosis:

Type(s) of expert by experience involvement:
(e.g. public speaking, staff training,
service development)

Was your involvement on a continuous, or one-off basis?

If continuous, how long were, or have, you been involved for?

Introduction

In this interview, I am going to be asking you about your experience of expert by experience activity, and how this may have impacted on you personally. I am particularly interested in how, if at all, it may have impacted on how you see yourself, and how you manage your diabetes. At the same time, you are also free to bring up other related topics that you think could help me understand the experience better.

Broad questions about the experience, e.g.:

- How did you come to be involved in expert by experience activity?
- How was your experience of being an expert by experience? / How did you experience being an expert by experience?
- How does your life before expert by experience activity compare with now?
- What does your work as an expert by experience mean to you?

Questions around personal impact, e.g.:

- Have you noticed any personal changes that have occurred since your expert by experience involvement?
- Are there any ways in which your expert by experience activity has impacted on how you see yourself?
- Are there any ways in which your involvement has impacted on your self-esteem or confidence?

Questions around condition management, e.g.:

- Are there any ways in which your expert by experience activity may have impacted on your relationship with your diabetes?
- Are there any ways in which your expert by experience activity may have impacted on how you manage your diabetes?

Conversation continuers/Probes, e.g.:

- Non-judgemental summary statements of what they have said in question form
- Expression of interest and encouragement to continue via nonverbal communication (e.g. nodding, ‘mhmm’, etc)
- That’s interesting, could you tell me more?
- Can you give me an example of what you mean?
- What did you make of that?
- How did that make you feel?
- How was that experience for you?

Ending questions, e.g.:

- Is there anything else you think I should know to understand the personal impact of being an expert by experience better?
- Do you think there is anything about the personal impact of being an expert by experience that we have missed?
- Are there any other questions you think I should ask?

Appendix J: Examples of Analytic Process

Participant 3, Memo 21
2nd March 2020
Concept: **EbE providing a structure for reflection**
UPDATE 22ND MARCH 2020: Now recoded to: **Building Self-Respect AND Storytelling**

Raw data: *umm it was a chance for me to- not just in that 20 minutes on the podium you know giving the talk, it's the preparation work behind that. I had to, you know I took the time to kind of plot my journey out, which I'd probably never done before, you just kind of, you know, you get on with it. You don't take enough time to reflect on how much umm- or what that journey looked like you know?*

Memo: The benefits aren't only from the talk itself, she got benefit from taking the time to plot out her journey for the first time – kind of like a life-line exercise in assessment? What would it be like if she did not put so much prep time into it? Would it have been less beneficial?

Raw data 2: *it was having the time to think about that and actually go 'wow, in the context of things I'm actually doing okay, I've got my GCSEs, I've got my A Levels, on top of-' you know, they say type 1 diabetes is a full time job but its four and a half full time jobs before you've even had a job interview, you know it's- its relentless. But I don't think the way clinic is set up allows space to acknowledge any of that with any type of clinician. Umm, you know, and there's certainly no psychology, or there wasn't at the time when I was in paediatrics even*

Memo 2: In writing her story, she has been given the space to stand back and recognise how well she coped in spite of all that was on her plate – something that there was no space for with her diabetes team.

Participant 3, Memo 22
2nd March 2020
Concept: **EbE and reflecting on her story has allowed her to get to know herself better**
UPDATE 1ST APRIL 2020: Now recoded to: **Storytelling**

Raw data: *So I think it allowed me to just have a bit of a think about things and get to know how I thought about things*

Memo: It has given her better insight into the way she is

Participant 3, Memo 23
2nd March 2020
Concept: **Ebe has increased her reflective capacity**
UPDATE 1ST APRIL 2020: Now recoded to: **Storytelling**

Raw data: *once you start- once you sort of- you see that a little bit, you realise 'actually, I need to reflect on stuff, this is-' you know and I've done more reflecting now since that period of time when I was asked to do that than I probably ever did before and that's been really really useful and really powerful.*

Memo: After realising the benefits of reflection, she has done more and more of it and she has learnt how useful and powerful it is to do – but what does she mean? In what ways is it useful and powerful?

Participant 3, Memo 24
2nd March 2020
Concept: **Reflecting on her experience has led to decreased resentment toward her team**
UPDATE 21ST MARCH 2020: Now recoded to: **Changing Dynamics with Healthcare Professionals**

Raw data: *So umm and I think as well it allowed me to- with that reflection be able to take a step back in my own clinic experience since then of actually 'my doctor knows a tiny little element of my life, I know me, I know the full story and what I think I'm being told and what I'm actually dealing with are often different things'. So it allows me to- I think its helped me to have a bit [pause] bit less resentment towards a lot of my team that I think I've built up for a number of years where I just didn't think they understood what this meant for me as a young person for a vast number of years*

Memo: Her increased reflective capacity has made her less resentful toward her team as it has enabled her to step back and recognise that they only see a small part of her, whereas before she had understood this in the context of them not listening or understanding her – this stepping backwards has enabled her to recognise the reasons for this and that perhaps these reasons aren't as damning as she had originally thought

---

Participant 3, Memo 25
2nd March 2020
Concept: **Exceeding your own expectations**
UPDATE 1st APRIL 2020: Now recoded to: **Building Self-Respect**

Raw data: *And I think there's an element of doing something that you never thought that you could do in the first place which was stand up and public speak and things like that*

Memo: Again, there is something powerful in doing things you didn't think you could do. This is something that has come up a few times across interviews now

---

Participant 3, Memo 26
2nd March 2020
Concept: **Being your own psychologist**
UPDATE 1ST APRIL 2020: Now recoded to: **Storytelling**

Raw data: *I think if somebody had probably asked me to do that, sit down and you know go through that, I probably wouldn- I'm not sure if I'd have been able to do that at the time and I'm not sure if being asked to do it would have probably made me, I don't know, I didn't go through this but you know if like, I'm wondering- I look back now and think like if a psychologist had asked me to explore some of those things, would I have been more [pause] emotional about it? But actually it was more powerful because it was umm [pause] it allowed me to explore the emotional side of diabetes but I didn't really get emotional about it. Does that make sense? Like it wasn't forced*

Memo: This is her response to me asking what it had been like to sit down and really reflect on her experiences in order to write her story. It sounds as though the timing of doing this was important – she may have been resistant to doing it at the time. She likens her experience to what it might have been like to sit with a psychologist and do this – maybe with a psychologist she might have become more emotional. To her mind, it was more powerful for her to explore the emotional side without getting emotional – what is that about? By not getting emotional, does that mean it was safer? Or maybe that she could take more of a 'wise mind' stance? It is interesting that she mentions a psychologist. Is this something she has thought about before? Is it because of my profession? Is it because of the way I asked the question? Is it like therapy to her?

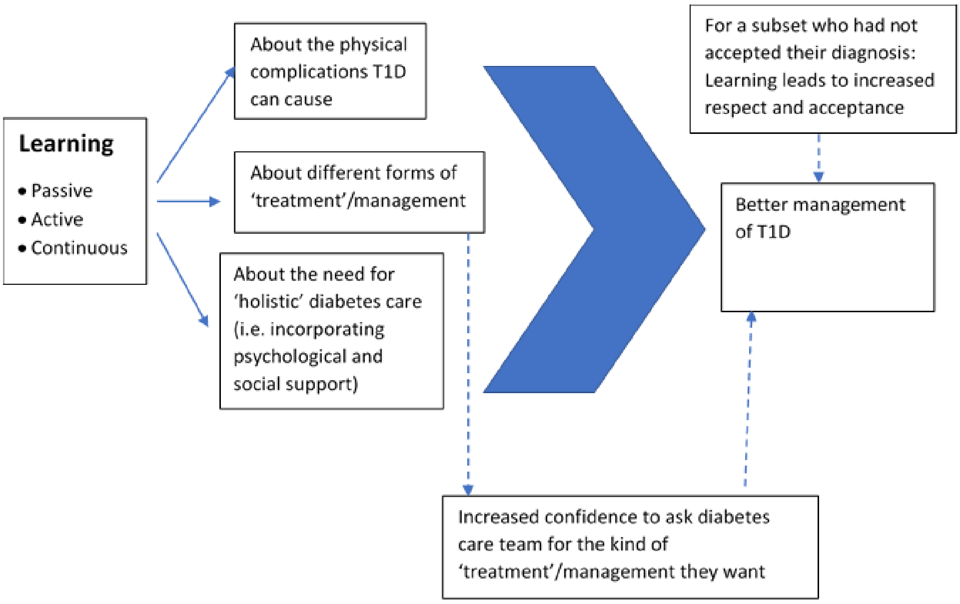
Summary Memo – **Learning**

Date: 21st March 2020
Concept: Learning via EBE – Now recoded to: **Learning**
Memos referred to in this summary: P1M10, P2M19,20,21,24&39, P5M11&13, P6M6, P7M7&9

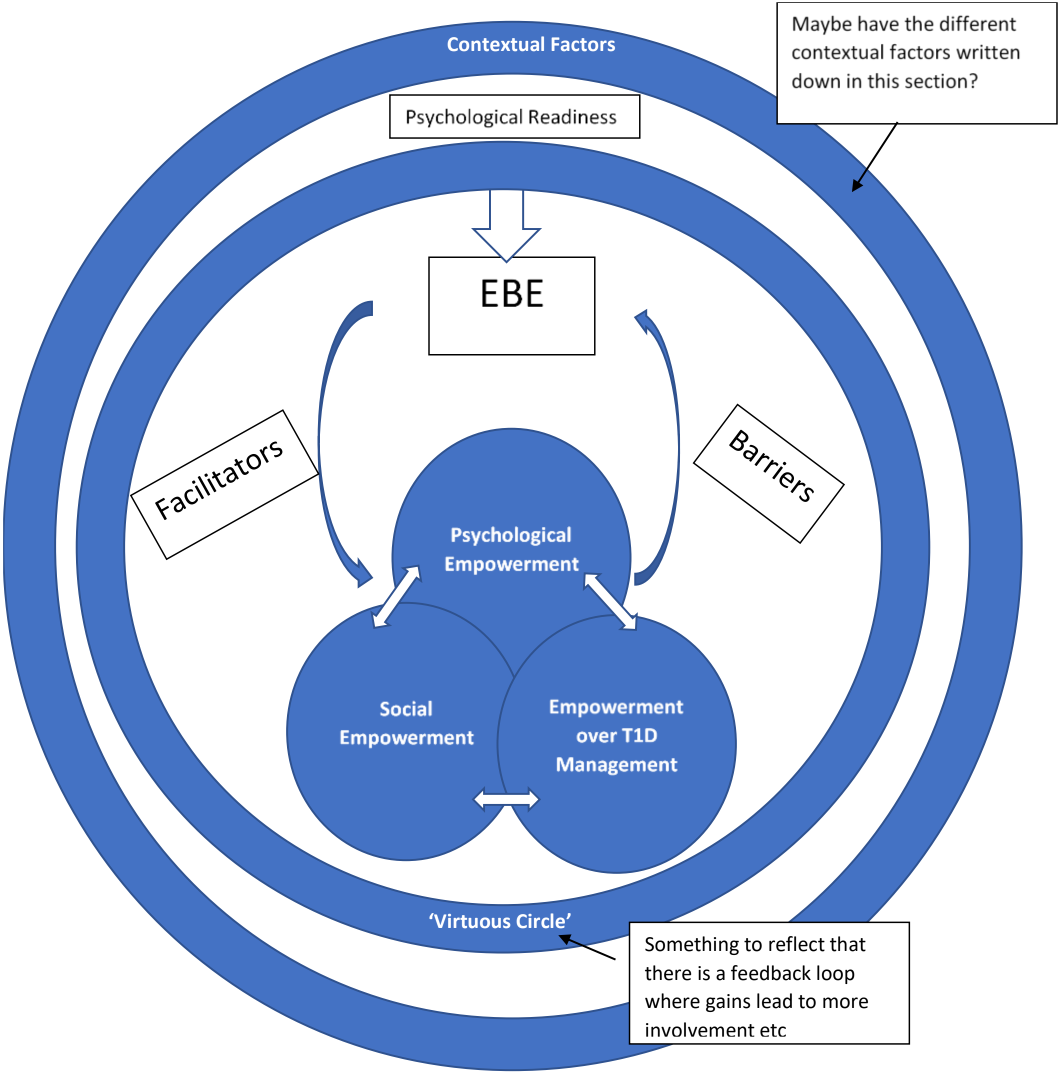
Memo
The idea of learning in the context of EbE has come up a few times in the interviews.
In the context of learning about diabetes:

- the learning can be passive, through listening to what others have to say at the EbE events they are attending (e.g. those teaching or speaking at conferences listening to their fellow EbEs or speakers) or active, through research for doing their talks or by asking questions stimulated by new things they have discovered via EbE work.
- The learning is continuous and constantly developing, it does not appear that there will be a stage during which learning about diabetes is finished
- The learning may be about lots of different things too; they may learn about diabetes as a physical condition, different forms of treatment or management, and about diabetes care being "way more holistic than just the physical" (P5M13)
- Through gaining this knowledge, participants expressed having the opportunity to better manage their diabetes (i.e. by learning more about the importance of good management, by knowing what advice or treatments to ask their team for and by having the confidence to ask these questions)
- For a subset of participants, the learning that took place through EbE helped them both to recognise that they had not yet accepted their diagnosis, and then through the learning they learnt to respect the condition more, and to accept that it was lifelong and that they would need to manage it, thus leading to better management. For those participants, there was a strong theme that you need to accept T1D to move forward with better management, and that EbE was a facilitator of the acceptance process via learning about the condition

So in terms of how the learning process might work and fit with other concepts or categories in the study:



Date: 9th April 2020
Initial integrative Diagram



Maybe have the different contextual factors written down in this section?

Something to reflect that there is a feedback loop where gains lead to more involvement etc

Is this too basic? Could possibly put the different concepts underpinning each of the subcategories in the intersects of the circles? Not sure if this would look too busy and wordy though? Could have arrows coming from each of these to demonstrate where these things fall out of?
Is the 'virtuous circle' element redundant given that all of the arrows do show the linkages back and forth between empowerment and EbE? It is an important concept on its own though as memos underneath this concern stuff like EbEs advocating for more EbE availability and also speaking about how it opens up career prospects

Appendix K: Table of Additional Quotations

Psychological Readiness	
"*Then I got my insulin pump and then everything changed and so I started being more involved with [EBE]*" (Participant 1) "*And uhh at this kind of point, to myself, I was still like 'don't care', like 'it's me, like I really don't care' and it was the emotional impact it had more on my [sibling] that I saw and uhh [pause] that kind of put things into perspective a lot… uhh so it was, it was my [sibling] that kind of kick started, kick- kicked me up the arse as some people might say*" (Participant 2) "*Because I was given that opportunity at a specific time, it was a bit of a turning point, I was AGE when it first happened, I think I have also been asked to do things now NUMBER years on from a patient experience point of view where I've actually felt I could give that baton to someone else … I don't need to take this on now… those opportunities need to come, but they need to come at specific times for people*" (Participant 3) "*I actually wanted to do something umm in diabetes… but uhh I never could find the vehicle and I think it was- I wasn't ready, I don't think I was quite ready uhh lots of things psychologically weren't there for me yet but- it was only at that point where I felt I'd reached my ceiling and- my- almost like a huge goal in my mind that I wanted to share*" (Participant 4) "*You know I always wanted to do that, it was always just about finding the right time, the right moment and having the right experience to do it?... it took years to do it but got there eventually*" (Participant 4)	
Facilitators	
Team Support	"*It can be nerve-wracking but there's always been someone there to make sure that I'm constantly- am I okay and things like- they've never kind of left me to be like 'oh you're doing this in front of 150 people' like 'have fun!' … there is that always that build up, but as soon as I'm there and like we start chatting to people and things like that I think it does help me calm down a bit more and I do have strategies now where I don't actually look at people [inaudible] up at people*" (Participant 2) "*Met them twice beforehand to check that they were comfortable in what they were saying. There's obviously gonna be nerves and that kind of thing… There is an element of coaching beforehand as well, you can't just expect anyone to rock up on a podium and things*" (Participant 3) "*It was quite relaxed cos like [health care professional]- she was in my team as a child, so she was like probably like my little safety net, and she came*" (Participant 6)

Transferrable Skills	“*My professional background is, I’m a [profession] by background and work with young people with sort of, low confidence, low self-esteem and so I thought ‘actually, I could bring that in to’- I see a lot of that in people who are- young people with diabetes as well and I’m not sure we always touch on the confidence element of things, we always kind of sort of stick on the medical side of it”*(Participant 3) “*At first I was a bit unsure cos I absolutely hate public speaking and speaking in front of people but [pause] I think its just, especially being back in [education], umm I have to do like presentations and they’re only in front of my class and things like that so they’re only small, but they do help me build confidence. Umm and especially the job I’m in now, but I’ll be leaving hopefully soon, they do, it kind of, it does build your confidence with people and being able to speak to people properly or, just having the confidence to say something at all [pause] uhh, so it just the confidence building cos in [education] I- before [education] I never would have done anything like that before”* (Participant 2)
Planning	“*It might be easier for me to draw on it technically sometimes but obviously not everybody understands diabetes so we- learning like simpler ways of explaining has helped me in a way to explain it further cos a lot of people understand it better”* (Participant 2) “*I couldn’t even speak openly I had to stick to the piece of paper and explain like ‘I’m just gonna read this out’”* (Participant 3)
Barriers	
Tokenism	“*If they don’t want the help then they don’t need to take that help or advice but, we are there to help them as much as they are there to help us… we live with the diabetes, we’ve got the experience so they should listen to us more, but some don’t like listening. They like to think that they know everything. Umm. So yeah, it’s a bit of a win-win situation, they just need to listen to the patients more than shrug them off… they’ll learn a lot more from patients than a book”* (Participant 1) “*I definitely think there’s some things I’ve been involved in where I feel I’ve been asked because I’ve ticked a box as being a person with diabetes involved, and there’s other things I’ve been involved in where I feel fully part of that process, where my voice is actually important enough to be wanted to be included. And there’s a big difference in that. Like sometimes you kind of feel a bit like a tokenistic ‘oh we’ve got somebody involved’. So it can really differ. And I think as well like sometimes you can tell if you’ve been asked to just look at something so that it’s been put in front of somebody with a condition and its ticked that box, or if you’ve been involved in ‘okay we’re gonna create this, what does it need to include?’ from the very beginning”* (Participant 3)

Practical Difficulties	"*It can be nerve-wracking but there's always been someone there to make sure that I'm constantly- am I okay and things like- they've never kind of left me to be like 'oh you're doing this in front of 150 people' like 'have fun!' … there is that always that build up, but as soon as I'm there and like we start chatting to people and things like that I think it does help me calm down a bit more and I do have strategies now where I don't actually look at people [inaudible] up at people"* (Participant 2) "*I think there's always downsides to public speaking I think there's [pause] you add extra strain, emotional strain definitely, to doing it umm, nerves stood in front of- If anyone ever says that they're okay standing in front of 100 people and doing a talk, they're talking absolute nonsense. So there's- you know, that's one thing, there's a bit of a strain to it"* (Participant 4) "*You don't know what's gonna be thrown at you either like, you stand in front of these and you might have some really dodgy questions. And I have had a dodgy question or two"* (Participant 4)
Feelings of Overwhelm	"*I think that's one of my bigger learning curves what I had to be able to do after- learning all of this because it is an endless amount of information umm you have to be able to make sure you can sit down like 'what headspace am I in?'"* (Participant 2) "*I was finding that like, I'd have my appointment and then at the end or the beginning we'd have a quick chat about 'oh what needs to be done next' and 'what's going on?' And then I said, 'do you know what, I need to keep these separate' and they totally agreed… now my clinic appointments are just for me, they're not about the project, they're not about umm [pause] yeah they're not about any of that stuff"* (Participant 5) *"I feel scared and so going to [event] I was like *gasp* 'I don't wanna speak in front of everybody' whereas [peer] was like 'yeah I wanna do this, I wanna do that'. I think I very much keep myself to myself in my own little shell… umm yeah its- its nice, its nice to be involved. But sometimes I think it is a bit over my head, I'm like *laughs* 'what is this?'"* (Participant 6)
Psychological Empowerment	
Paying it Back	"*I went to one of the [event] days… I signed up to it and I went along to it and I met other people there umm and I met [person], who works [as an EbE] and [they've] just been a rock then as a person… [they] just kept pushing me, pushing me, telling me do this, do this, do this and because of [person] I seen what [they've] come from, like from where [they] was to now and [they] had a similar story to me… Because of [person], obviously with the work [person] does now, I'm like 'look, I need to help out some way'"* (Participant 1) "*Because it such had- it's had such a positive effect on- on me … it's all had such a positive impact its easier for me now to start raising awareness with [healthcare professional] because you- we, we don't understand how important it is. And still a*

	lot of healthcare professionals don't understand how important it is. So umm this is why I go round and I- even though I'm in [education] myself and I have a full time job, but I always try to help as much as I possibly can" (Participant 2) "*I was unemployed I wanted to change things for younger people with diabetes cos that experience was awful and I found that they didn't really prepare me for young adult life with type 1 diabetes, they just- it's the medical side but I'm not in hospital most of the time I'm able to come in three times a year if I'm lucky. You know, so diabetes doesn't belong in a hospital, it belongs everywhere else and that doesn't happen- that never comes to the table in clinic settings or you can't explore what that means so [pause] and I think that's something that having that 20 minutes on a podium gives you is that 'hang on now, you're gonna listen to me on what diabetes means for me rather than what you think it means like my numbers'"* (Participant 3) "*I've gone full circle and kind of used all of that experience in between to hopefully now do something positive and that's- I suppose that comes into some of the reasons why I do the talking and standing there trying to help healthcare professionals its trying to give them a bit of a flavour of what it is like and uh some of those challenges"* (Participant 4) "*Obviously I'd heard of diabetes, but I'd never dealt with it, had anybody told me they were diabetic. I never knew anybody with diabetes and had I met somebody that did, truthfully I wouldn't have thought an awful lot about it. I never realised how serious it was umm and how much you know it involved, you know? Umm so when they approached me about doing it, I just thought 'if it can help somebody else that's gonna be in that position and give them a little bit of an insight and let people know that they're gonna be okay' you know, cos that would have really helped me if I'd have had something like that. And when I was diagnosed, I took it really hard umm so again if there'd been something that would give you that bit of reassurance from other people that are dealing and living with it, you know, that would have helped me. So it really interested me, just to help other people you know?"* (Participant 7)
Being a Voice	"*Umm its making sure that other people that do- are a bit quiet- cos I am not a person to be quiet either, if I've got something wrong I will let them know *laughs* erm but its- its making sure that other people other than me that may be a bit quieter with things, or a bit shy of being able to raise concern umm that they are heard no matter what… that's basically my point that people do have a quieter voice uhh need to be listened even if it is really quiet."* (Participant 2) "*Not everyone is like me. Someone might be extremely quiet their diabetes might be giving them such anxiety, which it can do… but like I said, I can voice my opinion, other people can't. Well, they can, but other people may find it difficult to"* (Participant 2)

	"*You know, that's something I definitely try to teach young people it's like 'you can argue back, not as in argue, you don't have to be nasty about it but you can have a voice you know? Like use it'. And that's the thing whether you use it in clinic, or a podium or online, or whatever it is that you use, it's important to nurture the confidence to do that I think and I don't think you'll change healthcare until more people- I don't think that- I think that's why I do with diabetes, the patient voice thing, or whatever*" (Participant 3) "*We're trying to make a difference through using our voice that's- I dunno, you hope that somebody's gonna listen*" (Participant 4)
Coming out of Hiding	"*Being able to talk about diabetes without the fear of feeling judged and, or somebody's judging me on my outcomes umm you know, just allows you to just be kinder to yourself I think and have a different umm different approach*" (Participant 3) "*Yeah massively, massively. Umm I think if you asked anybody I knew uhh before and after, I think there's umm, there's a huge amount of sh- there's a confidence shift. I've become far more comfortable in my own skin umm from sharing what I live with uhh [pause] just- I uhh- it's like a weight off your shoulders its umm feeling accepted for the first time, feeling umm- and even just you know simple, uhh I say simple things but- the treatment, like- for the very first time I'm sitting at tables doing my injections in front of people. Now, when I was- before this, I would be going to the toilet, I'd be hiding it, I'd be leaving the room, to not to- to ensure that I didn't have to do my injections in front of people, or my testing I would hide in the bag*" (Participant 4) "*Yeah challenges for me were huge around anxiety and definitely that's got easier. I think that's got easier as I've shared more of the worry, and more of the worry around the diabetes we've been talking about it, makes it a little easier…. being more comfortable to not have that extra thinking process of 'what are people thinking right now about my diabetes?'… I worry less about what other people think which was a diabetes-driven thing like you're thinking about the stigma, what does somebody think of this? What does somebody think of what I'm injecting? And because I was more comfortable sharing it, I worried so much less about that part. So that drives a little bit of worry out of my head which is good cos if I've already built that- that anxiety thing in my head that there's a little bit of it that's been shifted on cos of me being able to talk about it more*" (Participant 4) "*I actually have gone from completely hiding my diagnosis from my friends to now being like an advocate for it and like seeking out ways to talk about it and teach people about it*" (Participant 5)

	"*I think it again it just comes down to being more open? And having gone from hiding diabetes and being really ashamed of it to 'actually do you know what this is a massive part of my life and I do struggle with it?' So I've kind of allowed myself to show my weaknesses and my vulnerability umm and given myself permission to ask for help. Umm and that its okay not to be okay…. It's helped me to slow down in life and I don't just have to carry on and get on with it, I can umm [pause] things slowly and it's okay to struggle"* (Participant 5) "*I think probably hugely have gained loads of confidence from it but as a person I am very confident but as a diabetic I'm not. So I am very out there and would do anything, if somebody was like 'are you diabetic?' I'd of cried in my shell years ago"* (Participant 7)
Building Self-Respect	"*I personally am like 'oh my god as if I did that' kind of vibe like"* (Participant 2) "*And I think there's an element of doing something that you never thought that you could do in the first place which was stand up and public speak and things like that"* (Participant 3) "*On one hand I think I was able to look back and think that I'm incredibly lucky umm and being able to do the things I've done all throughout my life and on the other hand it's also made me realise I'm actually quite, I'm far more resilient than I would ever- than I was ever sort of patted on the back for again in clinic, and it always comes back to that never being good enough in my clinical experience"* (Participant 3) "*Sometimes there was a little bit in that early learning about 'come on, if I can get on a podium and talk about 'x' I can do 'y'' and things like that so it might be on odd days where I was struggling a bit more it kind of gave me the confidence in kind of like, 'if I could do this, I could do that' and reach back and use that going forward as well in thinking… it was good to have that to refer back to and I'll always have that to refer back to. I mean, I'm NUMBER years down the line now and I'm talking quite openly about that first experience quite a lot so it's something that you can't really- that you'll always have, you know?... that's something you will always have to refer back to and hopefully continue to grow from…There's definitely been a lot of growth I think, in myself as a person with diabetes and just as a person since then. Umm which I'm really grateful for"* (Participant 3) "*I think it's given me some more grace with myself"* (Participant 5)

	“*I’d probably say it helped my confidence because I’m quite a shy person… I thought ‘oh I’m gonna be really sort of, you know’ but when I watched the films, I was really pleased that I came across the way that I did, you know? So it did help my confidence in that aspect, yeah... I was just worried how I would come across cos, like I said, I’ve never done anything like that before umm and like I wouldn’t be the type of person to like speak out in public or anything because I would be too nervous, you know? So I was a bit worried that when they were doing the filming and stuff, would I say the right thing or the wrong thing? Will I act in a certain way that I don’t mean to? So that was just all sort of like on my mind, you know? So when I saw it and, you know, I was just pleased that I came across okay and I didn’t say anything wrong... So I was worried but umm it all came out really really well. So yeah that gave me a boost after I saw it then because it did turn out so good”* (Participant 7)
Storytelling	“*Once you start- once you sort of- you see that a little bit, you realise ‘actually, I need to reflect on stuff, this is-‘ you know and I’ve done more reflecting now since that period of time when I was asked to do that than I probably ever did before and that’s been really really useful and really powerful”* (Participant 3) “*We only ever have the one model of care that’s quite medical and do nothing else differently about that as well’. So, yeah, I was able to look back and- and just think about all this stuff in a way that I never had before and had I not had these experiences I probably still wouldn’t have had the chance to do that because nowhere in my care does that happen. You know? Nowhere am I asked to reflect and [pause] if I am asked to look back its only ever at, you know, my numbers and what I did wrong. So for example, if I go into clinic, the common thing is you know ‘oh your bloods are 24 here’. You’re pointing out something that for me then is obviously a fault which translates into a failure you know? And that builds up over time”* (Participant 3) “*It was a chance for me to- not just in that 20 minutes on the podium you know giving the talk, it’s the preparation work behind that. I had to, you know I took the time to kind of plot my journey out, which I’d probably never done before, you just kind of, you know, you get on with it. You don’t take enough time to reflect on how much umm- or what that journey looked like you know?”* (Participant 3) “*I’ve been able to be a bit more open with my family cos I’ve kind of got that sense of ‘okay, if I can talk to a room full of strangers, I can have a little discussion with my family’…. So I’ve been able to tackle really difficult situations umm with a bit more confidence, and a bit more removed because I feel like I’ve been able to maybe deal with things umm in a different way, on my terms, wasn’t forced into doing that but I’ve been able to have conversations I couldn’t have had previously”* (Participant 4)

	"*Just being comfortable as a human… hiding things is just not a comfortable place to be and you do that- you walk through life doing that because you worry about judgement, you worry about stigma, you worry about the things that people attach to you and assume about you based on their, their own ignorance… So it teaches you to be like that, especially when you're a child and you don't get to voice that and I never had the chance to really talk about that, that you- that's the way your brain then is always and until something maybe like this happens, until all of a sudden you get a chance to share it and offload it and this has become… a way of offloading it… its helped change a hell of a lot for me psychologically definitely"* (Participant 4) "*I think just being able to process it and talk about it with the team has made me- it's kind of broken the shame of it a lot, you know?"* (Participant 5)
Feeling Valued	"*And they're grateful for it…and it's just satisfying to make sure- cos I felt lonely I don't want others to feel lonely"* (Participant 1) "P*eople were constantly coming up to me and consultants and other professionals and they were like 'oh my god I'm really sorry I was crying listening to your story' and I'm like 'ohhh god' and they were like 'no'"* (Participant 2) "*I think yeah, it does make you think like something must be going somewhere if people are coming up approaching me and things like that"* (Participant 2) "I*t's been umm probably the best thing I've ever done umm in terms of how its helped people"* (Participant 4) "*I'm very proud… its uhh a bit mad when I think about it… sometimes its mindblowing… it does help to think back on what we've achieved but yeah its uhh sometimes I have to pinch myself"* (Participant 4) "W*hen we got there all our names were set out and stuff and it was really professional, yeah it was good yeah"* (Participant 6)
Social Empowerment	
Changing Dynamics with Healthcare Professionals	"*I used to go there and they used to be, umm, quite – I thought they were being quite rude and stuff like that. So I would be rude and whatnot back. And I thought they wasn't listening to the patients. Umm. But since getting involved with [organisation] and stuff like that, ummm, I managed to find out that a) they're just nurses and b) they're doing their job and it's not the nurses fault that I can't get an insulin pump, it's down to the consultant and this and that. Umm. But I used to miss appointments and stuff and now I go to them every time"* (Participant 1)

	“*Cos my diabetes team know I do things for charities I guess, or they know that I do stuff, I guess they look after me better I guess. Cos they know if I don’t I could get them in trouble, maybe? But I feel like- that’s what I feel like because I know people won’t be able to change insulin pumps every year and stuff like that whereas I was allowed to… I just feel like my diabetes team know that I do all this stuff and I’m on the [panel name] so they look after me very well. Umm whereas I’ve spoken to people that go to the same hospital as me that are on insulin pumps and they feel like they’re not getting the support that they need and stuff like that and I’m like ‘ohh, but they’re really lovely to me’ and stuff like this, and they’re like ‘well they’re not supporting me’ and I’m like ‘that’s strange that they’re not getting the support and I am’*” (Participant 1) “*Another thing I’ve learnt as well through all of this cos I was quite a ‘I want this, I want that, I want this’ and they were like ‘well you can’t’ and then that’s when we just went bang together proper logger heads and then I’d get upset and emotional and then like ‘no I’m not coming ever again’ *laughs* like ‘no one’s listening to me’. They were, I wasn’t listening to them. So I think that’s- even though it may sound like they weren’t listening, I think that’s when I’ve kind of like checked in and been like ‘ooh I’ve not listened to them, that’s what it is, that’s what the issue is here’ uhh and it is- and my relationship with my team is 100% better… like I’m not one to apologise if I knew I was in the wrong either so I have turned round and said ‘I’m very sorry, I was-‘ uhh, something that I’m not gonna repeat online for you but like on my behalf, like they’re trying to do their job and being as caring as possible and there’s me being a moany teenager because I’m not getting my way but they can see that too. They don’t want someone sticking themselves with 4 needles a day or more uhh but all they could do was help and advice which uhh I think that’s another- that’s the area I’ve been building up on- I’m seeing all areas now of umm healthcare professionals and their emotional side of things*” (Participant 2) “*So it wasn’t directly that one time, but it was talking more openly about those experiences and then wanting more experiences whether it be with healthcare professionals or talking with other people with lived experience, but then it allowed me to have the confidence to ask for an insulin pump umm and at the time the answer was no… but then working through that, you know, proving that I could check my blood sugars so many times a day that you need to for pump therapy, all of this- Umm but it allowed me then to have the confidence to say ‘actually, no this is what I want, I will- this is what I will’ you know, the hoops you have to jump through umm and that’s the best thing I’ve done as well*” (Participant 3) “*Maybe made me a bit more confident when I go into my meetings with my healthcare team, which is interesting cos I’ve always- I always had a bit of a stand-off relationship with my healthcare professionals for quite a long time… … The relationship you build up then for those appointments is always just ‘oh bloody hell, don’t really want to go today, just gonna*

	be talking about me, gonna be in there for-‘ feels like a telling- feels like you’re gonna get told off really. That’s what it felt like for a long time. Umm [pause] but almost like, by doing the sharing bit more, I almost went in there with a different attitude, it changed, and were like ‘they need to start seeing me as a person’ and that only came about from me going- being more open and talking about myself umm say to them, like almost to say to them ‘it’s just a number, why are we so focused on it? There’s so much else going well for me, this one number umm et cetera is not the be all and end all’. Umm but [pause] it took a long way to get to that, big time… But I wouldn’t have come to that decision unless I felt more confident about me and what I was up to” (Participant 4) “*I have a lot of respect for healthcare professionals and diabetes teams… I’ve realised that they’re not just checking up on you and gonna wag their finger at you when your numbers are bad, you know? Umm they genuinely care- well at least my team do. They genuinely care about the person and it’s not just about treating a patient… I’ve learnt that they’re not just doing their job”* (Participant 5)
Building a Community	“*It’s also given me the confidence then, so if I see people at events that are sitting on their own or something, I’ve got good group networks so I know like most people if I go to diabetes events I’ve got people I can sit with. But some people might not have. So I look around the room and if I see people without anybody ill call them over to join us and stuff like that. So yeah, its given me a lot of boost of confidence just so I can make friends then and help those that need it”* (Participant 1) “*Oh, I suppose that’s something I’ve seen about myself as well like, knowing that I’m not alone. No matter where I am, who I’m with, I’m not alone”* (Participant 2) “T*hat experience of just having three hours of free time and realised we all sat in the bar talking about type 1 diabetes, was so powerful and its having those accidental experiences sometimes where it’s not diabetes that leads, it’s the other stuff that links to the diabetes. That’s really really powerful… you know that peer support element was huge”* (Participant 3) “V*ery quickly I realised through sort of online community stuff that there was lots of other people like me… it made it cooler to live with type 1 diabetes… you felt like you were more on trend with other people and then you realise that there’s other people like you and yeah, it makes- it just makes it so much easier”* (Participant 4) “I*t’s made me realise I’m not as isolated as I felt umm because the whole education and peer support stuff is uhh its opened me up into a completely new world that other people feel what I feel and they think what I think and they experience what I experience and I’d never come across that before?* (Participant 5)

	“*Yeah, it was good. It’s good to know there’s other people that’s diabetic, so it was nice that there was a group of us that were all diabetic”* (Participant 6)
Empowerment over Condition Management	
Learning	“*It’s trying to get me to accept it as well. I was just completely in denial that I’ve got this forever, it’s not nice for someone to hear. But you do- people need that realisation and umm and I didn’t really understand what kind of- well I knew you could go blind, lose limbs or blah blah blah umm but from a young age- even though it’s not nice for someone to hear, I did digest in that conference that people- children need to learn about coping mechanisms…so it’s getting a better understanding, even though sometimes it’s not nice people need it. They need to be able to make sure that ‘I’m gonna be good with my bad times, but I’m gonna have my bad times’”* (Participant 2) “*I think that’s been the biggest thing with me is understanding diabetes more, being able to respect diabetes more cos unfortunately it [pause] *sigh* you have to accept it to move on”* (Participant 2) “*It’s changed the way I look at diabetes and the way I manage it… I’ve realised diabetes care is way more holistic than just the physical”* (Participant 5) “*It’s nice to be involved and even though I like just sitting there and listening its good though cos you gain loads of knowledge and it is good”* (Participant 6) “*It really just made me realise cos also there’s other people in these films, it wasn’t just me, it was clips from other people’s experiences… and you know, they were all fine. And it just made me think ‘there’s no reason for you not to be doing what you used to do’ you know. So seeing their experiences and that they sort of carried on helped. Yeah so it was good. It was nice”* (Participant 7) “*I hadn’t accepted my diagnosis and I knew I wasn’t looking after myself…So when the filming ended and I started to talk to umm the nurse in the hospital about how I was feeling and stuff, and just started to get things out there a little bit, and then start- and then that helped me then you know, start to accept it…I actually realised how much I hadn’t accepted what had happened. Do you know what I mean? So that really got me down, it really did make me realise like ‘you haven’t accepted this at all’. So really, the filming and everything it all just sort of came at the right time, and it all just kind of meshed into one*

	really and then I just, I just came out of it and I just accepted it and I'm fine now. But at that time it was, it was tough you know?" (Participant 7)
Motivating Improved Self-Management	"*When I became type 1 diabetic I uhh, I started having anxiety. I wouldn't go out, I was too scared to go places in case my sugars would drop low and stuff like that. But since getting involved with [organisation] and other charities it's given me that confidence to go to like [location] on my own and stuff like that. So without them charities helping me and supporting me, umm by putting me on the [panel name] panel, and other people that work in [organisation] via social media umm, pushing me to do things then, yeah, I would of been still stuck in this box room"* (Participant 1) "*I don't really feel there has been in like a negative way… I don't think there's been an expectation, its- and if it has it's been a welcomed expectation of like this is what- this is a good place to be"* (Participant 3) "*There can be like that pressure that we mentioned earlier, of like 'oh no umm if I struggle myself then does that mean I won't be able to do this anymore?' umm there's that kind of inner conflict*." (Participant 5) "*That's really motivated me to stay well cos I know that I have to be well to be involved in it. So umm although that can't be the only reason that I keep recovering, it's been a major motivation for me umm because- I didn't realise until I started doing umm like peer support and joining peer support groups and doing the healthcare professional education that I loved it so much until I started* " (Participant 5) "*Probably for the week after. It makes you think of like everything in perspective really and seeing everybody with the freestyle libres and the older ladies and stuff it makes you think like 'oh yeah you can live a longer life and everything will be fine' but yeah I think I very much just go back into my normal life… So like yeah it gives me the boost to like try and get things in check*" (Participant 6) "*So once the filming started and I was more in touch with my team at the hospital that's when all of this, the ball started rolling with all of this. They helped me- gave me the options that would make life easier for me and that sort of thing. So with those two changes as well that really made a difference... Yeah, so I saw the specialist during filming, when she put my mind at ease about the exercising and that sort of thing, umm and then she put me in touch with my team at another part of the hospital to talk about umm a pump and stuff*" (Participant 7)
Exploring New Technologies	"*When I started getting engaged, then I wanted to change my treatment which has worked for the better"* (Participant 1)

	“*And it’s been great to see a couple of young people that I’ve put forward for things, when they come back and say ‘oh my hba1c is now like coming down’ or they’ve gone on to a pump therapy. That’s something I’ve noticed quite a lot as well… they engage in different treatment which they wouldn’t of before… I certainly did and that’s something I’ve seen, or I’ve had feedback from young people as well that’ve wanted to engage in pump therapy which was not a conversation they’d of had previous as well” (Participant 3)* *“Wearing a CGM or having a pump means that you are constantly different…* The CGM is my first step so I wear a CGM on *my arm and having that on my arm is a sign that I’m different but it makes a huge huge difference to my management so I’m quite happy to accept that”* (Participant 4)
Activating Further Involvement	
“That is why I want to become a [healthcare professional] myself umm cos I do wanna prevent it” (Participant 2) *“So like I said, its opened far more doors which, has that impacted then on me continuing to feel in a good place with my diabetes because its continuing that confidence, it wasn’t just one isolated thing I did I reflected on it and moved on and that motivation kind of went down after a while”* (Participant 3) *“It’s only ever been a good thing. I just feel its opened doors and continued to help me manage my condition, or help me gain skills, or help me gain perspective, or help me gain reflections. You know, they’re all pretty positive things really”* (Participant 3) “*There should be more… cos like- well the only ones I’ve been invited to are very set apart, like I don’t even know how long ago it was that we went to [event] but I don’t- I assume that there’s hundreds of diabetics that they’re choosing between for each thing. But like more regular things would be nice”* (Participant 6)	

Word Count Statement

Thesis abstract	290

Chapter 1

Abstract	226
‘Whats new?’ and keywords	112
Main text (excluding tables, figures and references)	4967
Tables, figures and references	5754

Chapter 2

Abstract	187
Keywords	14
Main text (excluding tables, figures and references)	7201
Tables, figures and references	1399

Chapter 3

Main text (excluding references)	2552
References	656

Appendices	17176

Overall thesis

Abstracts and main text	15549
Tables, figures, references and appendices	24985
Other (title pages, declaration, acknowledgements and word count statement)	840

Total thesis word count	**41374**