DIABETIC Medicine

DIABETES UK
KNOW DIABETES. FIGHT DIABETES.

Developing a novel intervention for type 1 diabetes and disordered eating using a participatory action design process: Safe management of people with Type 1 diabetes and EAting Disorders studY (STEADY)

Journal:	*Diabetic Medicine*
Manuscript ID	DME-2021-00676.R1
Wiley - Manuscript type:	Research Article
Date Submitted by the Author:	18-Nov-2021
Complete List of Authors:	Zaremba, Natalie; King's College London Faculty of Life Sciences and Medicine Robert, Glenn; King's College London Florence Nightingale School of Nursing and Midwifery Allan, Jacqueline; King's College London Faculty of Life Sciences and Medicine HARRISON, AMY; King's College London Faculty of Life Sciences and Medicine Brown, Jennie; King's College London Faculty of Life Sciences and Medicine Konstantara, Emmanouela; King's College London Faculty of Life Sciences and Medicine Rosenthal, Miranda; Royal Free Hospital Pillay, Divina; Chelsea and Westminster Hospital NHS Foundation Trust beckwith, anita; King's College Hospital Treasure, Janet; King's College London Institute of Psychiatry Psychology and Neuroscience Hopkins, David; King's College London Division of Diabetes and Nutritional Sciences Ismail, Khalida; King's College London Department of Psychological Medicine Stadler, Marietta; King's College London Faculty of Life Sciences and Medicine
Keywords:	type 1 diabetes, psychological aspects, complex intervention, mental health

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Developing a novel intervention for type 1 diabetes and disordered eating using a participatory action design process: Safe management of people with Type 1 diabetes and EAting Disorders studY (STEADY)

Natalie Zaremba[1], Glenn Robert[2], Jacqueline Allan[1], Amy Harrison[1,3,4], Jennie Brown[1,5], Emmanouela Konstantara[1], Miranda Rosenthal[6], Divina Pillay[7], Anita Beckwith[5], Janet Treasure[8], David Hopkins[9], Khalida Ismail[10], Marietta Stadler[1,10]

1. Department of Diabetes, Faculty of Life Sciences and Medicine, King's College London, London, UK
2. Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care, King's College London, London, UK
3. Department of Psychological Medicine, King's College London, London, UK
4. Department of Psychology and Human Development, University College London, Institute of Psychiatry, London, UK
5. Diabetes Centre, King's College Hospital, London, UK
6. Diabetes Centre, Royal Free Hospital, London, UK
7. St Vincent Square Eating Disorder Unit, Chelsea and Westminster NHS Foundation Trust, London, UK
8. Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK
9. Institute of Diabetes Endocrinology and Obesity, King's Health Partners, London, UK
10. Department of Psychological Medicine, Diabetes, Psychology and Psychiatry Research Group, King's College London, London, UK

Corresponding Author: Marietta Stadler, Marietta.stadler@kcl.ac.uk

Manuscript word count: 3997

Abstract Word Count: 243

Disclosures: None to declare

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Novelty Statement

What is already known? Current eating disorder interventions are not effective for people with type 1 diabetes and disordered eating due to diabetes-specific barriers that make eating disorder treatment incompatible with diabetes management.

What this study has found? A novel intervention toolkit was developed with people with diabetes and experience of disordered eating and healthcare professionals using Experience-Based Co-Design. The toolkit is adaptable to individual patient needs and can be used with a wide range of disordered eating presentations.

What are the implications of the study? The new STEADY therapy toolkit will be tested in a feasibility randomised controlled trial.

Acknowledgements

We would like to thank all people with lived experience and healthcare professionals who attended the STEADY EBCD workshops for their contributions to the STEADY toolkit. In addition, we would like to thank the STEADY PPI group members for their input and support with the STEADY project design and scene-setter film. We would like to thank Anita Beckwith, Dr Roberta Bowie, Dr Marilia Calcia, Helen Rogers who assisted with the facilitation of EBCD workshops. We would like to thank Dr Helen Partridge for allowing STEADY EBCD workshops to take place during the 2nd annual Diabetes and Eating Disorders conference in Bournemouth. We would like to thank Dr Mette Due-Christensen and Prof Angus Forbes for their advice regarding the study design and facilitation of the EBCD workshops. We would like to thank Sarah Godley for transcribing all EBCD workshops.

Funding sources

This work was conducted as part of the National Institute for Health Research (NIHR) funded STEADY project (Safe management of people with Type 1 diabetes and EAting Disorders studY; CS-2017- 17-023) which examines the perspectives of people with disordered eating and type 1 diabetes and healthcare teams who treat people with type 1 diabetes and disordered eating with the overall objective of informing the development of a complex intervention and a Clinical Lecturer Starter Grant awarded by the Academy of Medical Science and/ Diabetes UK to MS. N.Z.'s salary was part funded by King's College London, Diversity & Inclusion, parenting leave funds awarded to M.S. and by NIHR via the NIHR Clinician Scientist award to MS; J.T. and K.I. are part funded by the NIHR Mental Health Biomedical Research Centre at South London and Maudsley NHS Foundation Trust and King's College London. M.S. was funded through a National Institute of Health Research (NIHR) Academic Clinical Lecturership, NIHR Clinician Scientist Fellowship and Academy of Medical Sciences Starter Grant for Clinical Lecturers (2017); AH's and JB's salaries were in part funded by the NIHR Clinician Scientist Award (CS-2017- 17-023) to MS. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health. AH is supported by the Medical Research Council.

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Abstract

Aim. To develop a cognitive behavioural therapy based intervention for people with type 1 diabetes and disordered eating using Experience-Based Co-Design as part of the Safe management of people with Type 1 diabetes and EAting Disorders studY (STEADY).

Methods. Fifteen people with type 1 diabetes and experience of disordered eating (33±11 years old, 22±12 years diabetes duration) and 25 healthcare professionals working in type 1 diabetes or eating disorders (44±9 years old; 14±10 years of professional experience) attended six Experience-Based Co-Design workshops from July 2019-March 2020 to collaboratively develop intervention content.

Results. We developed a cognitive behaviour therapy intervention "toolkit" that can be tailored for individual patient needs. Participants designed and revised toolkit materials to ensure acceptability and relevance for people with diabetes and disordered eating by engaging in guided discussion, brainstorming, and rapid testing to review toolkit prototypes in an iterative process. Workshop themes were 'Insulin titration'; 'Hypoglycaemia'; 'Coming to terms with diabetes'; 'Fear of weight gain'; 'Toolkit revision'; and 'Practical elements of STEADY therapy'. The intervention is focussed on improving diabetes self-care and embedded in a multidisciplinary healthcare approach. The intervention will be delivered in 12 sessions by a diabetes specialist nurse trained in cognitive behavioural therapy.

Conclusions. Through an iterative co-design process, people with type 1 diabetes and healthcare professionals collaboratively developed a novel intervention toolkit that can be used with a wide range of disordered eating presentations. The intervention will be tested in the STEADY feasibility randomized controlled trial.

Keywords

Type 1 diabetes mellitus, Eating disorder, Participatory action research, Cognitive behaviour therapy, Intervention, Experience-Based Co-Design, Qualitative

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Introduction

Type 1 diabetes and disordered eating (T1DE) includes unique features and behaviours that are not easily identified and treated by diabetes or eating disorder healthcare professionals, such as deliberate insulin omission as a purging behaviour, restrictive low-carbohydrate diets to reduce insulin doses, or bingeing in response to hypoglycaemia symptoms [1–3]. T1DE is associated with increased risk of mortality and severe acute and long-term complications of diabetes [4–7]. The prevalence of disordered eating in people with type 1 diabetes is estimated to be 8 to 36% with an additional 9 to 14% classified as 'sub-threshold' disordered eating [8–14].

The challenges of treating T1DE arise from a lack of established diagnostic and screening criteria, lack of training and resources about the condition, as well as systemic healthcare barriers that prevent diabetes and mental health teams to treat patients jointly [15]. There are currently no effective interventions for T1DE, primarily because existing eating disorder therapies are not compatible with diabetes management methods (e.g. people with diabetes must count carbohydrates to calculate insulin doses, measure or weigh their food, and eat foods high in sugar when their blood glucose is too low) [16]. However, highly experienced healthcare professional teams have described strategies discovered independently that have helped to support patients with T1DE [15].

The aim of the Safe management of people with Type 1 diabetes and EAting Disorders study (STEADY Phase I) project was to use a participatory action design process to develop a cognitive behavioural therapy (CBT) based intervention with focus on diabetes self-care for people with T1DE. STEADY is set within the Medical Research Council (MRC) Complex Interventions Framework [17] and will be tested in a randomised controlled feasibility trial (STEADY Phase II). This article describes the research and development of the STEADY intervention toolkit (STEADY Phase I).

Experience-Based Co-Design (EBCD) is a participatory action design process that has been traditionally used to improve existing health services through bringing together healthcare professionals and people with lived experience of a condition to co-design service improvements [18]. EBCD has previously been used to develop complex interventions within the MRC framework, but has not been used within the T1DE population [19–21].

Our study adjusted several elements of the six-staged EBCD process [22] to meet the needs of our participant group as well as the practicalities of intervention development. We used semi-structured individual interviews to identify key barriers and facilitators for recovery from disordered eating from the perspective of people living with diabetes [23] and the findings from focus groups with healthcare professional teams with special interest in T1DE [15] to develop material for the initial workshops. The development of a 'trigger film' is a core part of the EBCD process [24]. Following the advice of our Patient and Public Involvement (PPI) group, we developed a 10-minute 'scene-setter' film in lieu of a 'trigger' film due to negative associations of the word 'trigger'. Lastly, each

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

STEADY co-design workshop was highly targeted with several subthemes in each workshop to reduce the need for multiple workshops on the same topic.

The objectives of this paper are to: 1. share the STEADY EBCD process and lessons learned to help facilitate future use of EBCD in the context of type 1 diabetes complex intervention development, and 2. illustrate how the STEADY intervention toolkit was developed.

Methods

This study received ethical approval by the London-Surrey Borders Research Ethics Committee (18/LO/0812).

Development of EBCD workshop themes

Prior to the EBCD workshops, we conducted 23 semi-structured interviews with people with type 1 diabetes and current disordered eating (n=9), past disordered eating (n=5), or no history of disordered eating (n=9) [23]. Interviews were analysed using thematic analysis and grounded theory to identify maintenance cycles and common thoughts, behaviours, and feelings experienced by people with T1DE [23]. We also conducted focus groups with four healthcare teams with experience of treating people with T1DE and used thematic analysis to identify the main challenges and facilitators to treatment [15]. From these analyses we identified priority areas for the content of the EBCD workshops (fear of hypoglycaemia, fear of titrating insulin, fear of weight gain, acceptance of diabetes).

Development of the scene-setter film

The development of the 10 minute scene-setter film, led by the PPI coordinator (JA), used relevant clips from a documentary on diabulimia [25], self-recorded interviews provided by people with lived experience, and quotes from the previously conducted interviews that were read by actors with participants' consent. We presented the scene-setter film to the STEADY PPI group, who provided feedback before finalising the film. The film was shown at the beginning of the first five workshops.

Setting of the EBCD workshops

The first two EBCD workshops were embedded within the 2nd National Conference on Diabetes and Eating Disorders, Bournemouth Royal Hospital, UK. The remaining four were held at a central King's College London campus after working hours to allow participants to attend after work, university, or other commitments. Travel expenses and accommodation for participants who travelled from outside of London were reimbursed. This was to ensure participants of all backgrounds could attend and would not be disadvantaged by missing work, or being unable to afford the travel to attend the workshops.

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Attendance

Participants were given the option to attend as many workshops as they wanted, depending on their interest in the workshop theme. In the case that a participant chose to leave a workshop early due to discomfort with the topics, they were accompanied and followed up by a member of the study team to debrief and ensure they had appropriate support.

Accessibility and medical considerations

EBCD workshops were designed to be inclusive and accessible for all participants who were interested. The research team ensured support and modifications could be provided in all workshops for people who were partially sighted or blind, used mobility aids, had dietary needs, or required psychological support.

Treatments for hypoglycaemia were readily available to participants with diabetes. The research team, including facilitators at each table, were aware of hypoglycaemia symptoms and how to treat hypoglycaemia if necessary. In case of emergency (including severe hypoglycaemia or evidence of diabetic ketoacidosis), the research team was instructed to call 999 and provide first aid, as the workshops did not take place on hospital premises.

EBCD Workshops

Prior to each workshop, participants were sent copies of the participant information sheet, consent form, all practical workshop-specific information, and the Diabetes UK language matters guidance [26] to encourage a comfortable and collaborative environment for all attendees. Participants were invited to arrive 30 minutes early to allow everyone to get settled, ask questions, and consent to the study (Figure 1).

The workshops began by introducing the research team, the goals of the STEADY project, the EBCD process, and establishing rules of engagement for discussion (e.g. keeping discussions confidential, ensuring everyone had a turn to speak, following Language Matters guidance [26] etc.) The scene-setter film was shown, followed by a brief discussion in small groups about the message of the film. Next, a member of the research team gave a short presentation of the goals of the particular workshop, introducing the main theme and subthemes (Tables 1-5) that would be discussed.

Participants sat at tables in small groups focused on a subtheme with a member of the research team facilitating the discussion. For the first two workshops, participants were allocated to a subtheme to save time in the limited schedule in the national conference. In subsequent workshops participants chose which subtheme they were most interested in.

Each table was provided with relevant paper visual materials for their subtheme (diagrams of eating disorder maintenance cycles, anonymised quotes from interviews,

newly developed toolkit pages, etc.) Participants used these materials in an interactive way (Supplementary Material 1) to guide discussion and provide suggestions for toolkit development (e.g. writing notes on toolkit materials, using sticky notes to move ideas around diagrams as discussion progressed or grouping ideas together, etc.) Facilitators used guided discussions and brainstorming approaches for the toolkit content and used rapid testing for new iterations of toolkit materials and CBT exercises. Participants were encouraged to read through toolkit iterations as if they were the patient or healthcare professional using the material at a therapy session, and to discuss items that were helpful or unhelpful, irrelevant in the context of T1DE, the feasibility of a particular instrument in a therapy session, and any ways tools could be improved. Groups were instructed to work on two specific aspects of their subtheme and were prompted to switch halfway through the allotted time. At the end of each workshop, the facilitator from each table presented a summary of their discussions to the wider group.

Insert figure 1 here

Analysis and development of the STEADY toolkit

Workshops were audio-recorded and transcribed, and paper materials were collected at the end of each workshop to ensure that all contributions were captured. Transcripts and written data were analysed by the multidisciplinary research team and converted into toolkit materials in an iterative process. Two participants with diabetes reviewed sections of the STEADY toolkit outside of the EBCD workshops, providing on going support through its development. A diabetologist, diabetes specialist nurse, and clinical psychologist (MS, JB, and AH) finalised the outcomes into integrated T1DE CBT exercises and diabetes education materials for the STEADY toolkit.

Results

Participants

Fifteen participants with type 1 diabetes (14 women/1 man; 33±11 years old; diabetes duration 22±12 years, Supplemental Table 1) and 25 healthcare professionals (22 women/3 men; 44±9 years old; 14±10 years in their profession, Supplemental Table 2) took part in the EBCD workshops. Two participants were healthcare professionals who also had type 1 diabetes, however they are described only in the healthcare professional group.

Workshops

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

We held six EBCD workshops from July 2019 to March 2020 with the themes: 1. Insulin titration; 2. Hypoglycaemia; 3. Revising the 'Insulin titration' and 'Hypoglycaemia' toolkits; 4. Coming to terms with diabetes; 5. Fear of weight gain; and 6. Practical elements of STEADY. Most participants took part in multiple workshops throughout the EBCD process. Participants with diabetes attended 3.26±1.16 workshops, while healthcare professionals attended 1.96±1.01. Workshops had a mean attendance of 16.5±4.93 participants (Supplemental Table 3).

Workshop 1: Insulin titration and 2: Hypoglycaemia

Participants in the Insulin titration and Hypoglycaemia workshops were presented with six theoretical models of maintenance cycles in each workshop (Tables 1 and 2) that had been developed from semi-structured interviews [23]. Facilitators guided discussions to refine the cycles through participants' observations and identified recovery strategies and opportunities for intervention for each maintenance cycle.

It became clear from the first two workshops that individualised and stepwise care plans were essential to recovery (Tables 1 and 2) and a standardised 12-session manual would not be sufficient for this group. Due to the variability of the clinical presentation of T1DE, an intervention would need to be tailored to the specific concerns and requirements of the individual. Subsequent workshops reframed the STEADY manual as the STEADY toolkit, which would include exercises that focused on different aspects and presentations of T1DE that could be chosen by the therapist for each patient's needs.

Insert Tables 1 and 2 here

Workshop 3: Toolkit revision

The third workshop focused on revising materials developed from the first two workshops. The 'Insulin titration' subgroup considered the types of questions that could best explore insulin omission maintenance cycles in patients (Table 3). For example, exploring what recovery will look like for a patient and how it will impact their life as a whole helps to think about the longer-term impact of recovery. Practical tips for taking small steps to achieving Specific, Measureable, Attainable, Realistic, Timely ('SMART') goals were also suggested, such as breaking the day into sections (morning, afternoon, evening) to allow for a "fresh start" if they didn't meet a goal earlier in the day. A gradual and collaborative approach was discussed to re-introducing insulin, rather than expecting the patient to inject full doses of insulin immediately while starting treatment. Participants felt this would be more manageable and help to create empowerment and provide gradual progress.

Participants in the 'Hypoglycaemia' subgroup provided examples of how the structure of the tools could be improved by restructuring items on the page and breaking down exercises into smaller and more focused questions (Table 3). Suggestions of practical

ways to cope with hypoglycaemia symptoms at elevated glycaemia levels ("phantom hypos") included planning to increase insulin and experiencing the "phantom hypo" in a safe environment (such as while watching a movie at home with a friend).

Insert Table 3 here

Workshop 4: Coming to terms with diabetes

Creating a trusting and non-judgemental relationship between the healthcare professionals and the person with diabetes was deemed incredibly important for participants (Table 4). Feelings of judgement, failure, fear of complications, and pressure for perfectionism were all common experiences for people with diabetes that led to disengagement. Feeling that their diabetes team did not understand the psychological toll of their efforts in diabetes management led to feeling that there was no point in trying to recover.

People with diabetes felt that their relationship with food had been strained since their diagnosis because of the constant focus on food, requirement to count carbohydrates, weigh and measure food, and eat sugary foods during hypoglycaemia (Table 4). Not all participants with diabetes received education in carbohydrate counting at diagnosis, which caused frustration due to fluctuating blood glucose levels they did not know the cause of. Other participants felt that pressure to count carbohydrates led to unhealthy perfectionist behaviours and restriction. Participants suggested ways of trying to reduce perfectionism such as mindfulness, yoga, and CBT.

Participants felt it was important to find self-worth in other aspects of their lives, and not only in their appearance or diabetes management (Table 4). The concept of body neutrality was helpful to allow participants to acknowledge their body for what it is without the pressure to feel positively or negatively about it. Body image is also affected by diabetes technology like glucose monitors and insulin pumps and having to inject in front of other people. Participants emphasised the importance of having peer support and highly knowledgeable and empathetic healthcare professionals who understand the impact of this on someone with an eating disorder. Being prepared for physical implications of recovering from T1DE (such as rehydrating and gaining weight when injecting insulin) before beginning the process can also help people with T1DE cope with the physical effects of recovery.

Insert Table 4 here

Workshop 5: Fear of weight gain

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Practical suggestions for preparing people with T1DE for re-nutrition and re-introducing insulin included establishing strong routines so basic diabetes management behaviours (taking background insulin, checking blood glucose first thing in the morning) can be done on "autopilot" without causing distress (Table 5). It was also important for participants to acknowledge that as glucose levels are lowered, people with T1DE may experience more emotions that were 'numbed' by previously high glucose levels. Participants felt it was important for patients to establish a plan with their healthcare professionals for coping with these new emotions.

The body image subgroup focused on ways to achieve a "good enough" body image and ways that diabetes influences thoughts and feelings about body image, weight, and shape (Table 5). Helpful CBT exercises include focusing on the bigger picture of recovery rather than on specific details, and taking part in activities where body image, weight, and shape are not on the patient's mind and focusing on the enjoyment of the activity itself.

Participants felt strongly that eating plans must be developed in a dynamic and collaborative way, allowing for adaptation throughout the therapy process (Table 5). Different examples may be useful as a starting point, then individualised according to each person. Providing examples of what 100-200 carbohydrates per day looks like in terms of meal plans and visual images can be helpful.

Insert Table 5 here

Workshop 6: Practical elements of STEADY

The final workshop related to practical elements of the STEADY intervention and the possibility of a smartphone application to help facilitate therapy. Participants were enthusiastic about an app for STEADY and believed it would be a useful tool to help complete CBT exercises, schedule appointments and send information between the participants and the study team. Participants felt that the app should be customisable to the individual's therapy, hiding any content that is not relevant to their treatment. It was emphasised that the application would be a tool to facilitate STEADY, and not a mandatory part of the intervention, all materials available on the app will be available in an alternative format for people who prefer paper or web-based materials. Further details of the app development will be described in a future publication.

Other practical suggestions from this workshop include flexibility for in-person, telephone, or video-based therapy sessions to reduce the need to travel. This is particularly relevant in the current context of COVID-19, where people with T1DE are at higher risk. Further details will be described in a publication of the STEADY feasibility randomised controlled trial intervention protocol.

Feedback after the workshops

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Feedback during and after the workshops was generally positive, with most participants returning to attend multiple workshops and inviting friends and colleagues with relevant experience to participate as well. After the workshops, anonymous feedback was collected via SurveyMonkey and emails sent directly to the research team. Participants wrote that they felt listened to and that their ideas were taken seriously. One healthcare professional in the first workshop reported being nervous that they may say something that would trigger a participant with T1DE. However both healthcare professional participants and participants with diabetes reported enjoying working with the other group and learning from their experiences. Feedback was implemented wherever possible in subsequent workshops (e.g. extending workshops to 2-hours, participants choosing the subthemes to work on, being told the subthemes in advance, etc.)

Final STEADY toolkit

The STEADY toolkit was revised and finalised by the research team and consists of treatment plan templates (sick day rules, hypoglycaemia treatment plan, mental health and medical emergency plan), STEADY CBT session guides and formulation worksheet, psychoeducation tools, and T1DE-specific CBT exercises. A therapist handbook and patient worksheets have been developed and are designed for the therapist to select content that is provided to the patient as handheld notes (or digital content sent through the app or email) on a regular basis during therapy sessions in accordance with their therapy and treatment needs.

Discussion

We used the EBCD process to develop a novel, complex intervention for people with T1DE that bypasses the common problems of treating this group; primarily the lack of therapy tools specific to this population, the lack of eating disorder resources for diabetes healthcare professionals and vice versa, and inflexible treatment plans. The co-design process was highly collaborative and made use of the experience of all individuals involved, the resulting STEADY toolkit will be suitable for a variety of T1DE presentations due to its adaptable, modular format.

Participants with diabetes and healthcare professionals with experience of treating T1DE reviewed multiple iterations of materials and explained why a particular tool was triggering or why it was not relevant to people with T1DE and provided alternative suggestions. Healthcare professionals provided insight on treatment modalities and pathways and discussed the usability of toolkit materials. Discussions between participants helped generate useful dialogues about treatment, the problems healthcare professionals and people with diabetes face, and how to create solutions within STEADY. Feedback from both healthcare professionals and participants with diabetes was positive and reflected a collaborative process. While not all suggestions are feasible at this stage of the STEADY project, they will be useful for future iterations of the intervention.

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

One reason we believe EBCD was a successful process within this project was that diabetes healthcare teams are often multidisciplinary, particularly in larger diabetes centres where many of our healthcare professional participants work and are used to collaborating with patients on their treatment. It has been previously reported that diabetes and mental health teams who have access to each other, and teams who have trusting and collaborative relationships with patients are able to create more effective solutions for treating T1DE [15]. Whilst the healthcare professionals in STEADY were recruited for their experience, teams who have fewer opportunities to collaborate with other disciplines or who collaborate less with patients may not have worked as well together.

Visual tools (maintenance cycles, diagrams of relationships, quotes, CBT exercises) and discussion prompts to guide reflection were key in the EBCD workshops to guide the development of the STEADY toolkit. Materials reflected the focus of each workshop and were targeted at different types of work – e.g. 'Insulin titration', 'Hypoglycaemia', and 'Coming to terms with diabetes' workshops were more conceptual and developmental with materials to facilitate more exploratory questions, while the 'Toolkit revision' and the 'Practical elements of STEADY' workshops targeted more practical revisions. Viewing maintenance cycles allowed people with T1DE to express where they saw themselves and healthcare professionals to reflect on their experiences with patients, how each step of the cycle impacted diabetes and thoughts of recovery, as well as express additional considerations to cycles that they have experienced. The 'scene-setter' film and anonymised quotes allowed participants to reflect on the many different aspects of disordered eating in T1DE and how people's individual experiences led to different behaviours.

Viewing and testing existing and newly developed materials was essential to understanding the appropriateness of the tools. Several times in the process, participants with diabetes viewed a tool as being triggering, harmful, or irrelevant for T1DE, and gave insight on aspects of standard therapies that could lead to disengagement. An example of this is a CBT "behavioural experiment" used in eating disorder therapy in people without diabetes; the patient is asked to observe their weight gain over a period of time. Participants in the EBCD workshop expressed that weight gain is more drastic for people with T1DE than without diabetes through rehydration when re-introducing insulin, and these reflections would be more distressing for them. These participant reflections were crucial for the development of STEADY toolkit materials, because it illustrated how existing therapy tools are insufficient and potentially harmful, therefore they must be redesigned with the appropriate context in mind.

This study had a number of strengths that benefited the development of the STEADY toolkit. First, EBCD is a method that draws on the experience of patients, who are experts of their own condition, and healthcare professionals who have experience working with this population. Therefore, all materials were developed by people who have a profound understanding of what barriers people with T1DE face in recovery and their treatment needs. Second, as EBCD is an iterative process, newly developed materials were reviewed multiple times. Having healthcare professionals from both diabetes and eating

disorder specialties in one place was useful for bringing together expertise of two fields that do not often have the opportunity to communicate effectively to come up with treatment solutions. Third, this is the first time EBCD has been used in this population, and the successful collaboration between healthcare professionals and people with diabetes provides a new collaborative approach for designing future type 1 diabetes services.

While we had a wide range of people with experience of T1DE, the opinions expressed are specific to this group and there may be other experiences or presentations of T1DE that have not been considered. Second, our participants with diabetes were primarily recovered from their disordered eating, and were selected purposefully for this reason. People with T1DE who have not recovered could have been more easily triggered by some of the difficult topics that were discussed at workshops and potentially could have been harmed through discussions of disordered eating at an early stage of their recovery journey.

The STEADY toolkit will be tested in a feasibility randomised controlled trial with 40 participants randomised to the STEADY intervention arm or treatment as usual control arm. The trial will examine feasibility of the STEADY intervention, with the primary biomedical outcome of HbA1c and time in range in the STEADY intervention versus control group. The trial will include a process evaluation sub-study to explore the feasibility, appropriateness and acceptability of STEADY, and will provide opportunity for refining the STEADY toolkit for future use.

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

References

1. Allan J (2015) Understanding poor outcomes in women with type 1 diabetes and eating disorders. J Diabetes Nurs 19:99–103

2. Merwin RM, Dmitrieva NO, Honeycutt LK, et al (2015) Momentary Predictors of Insulin Restriction Among Adults With Type 1 Diabetes and Eating Disorder Symptomatology. Diabetes Care 38(11):2025–32. https://doi.org/10.2337/dc15-0753

3. Vallis M, Jones A, Pouwer F (2014) Managing hypoglycemia in diabetes may be more fear management than glucose management: a practical guide for diabetes care providers. Curr Diabetes Rev 10(6):364–70

4. Feltbower RG, Bodansky HJ, Patterson CC, et al (2008) Acute complications and drug misuse are important causes of death for children and young adults with type 1 diabetes: results from the Yorkshire Register of diabetes in children and young adults. Diabetes Care 31(5):922–6. https://doi.org/10.2337/dc07-2029

5. Goebel-Fabbri AE, Fikkan J, Franko DL, Pearson K, Anderson BJ, Weinger K (2008) Insulin restriction and associated morbidity and mortality in women with type 1 diabetes. Diabetes Care 31(3):415–9. https://doi.org/10.2337/dc07-2026

6. Skrivarhaug T, Bangstad HJ, Stene LC, Sandvik L, Hanssen KF, Joner G (2006) Long-term mortality in a nationwide cohort of childhood-onset type 1 diabetic patients in Norway. Diabetologia 49(2):298–305. https://doi.org/10.1007/s00125-005-0082-6

7. Stadler M, Peric S, Strohner-Kaestenbauer H, et al (2014) Mortality and incidence of renal replacement therapy in people with type 1 diabetes mellitus--a three decade long prospective observational study in the Lainz T1DM cohort. J Clin Endocrinol Metab 99(12):4523–30. https://doi.org/10.1210/jc.2014-2701

8. Bachle C, Lange K, Stahl-Pehe A, et al (2015) Symptoms of Eating Disorders and Depression in Emerging Adults with Early-Onset, Long-Duration Type 1 Diabetes and Their Association with Metabolic Control. PLoS One 10(6):e0131027. https://doi.org/10.1371/journal.pone.0131027

9. Colton P, Olmsted M, Daneman D, Rydall A, Rodin G (2004) Disturbed eating behavior and eating disorders in preteen and early teenage girls with type 1 diabetes: a case-controlled study. Diabetes Care 27(7):1654–9

10. Bachle C, Stahl-Pehe A, Rosenbauer J (2016) Disordered eating and insulin restriction in youths receiving intensified insulin treatment: Results from a nationwide population-based study. Int J Eat Disord 49(2):191–6. https://doi.org/10.1002/eat.22463

11. Colton PA, Olmsted MP, Daneman D, et al (2015) Eating Disorders in Girls and Women With Type 1 Diabetes: A Longitudinal Study of Prevalence, Onset, Remission, and Recurrence. Diabetes Care 38(7):1212–7. https://doi.org/10.2337/dc14-2646

12. Jones JM, Lawson ML, Daneman D, Olmsted MP, Rodin G (2000) Eating disorders in adolescent females with and without type 1 diabetes: cross sectional study. BMJ 320(7249):1563–6

13. Colton PA, Olmsted MP, Daneman D, Rydall AC, Rodin GM (2007) Five-year prevalence and persistence of disturbed eating behavior and eating disorders in girls with type 1 diabetes. Diabetes Care 30(11):2861–2. https://doi.org/10.2337/dc07-1057

14. Peveler RC, Bryden KS, Neil HA, et al (2005) The relationship of disordered eating habits and attitudes to clinical outcomes in young adult females with type 1 diabetes. Diabetes Care 28(1):84–8

15. Zaremba N, Watson A, Kan C, et al (2019) Multidisciplinary healthcare teams' challenges and strategies in supporting people with type 1 diabetes to recover from disordered eating. Diabet Med 37(12):1992–2000. https://doi.org/https://doi.org/10.1111/dme.14207

16. Clery P, Stahl D, Ismail K, Treasure J, Kan C (2017) Systematic review and meta-analysis of the efficacy of interventions for people with Type 1 diabetes mellitus and disordered eating. Diabet Med 34(12):1667–1675. https://doi.org/https://doi.org/10.1111/dme.13509

17. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M (2008) Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ 337:a1655. https://doi.org/10.1136/bmj.a1655

18. Bate P, Robert G (2007) Toward More User-Centric OD: Lessons From the Field of Experience-Based Design and a Case Study. J Appl Behav Sci 43(1):41–66. https://doi.org/10.1177/0021886306297014

19. Ramfelt K, Petersson C, Åkesson K (2020) Experiences From a Coaching Program for Parents of Children and Adolescents With Type 1 Diabetes Developed Through Experienced-Based Co-Design (EBCD). J Patient Exp 7(6):1181–1188. https://doi.org/10.1177/2374373520969005

20. Raynor DK, Ismail H, Blenkinsopp A, Fylan B, Armitage G, Silcock J (2020) Experience-based co-design—Adapting the method for a researcher-initiated study in a multi-site setting. Health Expect 23(3):562–570. https://doi.org/10.1111/hex.13028

21. Tsianakas V, Robert G, Richardson A, et al (2015) Enhancing the experience of carers in the chemotherapy outpatient setting: an exploratory randomised controlled

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

trial to test impact, acceptability and feasibility of a complex intervention co-designed by carers and staff. Support Care Cancer 23(10):3069–3080. https://doi.org/10.1007/s00520-015-2677-x

22. Donetto S, Pierri P, Tsianakas V, Robert G (2015) Experience-based Co-design and Healthcare Improvement: Realizing Participatory Design in the Public Sector. Des J 18(2):227–248. https://doi.org/10.2752/175630615X14212498964312

23. Harrison A, Zaremba N, Brown J, et al (2021) A cognitive behavioural model of the bidirectional relationship between disordered eating and diabetes self care in people with type 1 diabetes mellitus. Diabet Med 38(7):e14578. https://doi.org/https://doi.org/10.1111/dme.14578

24. Point of Care Foundation (2013) What is Experience-based co-design? In: Point Care Found. https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/step-by-step-guide/1-experience-based-co-design/. Accessed 18 Jul 2021

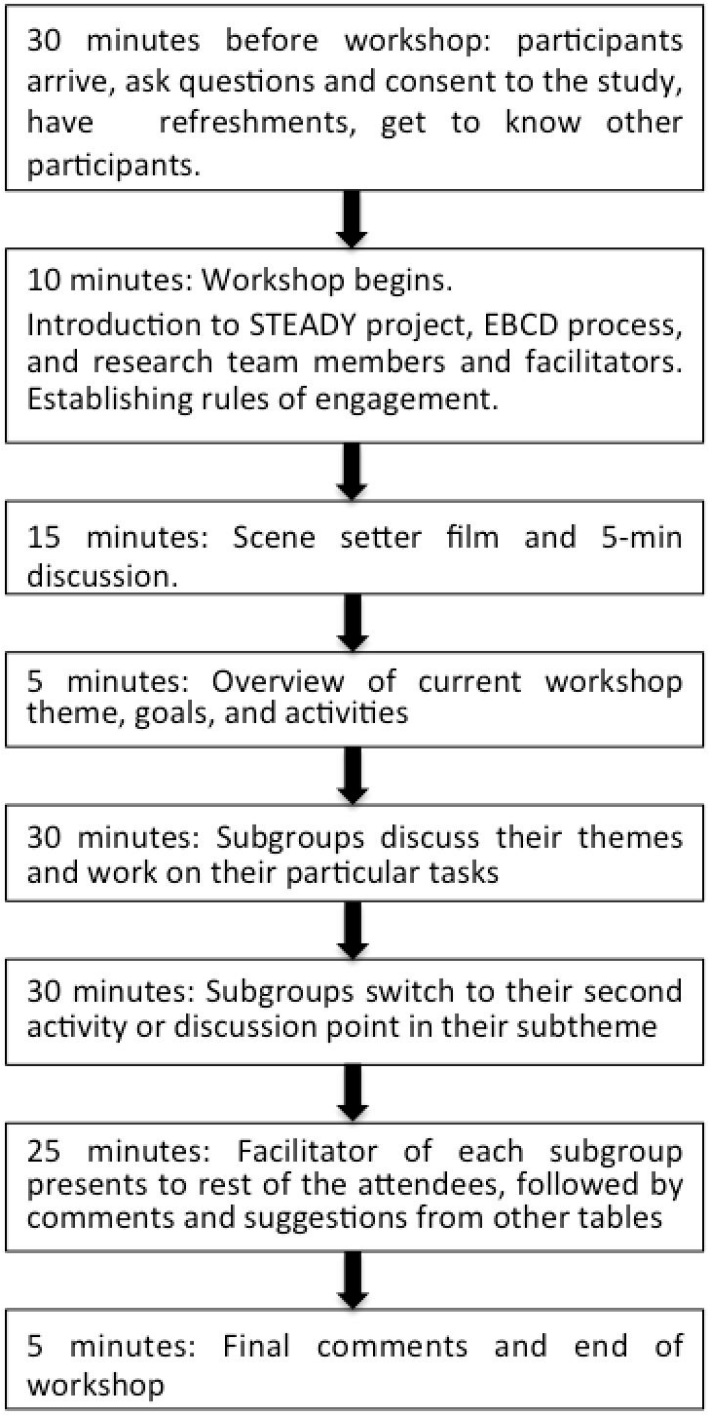
25. BBC (2017) Diabulimia: The World's Most Dangerous Eating Disorder

26. NHS England (2018) Language Matters: Language and diabetes

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Figures and Tables

Figure 1. Schedule of EBCD workshops



RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Table 1: Summary of themes, subthemes, and concepts introduced into STEADY toolkit from workshop 1: Insulin titration

Subthemes	Discussion prompts and exercises	Concepts and practical ideas brought into STEADY toolkit	Quotes
Insulin equals fat **Insulin omission is my magic weight loss tool** **Food doesn't "count" if I don't inject** **Insulin omission gives me control over my diabetes** **Insulin omission is addictive** **Fear of taking first steps to insulin titration**	- Maintenance 'vicious' cycles, printed on A3 paper - Smaller diagrams of vicious cycles - Anonymised quotes from interviews	- Insulin injection plans must be adaptable and personalised to each patient - Focus on how reintroducing insulin will lead to positive changes (energy, better mood - Be clear on what happens to body weight when re-introducing insulin - Important for HCPs and toolkit to be non-judgemental and not using complications as a scare tactics, must build trusting relationship - Identifying core reasons for omitting insulin (weight loss, to numb emotions, to control, the "thrill") - Helping patients cope with negative emotions that emerge as they re-introduce insulin - Addressing recovery as a longer process that will take place gradually, encouraging small steps - Addressing perfectionism and all-or-nothing thinking about diabetes management - Including the Diabetes Distress Scale in the toolkit - Adapting basic diabetes education, focusing on bigger picture of nutrition, quality of life, regular eating	- "…it's because everyone's different so it then comes down to being a bit bespoke" - "just doing it slowly and slowly, …, I find that if all of a sudden you start taking your insulin, I feel like I'm more at risk of going hypo. Then, because you don't like that feeling you then stop the insulin again." - "I think a lot of what we hear is fear of disappointing. It means you're going to lie to people… [I want my healthcare professional to say] 'Don't worry, I understand, we can help you fix this,' as opposed to just 'Why aren't you doing your insulin? You need to get your HbA1c back now otherwise you're going to fall apart and lose all your eyes, and toes, and everything'" - "I actually recently had a DKA, [from a pump failure]. I went to my clinic after … and I was made to think, 'again I have failed'" - "[you may be] fearful of complications and you want to take your insulin, and that builds an anxiety which makes you want to go back to the foggy mind." - "… maybe if we didn't focus quite so much on the diabetes but were thinking with them about how do we help you achieve other things, [diabetes] doesn't need to be the thing at the forefront"

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Table 2: Summary of themes, subthemes, and concepts introduced into STEADY toolkit from workshop 2: Hypoglycaemia

Subthemes	Discussion prompts and exercises	Concepts and practical ideas brought into STEADY toolkit	Quotes
Hypo symptoms are triggered at elevated level **Fear of severe hypoglycaemia** **Hypos force me to eat** **Hypos are the only time I can eat sweets** **Hypo avoidance through insulin restriction** **Binge eating triggered by hypos**	- 6 maintenance 'vicious' cycles, printed on A3 paper taped onto chart paper, allowing participants to use sticky notes to place tools and strategies for intervention at the appropriate place in the cycle - Smaller diagrams of cycles - Anonymised quotes from interviews	- Re-learning to match insulin to food - No 'good' food or 'bad' food, all foods are allowed - Allowing space in your diet for treats that you plan for and bolus appropriately - Individualising treatment plans to each person - Legitimising fear of hypos - Gradually reducing hypo symptoms at elevated glucose levels by having a set plan for hypo symptom treatment - It is okay and normal to have a high BG after eating, as long as it comes down after a few hours - Reducing feelings of guilt - Using Flash/CGM monitoring to get ahead of drastic highs or lows	- " I remember a dietician I worked with would say, 'There's no good food, there's no bad food, there's just food … cakes have a purpose as do carrots.'" - "When you look at [the cycle], I feel like I've got to come up with something, an idea of how to fix it, and how to stop the cycle, and I'm thinking that if I come up with that, there's going to be something about that being too prescriptive … I have a feeling that you got to get the pace right" - "having a specific hypo treatment that I always use for a hypo, reduces the risk of me overeating and therefore the risk of getting back into the cycle, and it also takes away the stress of having to decide what to eat." - "that feeling of failure and that feeling of guilt that, 'Oh God, I'm going to have to go to clinic and get told off.'" - "technology can help address some of those problems by helping you monitor your blood sugar more frequently and catching it when it's not so high or so low, so you don't need to treat so drastically."

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Table 3: Summary of themes, subthemes, and concepts introduced into STEADY toolkit from workshop 3: Toolkit revision

Subthemes	Discussion prompts and exercises	Concepts and practical ideas brought into STEADY toolkit	Quotes
Insulin titration	- Bound toolkit materials developed from previous workshop for each participant: Insulin titration plan - Diagrams of maintenance cycles	- Comments regarding which tools would be useful at which stage of recovery - Adjustments in format of questions – splitting into more manageable groups and putting more emotionally difficult questions later in the exercise - Suggestions about language e.g. "adjustment dose" vs. "correction", "keeping safe" vs. "minimising risk", no blaming language - Gradual reintroduction of insulin, agreed upon by the patient and therapist - Use of SMART goal setting - Breaking the day down into sections (morning, afternoon, evening) and seeing each section as a fresh start to work on goals. - Use of flow charts and visual tools to facilitate treatment decisions - Visualising how recovery will impact the patient's whole life, not just diabetes management. Work on what is most meaningful for the patient	- "I think my first thought was, at what point of treatment or recovery would this be introduced? I think, because for me if it had been very early, at the beginning, it would have completely freaked me out" - "one of the things I identified with [my diabetes nurse] was regular contact with her, and also slowly increasing the amount of insulin, and bringing my blood sugars down slowly, because that felt more manageable" - "the word 'correction' implies that you're wrong [leading to shame/guilt], so we avoid that term entirely, we just say 'adjustment dose'" - "I like those questions about 'how does it make you feel, how does it impact on things you'd like to do', because it treats the person as a whole person" - "keeping written records of stuff, […] because I quite often found it easier to identify things if I'd written it down instead of talking"

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Hypoglycaemia	- Bound toolkit materials developed from previous workshop for each participant - Diagrams of maintenance cycles	- Providing examples of easily available hypoglycaemia treatments that were include of dietary requirements (vegan, gluten free, kosher, halal, free from caffeine, etc.) - Planning a "phantom hypo" so it can be experienced in a safe environment with a plan to help distract from unpleasant symptoms - Adding examples of safe actions to take to cope with "phantom hypo" symptoms (e.g. taking sugar-free versions of usual hypo treatment) - Including maintaining factors of fear of hypoglycaemia (e.g. rebound hyperglycaemia, or subsequent hypoglycaemia later in the day) - Hypoglycaemia fear in specific situations (work, travel, at night, in a new environment)	- "Loads of these questions actually seem really, really relevant until it's got that word 'severe' in there … I'm not scared of severe hypos, I'm scared of hypos" - "There were two questions quite near the top, 'Can you describe thoughts or images of what a severe hypo may be like, and how likely do you think that is to happen?' I think these need to be closer to the bottom, because, first of all they won't apply to everyone, and also, if you manage to make your way through those [lighter questions] then maybe you can [answer] the heavy ones" - "I'd like to see a few more questions on particular scenarios. I know a lot of people are worried about hypos at night for example […] at work, hypos at school, hypos when staying somewhere unfamiliar."

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Table 4: Summary of themes, subthemes, and concepts introduced into STEADY toolkit from workshop 4: Coming to terms with diabetes

Subthemes	Discussion prompts and exercises	Concepts and practical ideas brought into STEADY toolkit	Quotes
Relationship to diabetes	- Anonymised quotes from prior interviews - Visual representations of relationships between diabetes, food, and body image - Example strategies for improving relationship to diabetes, food, body image from prior interviews	- Finding people who understand what you're going through - Relationship with diabetes can fluctuate over time - Understanding that diabetes can affect all areas of your life - Relationship with healthcare professionals can provoke negative feelings about diabetes (feelings of judgement and failure, fear of complications, perfectionism) - Diabetes treatment should include emotional, social, psychological health - Usefulness of diabetes technology should be assessed for each patient – it can provide helpful data and accountability for diabetes management for some, but creates anxiety and perfectionist thinking for others	- "I find the only thing that could possibly make me feel better is talking to my Type 1 [friends], and just going, 'It sucks,' and everyone else going, 'Yeah, it's evil.'" - "I know how the diabetes works, I can carb count, I know how all of that does, but it's the eating disorder that gets in the way" - "There's so much more to diabetes than the numbers, and I think so many healthcare professionals don't realise that. Like, I mean, my A1c was fine, and that's great, but I was panicking, I had so much anxiety and so much depression, and I went to my consultant and said, 'I worry I'm going to die in my sleep,'" - "[I got a Dexcom] and it was such a stress relief. Like, all of a sudden I wasn't panicked all the time about whether I was too high or too low, or whatever, and I could just know … [but on the other side] I must have looked at [it] four times during [the scene setter film], and it's really silly because of course I had a sandwich it's going to go up, like, why am I obsessing over it?" - "I need that accountability [with my diabetes team], if I didn't have my Libre, I could still fake my numbers, and I don't want to put myself in that position."

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Relationship to food	- Education around carb counting and dose adjustments can be very helpful but can also drive perfectionism, obsessive behaviours, and restriction. - Learning a relaxed approach to food can be helpful – allowing a wide range of foods, not restricting yourself to certain food groups - Making small changes and recognizing progress	- "[As a child with set insulin doses] I was feeding the insulin, but the perfectionism was a key part of it, the weighing, the obsession … six times a day being forced to eat, and then I started to use food as a sedative." - "You're having to use food as part of your treatment through your diabetes rather than enjoyment" - "It was about my tiny, tiny little steps I took were about being courageous […] just trying to stop and think, 'I'll just be brave and see how it feels if you don't have a chocolate'"
Relationship to body image	- Finding self-worth outside of body image - Using 'body neutrality' to accept your body without feeling pressure to be positive or negative - Acknowledging how diabetes technology influences body image (injections, devices, body 'doesn't work') - Being prepared for the physical effects of re-introducing insulin (such as gaining weight due to rehydration)	- "Being able to tolerate imperfection in the body and things not being okay, and really grounding people, grounding exercises in general I think are hugely, hugely helpful." - "[The eating disorder is] how you react to that betrayal, like, your body is betraying you, it's doing something it's not supposed to do" - "I never, ever wanted to know about an Omnipod, because I was, like, 'I have enough lumps and bumps thank you very much'" - "…going to the pool with gammy waterproof tape on my arm … the border of it is peeling off, there are black marks … bruises on my legs from my injections as well"

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Table 5: Summary of themes, subthemes, and concepts introduced into STEADY toolkit from workshop 5: Fear of weight gain

Subthemes	Discussion prompts and exercises	Concepts and practical ideas brought into STEADY toolkit	Quotes
Body image, eating, weight and shape	- Bound materials developed from previous workshops - Existing eating disorder CBT exercises adapted for diabetes	- Developing "good enough" feelings about diabetes can contribute to "good enough" body image - Exploring enjoyable activities where you are not concerned with eating, weight, and shape - Using CBT activities that explore the bigger picture rather than focusing on the details of your body or weight gain - Asking loved ones not to use "I understand" when they don't live with the condition and don't have the same experiences.	- "I think clinicians perpetuate [negative body image] because I've gone to clinic and been told I'm overweight and that I need to lose weight by the nurse, and to exercise more." - " [In CBT, the therapist asked], 'So, what would your best friends say about you, if they were trying to describe you what would they say?'… and you, look back on it, how much of that is to do with what you what you look like, or your weight, and it never is. [It] makes you think about that wider picture of what you are as a person." - "When I'm playing with the dogs I never even think about [my body]… ' - "The reason that you don't control your diabetes is because it's the only thing that you actually have control over … It's not me failing at control..."
Psychoeducation about re-nutrition and re-introduction of insulin		- it is important for healthcare professionals to be honest that patients will gain weight, and explore how to cope with this - Language of hypoglycaemia can be infantilising – it is better to frame hypo treatment as 'treatment' instead of sweet 'treat' - Establishing routines to do basic diabetes self-management on "autopilot" - Reducing blood glucose levels can mean	- "[The thought experiment should be exploring] even if I put on weight, 'Well, did your friends say anything?' 'No.' 'Were they really pleased to see you?' 'Yes.' 'Were you really pleased to see them?' 'Yes.' 'Is that something you'd like to do more of?' … It's preparing them that the weight gain is going to come but diverting their attention from it to say, 'Look, this is going to happen but you can get your life back.'"

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

	experiencing more uncomfortable feelings that were previously 'numbed' by high glucose levels.	- "…, but I'm Type 1 diabetic with an eating disorder, so actually it's things like the unwanted calories for [hypo] treatment, how does this affect how I feel about my eating disorder?" - "… I'm taking my insulin again, and then I feel rubbish and it feels like I'm almost being punished for doing the right thing"
Eating plans and establishing regular eating	- Eating plans must be individualised and adaptable. - Allowing patients to exercise throughout their therapy and supporting them with exercise and insulin adjustments as an adjunct to therapy - Reframing the thought "100-200 carbs a day" to show what that looks like in actual food. Visual images can be helpful as a starting point. - Having go-to meals that don't require too much thought or preparation	- "With regards to structured planning with food, I know you said this shouldn't be the main focus … but what may work for one person may not work for another… [having a set plan] might work better for me" - "So, if you really value your training for the day, then maybe your first change is around being able to support doing your training […] then you think about moving onto the next step, but based on something that's directly meaningful for you" - "I know that when I come in late at home and I'm thinking, I'm really quite tired and I don't really want to cook a full big meal, my go-to food is make an omelette … you've got yourself a decent meal and it's taken less than five minutes … it's my go to"

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Supplemental Tables

Supplemental Table 1: Summary of 15 participants with type 1 diabetes at EBCD workshops

Age	Years living with diabetes	Workshops attended
35	19	5
31	12	5
34	32	4
25	20	4
20	13	4
26	10	4
67	54	3
36	29	3
40	29	3
29	28	3
29	20	3
25	10	3
28	7	3
31	29	1
40	18	1
27	N/A Support person for participant with diabetes	1

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Supplemental Table 2: Summary of 25 healthcare professional participants at EBCD workshops

Job title	Subspecialty	Years in profession	Workshops attended
Diabetes specialists			
Diabetes Consultant	Diabetes	10	4
Diabetes Nurse Specialist	Diabetes	20	4
Diabetes Nurse Specialist	Diabetes	27	3
Diabetes Research Nurse	Diabetes	2	3
Diabetes Consultant	Diabetes	17	2
Diabetes Consultant	Diabetes	26	1
Diabetes Nurse Specialist	Diabetes	33	1
Diabetes Nurse Specialist	Diabetes	23	1
Clinical Research Fellow	Diabetes	10	1
Mental health specialists			
Consultant Psychiatrist	Diabetes	17	3
Consultant Psychiatrist/ liaison	Diabetes	12	3
Clinical Psychologist	Diabetes	11	3
Clinical Psychologist	Diabetes	11	2
Clinical Psychologist	Diabetes	10	2
Consultant psychiatrist	Eating disorders	10	2
Consultant psychiatrist	Eating disorders	2	2
Professor of Psychiatry	Eating Disorders	41	1
Clinical Lecturer Eating Disorders	Eating disorders	13	1
Clinical psychologist	Eating disorders	12	1
Family and Systemic Psychotherapist	Diabetes	5	1
Trainee Family Therapist	Eating disorders	3	1
Dietetics			
Dietitian	Diabetes	19	3
Dietitian	Diabetes	10	2
Dietitian and CBT therapist	Eating disorders	13	1
Dietitian	Eating disorders	7	1

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

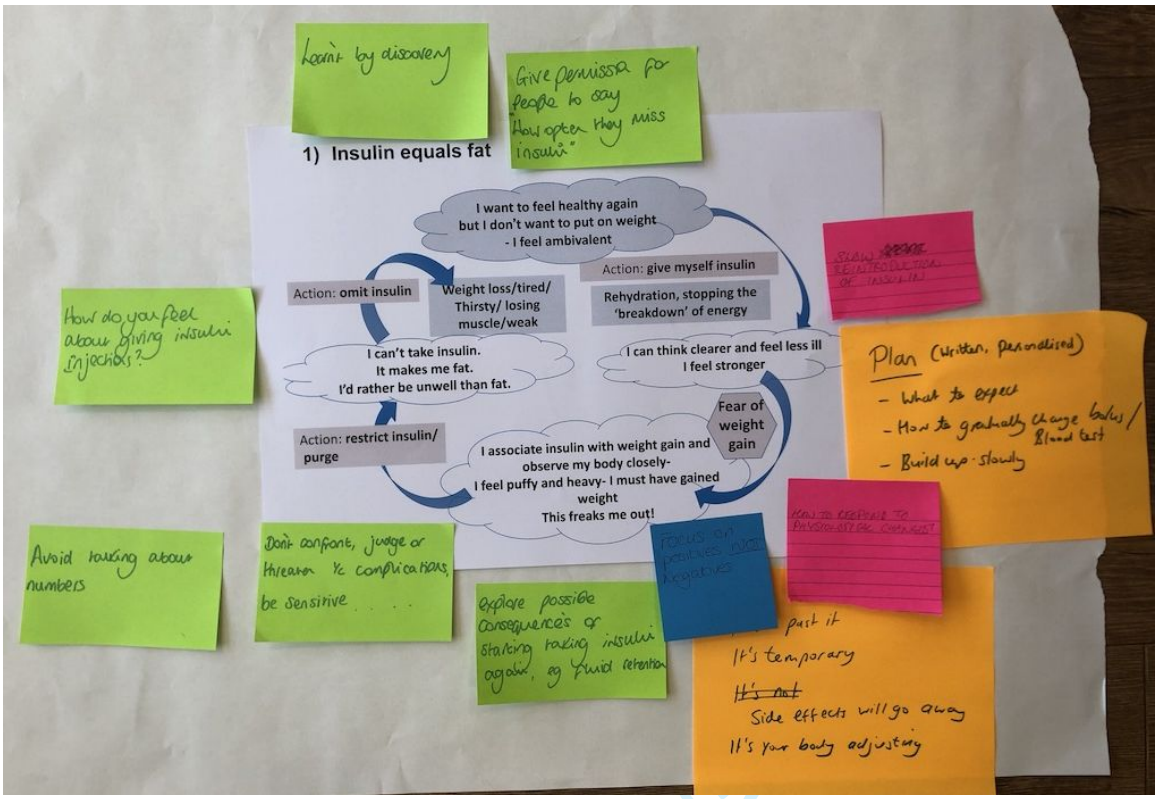
Supplemental Table 3: Participants at each EBCD workshop

Workshop	People with diabetes	Healthcare professionals	Total
1. Insulin Titration – Exploring maintenance cycles of insulin omission, which contribute to feelings of control over diabetes, weight loss, fear of injecting insulin and feelings of addiction	7	13	20
2. Hypoglycaemia – Exploring maintenance cycles of hypoglycaemia related disordered eating and/or insulin restriction which lead to hypoglycaemia symptoms at elevated glucose levels, binging, omitting insulin, feeling restricted in food choices, and afraid of exercise	8	14	22
3. Toolkit revision – Revising STEADY toolkit materials developed from prior workshops	7	3	10
4. Coming to terms with diabetes – Exploring how to adjust to living with diabetes, and how diabetes influences relationship to food and body image	11	8	19
5. Fear of weight gain – Exploring therapeutic tools used to address fear of weight gain	9	8	17
6. Practical elements of STEADY – Exploring the practicalities of therapy and development of a smartphone app to facilitate therapy	8	3	11

RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

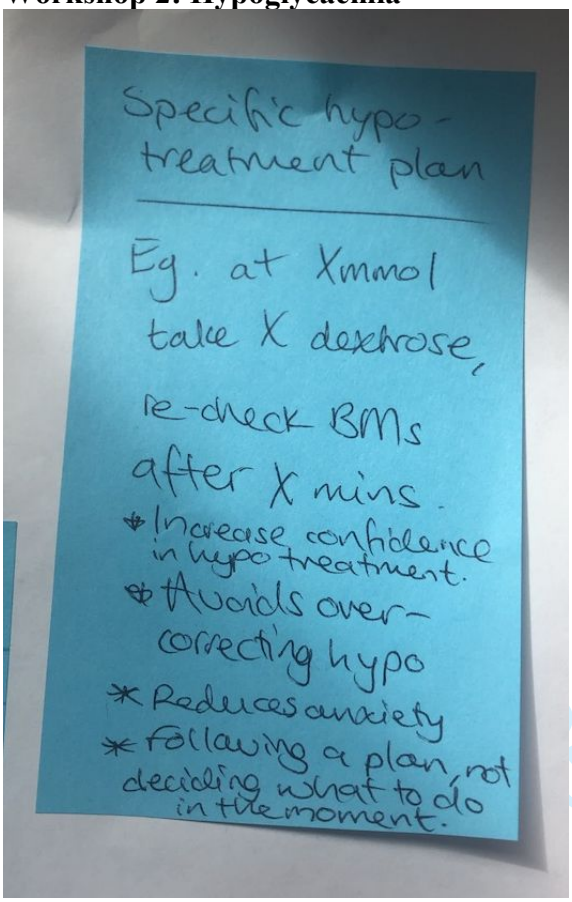
Supplementary Material 1: Examples of interactive material and data collected from Experience-Based Co-Design workshops

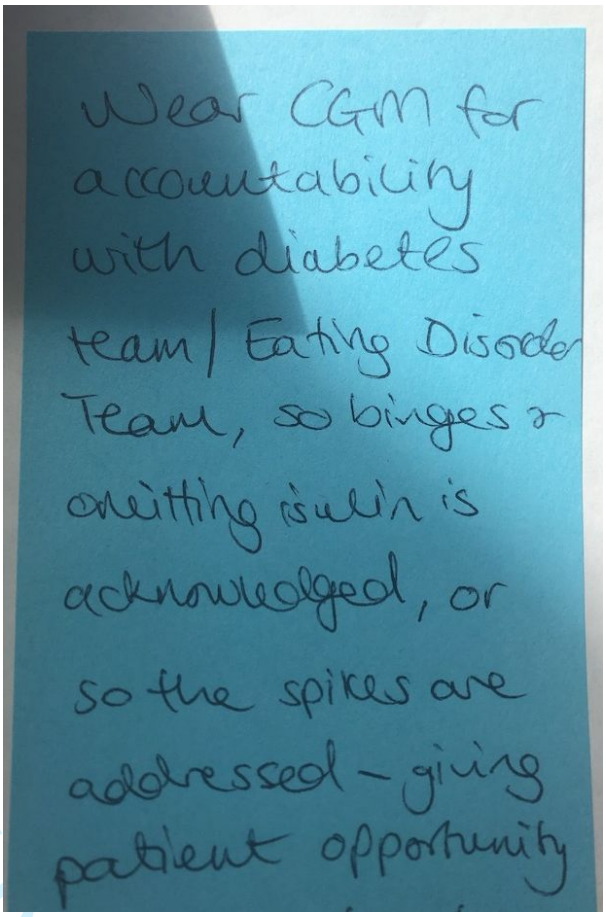
Workshop 1: Insulin Titration



RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

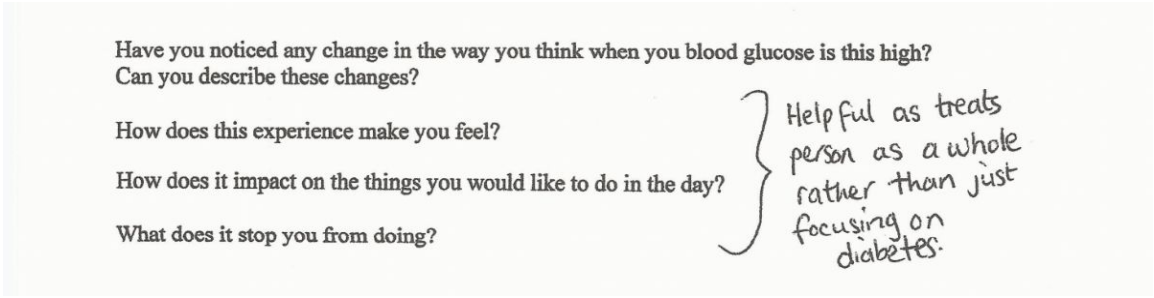
Workshop 2: Hypoglycaemia

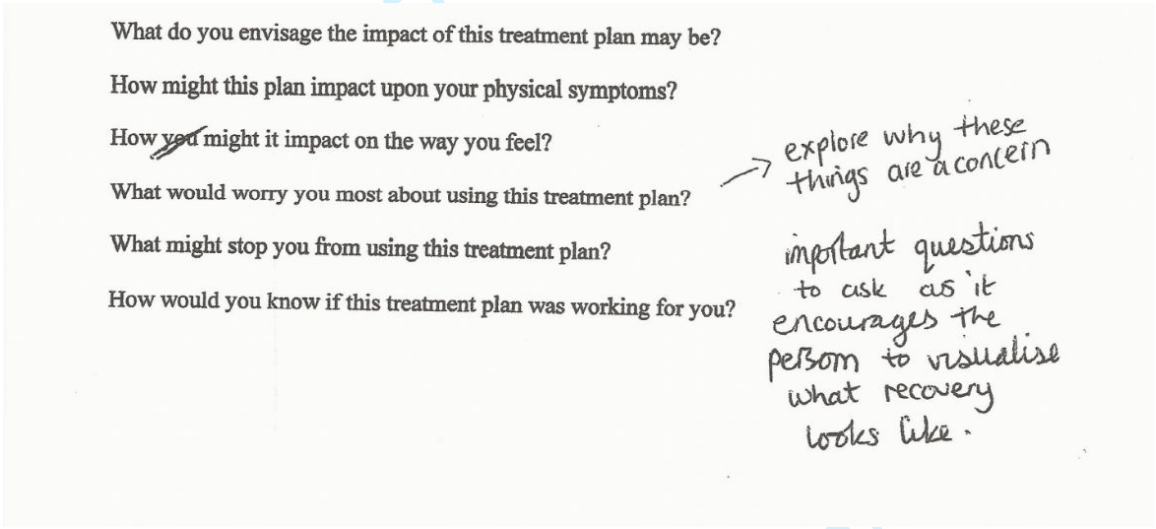


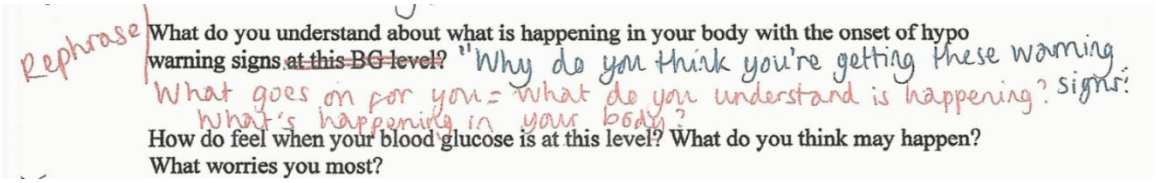


RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Workshop 3: Toolkit Revision







RUNNING TITLE: Developing a novel intervention for type 1 diabetes and disordered eating

Workshop 4: Coming to terms with diabetes