

# BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email [info.bmjopen@bmj.com](mailto:info.bmjopen@bmj.com)

# BMJ Open

## Co-designing interventions to improve psychological and social adaptation among adults with new-onset type 1 diabetes in Denmark and the United Kingdom

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2021-051430
Article Type:	Original research
Date Submitted by the Author:	22-Mar-2021
Complete List of Authors:	Due-Christensen, Mette; Steno Diabetes Center Copenhagen, Health Promotion Research; King's College London, Faculty of Nursing, Midwifery and Palliative Care Joensen, Lene; Steno Diabetes Center Copenhagen, Health Promotion Research Sarre, Sophie; King's College London, Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care Romanczuk, Ewa; Odense Universitetshospital, Steno Diabetes Center Odense Wad, Julie; Steno Diabetes Center Copenhagen Forde, Rita; King's College London, Faculty of Nursing, Midwifery and Palliative Care Robert, Glenn; King's College London, Faculty of Nursing, Midwifery and Palliative Care Willaing, Ingrid; Steno Diabetes Center Copenhagen, Health Promotion Research Forbes, Angus; King's College London, Division of Care in Long-term Conditions
Keywords:	DIABETES & ENDOCRINOLOGY, QUALITATIVE RESEARCH, General diabetes < DIABETES & ENDOCRINOLOGY

SCHOLARONE™  
Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

1  
2  
3 1 **Title:** *Co-designing interventions to improve psychological and social adaptation among adults with*  
4 *new-onset type 1 diabetes in Denmark and the United Kingdom*  
5  
6

7 3

8  
9  
10 4 Corresponding author: Mette Due-Christensen, Steno Diabetes Center Copenhagen, Niels Steensens  
11 Vej 2, 2820 Gentofte, Denmark. E-mail: mdue0015@regionh.dk  
12

13 6 Lene E Joensen, Diabetes Management Research, Steno Diabetes Center Copenhagen, Gentofte,  
14 Denmark  
15 7

16  
17 8 Sophie Sarre, Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, United  
18 Kingdom  
19 9

20  
21 10 Ewa Romanczuk, Steno Diabetes Center Odense, Odense Universitets Hospital, Odense, Denmark  
22

23  
24 11 Julie Lindberg Wad, Diabetes Management Research, Steno Diabetes Center Copenhagen, Gentofte,  
25 Denmark  
26 12

27  
28 13 Rita Forde, Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, United  
29 Kingdom  
30 14

31  
32 15 Glenn Robert, Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, United  
33 Kingdom  
34 16

35  
36 17 Ingrid Willaing, Diabetes Management Research, Steno Diabetes Center Copenhagen, Gentofte,  
37 Denmark  
38 18

39  
40 19 Angus Forbes, Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, United  
41 Kingdom  
42 20

43  
44 21 Word count: 3983  
45

46 22

47  
48 23

49  
50 24

51  
52 25

53  
54 26

55  
56  
57  
58  
59  
60

1  
2  
3 1 **ABSTRACT**

4  
5 2 **OBJECTIVE**

6  
7  
8 3 To develop supportive interventions for adults with new-onset T1D to facilitate positive adaptive  
9 4 strategies during their transition into a life with diabetes.

10  
11 5 **DESIGN**

12  
13  
14 6 The study used a co-design approach informed by Design Thinking to stimulate participants'  
15 7 reflections on their experiences of current care and generate ideas for new supportive interventions.  
16  
17 8 Visual illustrations were used to depict support needs and challenges. Initial discussions of these needs  
18 9 and challenges were facilitated by researchers and people with diabetes in workshops. Data  
19 10 comprising transcribed audio recordings of the workshop discussions and materials generated during  
20 11 the workshops was analyzed thematically.

21  
22  
23  
24 12 **SETTINGS**

25  
26  
27 13 Specialized diabetes centers in Denmark and the United Kingdom

28  
29 14 **PARTICIPANTS**

30  
31 15 Adults with new-onset T1D (n=24) and health care professionals (HCPs) (n=56) participated in six  
32 16 parallel workshops followed by four sequential workshops with adults (n=29) and HCPs (n=24)  
33 17 together.

34  
35  
36 18 **RESULTS**

37  
38  
39 19 The common solution prioritised by both adults with new-onset T1D and HCP participants was the  
40 20 development of an integrated model of care addressing the psychological and social elements of the  
41 21 diagnosis, alongside information on diabetes self-management. Participants also indicated a need to  
42 22 develop the organisation, provision, and content of care, along with the skills HCPs need to optimally  
43 23 deliver that care. The co-designed intervention included three visual conversation tools that could be  
44 24 used flexibly in the care of adults with new-onset T1D to support physical, psychological, and social  
45 25 adaptation to T1D.

46  
47  
48  
49  
50  
51 26 **CONCLUSION**

52  
53  
54 27 This co-design study has identified the care priorities for adults who develop T1D, along with some  
55 28 practical conversational tools that may help guide HCPs in attending to the disruptive experience of  
56 29 the diagnosis and support adults in adjusting into a life with diabetes.

57  
58  
59 30

1  
2  
3 1 Strength and limitations of this study  
4  
5

- 6 2 • The study included a diverse sample of adults with new-onset T1D from two countries  
7  
8 3 • A large number of health care professionals across multiple disciplines from two countries  
9  
10 4 took part in the study  
11  
12 5 • The broad approach including many different perspectives increases the transferability of the  
13  
14 6 results to other contexts  
15  
16 7 • Although we did not find any discrepancy between perspectives across gender, a limitation of  
17  
18 8 the study is the relatively small number of male participants  
19  
20 9 • People with diabetes have been involved in the design and conduct of the study from  
21  
22 10 inception  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## 1 INTRODUCTION

2 A diagnosis of Type 1 diabetes (T1D) can occur at any age, with around 50% of cases presenting in  
3 adulthood.(1, 2) Developing T1D as an adult can be very disruptive, as adults have already formed  
4 many aspects of their lives: employment, relationships, and lifestyle habits.(3, 4) The diagnosis  
5 introduces new responsibilities for acquiring and maintaining time-consuming self-management skills,  
6 and fears about hypoglycaemia and future diabetes complications, all of which may affect self-identity  
7 and life-plans.(5, 6) Previous research has identified that accommodating the demands of T1D into  
8 established life routines can lead to significant psychological and social challenges for adults with new-  
9 onset T1D.(7, 8) These challenges include difficulties in coming to terms with the diagnosis of T1D;  
10 experiencing added complexity and disruption of daily life due to managing diabetes alongside other  
11 demands; and feeling stigmatised and anxious about how the diagnosis will affect social relationships  
12 and employment.(3, 4)

13 During the disruptive period following diagnosis many adults feel that their psychological and  
14 emotional needs are not adequately addressed by health care professionals (HCPs).(9, 10) Adults with  
15 new-onset T1D perceive that the focus of their interactions with HCPs is on providing them with the  
16 technical skills needed for blood glucose management to achieve 'good' blood glucose levels.(4) This  
17 focus, when pursued without attending to the psychological and social challenges following the  
18 diagnosis of T1D, can create a sense of frustration and failure in the person with diabetes when  
19 optimal blood glucose levels are not achieved.(3, 4) Furthermore, the person may consequently be  
20 less likely to engage with their self-management behaviours, thereby increasing the risk of future  
21 burdensome and costly diabetes complications.(4, 11) Hence, early intervention to support adults in  
22 developing positive adaptive strategies and self-management routines in everyday life following  
23 diagnosis may reduce these problems and may improve long-term physical and mental health  
24 outcomes.

25 National and international guidelines(12, 13) highlight the importance of addressing the  
26 psychological and social needs of adults with diabetes, however, there are no specific  
27 recommendations for how to address these needs in the adult onset T1D population. While HCPs  
28 generally recognise the importance of providing psychological and social support for adults with  
29 diabetes,(14, 15) studies have reported minimal inclusion of such issues in routine diabetes care due  
30 to lack of training, tools and skills to engage in conversations about psychological and social  
31 aspects.(16-18) Furthermore, access to specialist psychology services is limited in most areas.  
32 Structural barriers such as consultation time constraints due to a focus on fulfilling the requirements  
33 set by clinical guidelines and an emphasis on glucose targets also limit the capacity for psychological  
34 and social support.(9, 17) Previous studies have reported that HCPs tend to overload people with

1 information on diabetes self-management, focusing on technical issues rather than providing  
2 psychological and social support due to a fear for the person's physical safety.(4, 9) Such studies  
3 have also found that this emphasis on diabetes treatment together with the risks of hypoglycaemia  
4 and long-term complications can induce a sense of anxiety in adults with new-onset T1D.(4, 9)

5  
6 Overall, existing evidence shows a disconnect between the needs of adults with new-onset T1D and  
7 current early-stage care, with potentially negative consequences in relation to the person's  
8 acceptance of and engagement with their diabetes; thereby, increasing the risks of future physical  
9 and psychological morbidity. To address this problem, we have undertaken a co-design study with  
10 adults with new-onset T1D and HCPs in Denmark (DK) and the United Kingdom (UK). The aim was to  
11 explore care priorities for adults with new-onset T1D and to develop supportive interventions to  
12 facilitate a more positive transition into life with diabetes- physically, emotionally, and socially - that  
13 could be tested in future feasibility trials.

## 14 15 **DESIGN AND METHODS**

16 The study used a co-design approach informed by Design Thinking to explore and develop  
17 interventions to support adults in adapting to T1D.(19) The co-design approach in the study was  
18 aligned with early stages of the Medical Research Council framework on developing and evaluating  
19 complex interventions to explicate mechanisms for intervention and to identify potential intervention  
20 components for future testing.(20) Design-thinking typically has three integrated phases centered on  
21 stakeholder engagement and participation.(21) The first phase (*Inspiration*) relates to exploring the  
22 target groups' physical, social, and emotional needs. The second phase (*Ideation*) includes a process  
23 for stimulating the target population to generate, develop, and test ideas that might be a solution to  
24 the needs defined in the ideation phase. In the third phase (*Implementation*) prototypes developed in  
25 the ideation phase are tested.

26 This paper presents our findings from the ideation phase, the inspiration element of the process has  
27 been reported elsewhere.(4, 9, 22) Prototypes that resulted from the ideation phase reported here  
28 will be tested in future feasibility trials.

### 29 30 **Study Settings and Participants**

31 The study participants were recruited from four specialist diabetes clinics in DK and two in the UK,  
32 with approximately 250 and 80 new cases of adult-onset T1D annually, respectively. The rationale for  
33 this was to consider the experiences of adults in different settings to enhance the transferability of  
34 the study outputs. T1D care in DK and the UK is similar in that it is provided by multidisciplinary



1  
2  
3 1 specialist diabetes teams, with the only major difference being the offer of group-based evidence-  
4 based structured self-management education programs in the UK from 6-12 months following  
5 diagnosis however, the uptake is low.(23, 24)  
6  
7

8  
9 4 Eligibility criteria for study participants included: adults ( $\geq 18$  years) diagnosed with T1D within the  
10 past five years to ensure recollection of diagnosis and HCPs with >1-year experience of providing care  
11 for adults with new-onset T1D. Of 82 adults with new-onset T1D invited to participate in the study, 36  
12 accepted the invitation, and 31 attended one or more workshops. Participants were recruited  
13 according to ethical approval in each country. In the UK potential participants were purposively  
14 sampled to achieve maximum variation in terms of age and gender and invited by letter. In DK eligible  
15 participants were approached by clinicians following out-patient appointments. All members of the  
16 multidisciplinary diabetes team in each clinic (ranging from 4-35 HCPs) were invited to participate via  
17 email.  
18

### 19 13 **Patient and Public Involvement**

20 14 People with T1D have been involved in the design and conduct of the study. One person with T1D was  
21 a co-applicant on one of the grants. They were also part of the advisory group with four other people  
22 with T1D, a representative from a patient organisation and two health care professionals in addition  
23 to the research team. The advisory group have played a central role in making sure that the study and  
24 its outputs are patient centred.  
25

### 26 19

### 27 20 **Data Collection**

28 21 We first conducted nine parallel workshops (adults with new-onset T1D in groups (n=24) and HCP in  
29 groups (n=56)) and then four integrated workshops (adults with new-onset T1D (n=29) and HCP (n=24)  
30 in a joint workshop) to stimulate the target populations to generate, develop, and test ideas for new  
31 supportive interventions. Workshops were conducted from June 2018 to October 2019. Data included  
32 audiotaped discussions from all workshops which were transcribed and sticky notes and flip charts  
33 with participants' feedback. (For an overview of the process see table 1). In the UK three adults with  
34 T1D from the study advisory board undertook training in group facilitation together with the UK  
35 research team to co-facilitate the parallel and integrated workshops. In DK workshops were facilitated  
36 by members of the research team. The research teams consisted of experienced clinicians and  
37 researchers.  
38

39 31 Workshops for adults with new-onset T1D were conducted either in university or diabetes clinic  
40 rooms. Workshops for HCPs took place in the participating diabetes clinics. The parallel workshops  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 1 lasted two hours each. The integrated workshops were also conducted either in university (n=2) or  
4  
5 2 diabetes clinic rooms (n=2), they were 3 hours long with breaks for food and refreshment.

6  
7 3 Ethical considerations

8  
9 4 Written consent was obtained from all participants. The study was approved by the Danish Data  
10  
11 5 Protection Agency (VD-2018-196, I-Suite 6439) and The North West Research Ethics Committee  
12  
13 6 (15/NW/0528) in the UK.

14  
15 7 Workshop methods

16  
17 8 The parallel workshops were structured to enable smaller group discussions to stimulate participants  
18  
19 9 to reflect on their experiences. Illustrations depicting the common support needs and challenges  
20  
21 10 expressed by adults with new-onset T1D and HCPs in the inspiration phase(4, 9, 22) were used to  
22  
23 11 stimulate group discussions (see figure 1 for examples). Following these facilitated discussions,  
24  
25 12 participants were asked to vote on the three challenges they considered the most important to  
26  
27 13 address. Brain-storming exercises in smaller groups were then used to generate as many ideas and  
28  
29 14 solutions as possible related to the prioritized challenges.

30  
31 15 [insert figure 1 here]

32  
33 16 In the integrated workshops adults with new-onset T1D and HCPs voted on their top two priorities  
34  
35 17 and then worked together to develop interventions to address these. Ideas and solutions from  
36  
37 18 previous workshops were summarised onto cards and combined with new ideas which were gradually  
38  
39 19 refined to provide prototypes of tools to support adults with new-onset T1D. Preliminary prototypes  
40  
41 20 were collated and integrated by the advisory board. The prototypes were circulated via email to  
42  
43 21 workshop participants for verification, comments, and further suggestions for refinements. Over  
44  
45 22 several iterations through emails and conversations the prototypes were further refined into a  
46  
47 23 deliverable format for testing in future feasibility trials.

48  
49 24

50  
51 25

52  
53 26

54  
55 27

56  
57 28

58  
59 29

60

Table 1 Summary of study data types and collection points

Data collection point	Objective	Participants	Activities	Data types
<b>Inspiration phase (previous studies)</b>				
Interviews(4, 22)	To explore the experience of diagnosis, support needs and challenges	Adults with new-onset T1D	Longitudinal semi-structured individual interviews (two interviews over 6-8 months)	Transcribed interviews
Focus groups(9)	To explore preferences and needs in relation to providing support to adults with new-onset T1D. Identify barriers and enablers, reflections on current procedures, processes and care provision at diagnosis, HCPs' perceptions of issues relating to provision of support to adults with new-onset T1D and reflections on and the identification of dilemmas/challenges in current care.	HCPs	Exercises: Story dialogue (HCPs sharing their experience of a particular consultation) Presentation of experiences of adults with new-onset T1D using quotes and illustrations to facilitate discussion (from previous studies)	Transcriptions of discussion Notes from participants Field notes Story dialogue notes
<b>Ideation phase</b>				
Workshops for adults with new-onset T1D (n=3)	To validate findings from previous studies. To prioritise among identified challenges and generate preliminary ideas and develop solutions	Adults with new-onset T1D	Exercises: Prompt questions such as: <i>What do you think is the most important thing when supporting adults with new-onset T1D?</i> Illustrations and quotes of adults with new-onset T1D experiences from previous studies	Sticky notes with ideas and solutions Field notes Transcription of audio-recorded group discussions
Workshops for HCPs (=6)	To validate findings from previous studies. To prioritise among identified challenges from previous work To generate ideas and develop solutions to these challenges	HCPs	Illustrations depicting the identified challenges were used to encourage discussion before prioritising which were most important to focus on	Transcription from audio-recorded group discussions Preliminary ideas on sticky notes and field notes
Integrated workshops (n=4)	Prioritise among the identified challenges and the ideas from individual workshops Build on previous ideas and develop prototypes of support tools	Adults with new-onset T1D and HCPs	Presentation of priorities and ideas and solutions from previous workshops Alterations of solutions, design of prototypes	Transcription from audio-recorded group discussions Sticky notes Preliminary prototypes
Feedback	To obtain feedback from potential users of the prototype in relation to usability, relevance, and design	Adults with new-onset T1D and HCPs	Presentation of preliminary prototypes, structured feedback to specific questions via email or in meetings with HCPs	Revised prototypes ready for field testing

## 1 Data analysis

2 Anonymised data from the workshops were analysed thematically for common themes among the  
3 suggested ideas and solutions for each prioritised challenge across sites and countries. The analysis  
4 followed Braun and Clarke's(25) method, which is based on a five-step process:

5 1) becoming familiar with the data by reading and re-reading the outputs from workshops  
6 (transcriptions, post it notes, summary notes), and making notes of early impressions

7 2) generating initial codes, through looking across the dataset to compare challenges, ideas and  
8 solutions for similarities and differences within and across sites and countries

9 3) searching for common themes, by comparing the relationships between the ideas and solutions  
10 related to the prioritised challenges and organising them into broader themes

11 4) reviewing themes, by identifying patterns across the themes and labelling overarching themes for  
12 the challenges, ideas, and solutions

13 5) defining and naming themes through refining the relationships between the challenges and the  
14 suggested solutions and ideas.

15 The initial coding of workshop data was conducted by local members of the research team and  
16 discussed with the first author (MD-C). The coding was compared for similarities and differences  
17 between sites and countries in preparation for theme development. MDC developed preliminary  
18 themes in collaboration with SS and AF (UK) and ER and JLW (DK). These were then discussed with and  
19 refined by members of the research teams across the sites during the initial steps of the analysis  
20 process. Subsequently the whole team met to agree on the final themes and prototypes of tools.

## 22 RESULTS

23 Of the 31 adults with new-onset T1D participating in the study, 16 (52%) were from DK, 20 (64%) were  
24 women, median diabetes duration was 2.5 years (IQR 1.5-3.5) and median age was 42 years (IQR 34-  
25 51.5). Of the 61 HCPs participating in the study, 44 were from DK (71%). Thirty-six were nurses (59 %),  
26 14 doctors (23%), 8 dieticians (13 %) and 3 (5 %) others (i.e., psychologists). They had a median of 15  
27 years (IQR 10-20) of experience of caring for adults with new-onset T1D. Twenty-eight participants (16  
28 adults with new-onset T1D and 12 HCPs) took part in more than one workshop (see Table 2).

1  
2  
3 **1** *Table 2 Participants in parallel and integrated workshops*

	<b>UK</b>	<b>DK</b>	<b>TOTAL</b>
<b><i>Adults with new-onset T1D n (%)</i></b>	<b><i>n=15</i></b>	<b><i>n=16</i></b>	<b><i>n=31</i></b>
Female	11 (73.3)	9 (56.2)	20 (64.5)
Male	4 (26.7)	7 (43.8)	11 (35.5)
Age median*	42 (32.5-57.5)	43.5 (35-46.8)	42 (34-51.5)
Years with diabetes*	3.5 (2-3.6)	2 (1.4-3)	2.5 (1.5-3.5)
<b><i>Health care professionals n (%)</i></b>	<b><i>n=17</i></b>	<b><i>n=44</i></b>	<b><i>n=61</i></b>
Dietician	2 (11.8)	6 (13.6)	8 (13.1)
Doctor	6 (35.3)	8 (18.2)	14 (23)
Nurse	7 (41.2)	29 (65.9)	36 (59)
Other**	2 (11.8)	1 (2.3)	3 (4.9)
Years in diabetes care*	12 (2.5-16.5)	16.8 (11-25)	15 (10-20)

\*Median IQR (25%-75%) \*\*Other = researcher, psychotherapist, psychologist

Missing data on years in diabetes care for HCPs: UK=1, DK=2

### 2 3 **Prioritizations**

4 Top priorities differed slightly among the parallel workshops. The three challenges most commonly  
5 given the highest priority across the workshops for adults with new-onset T1D were: a) coming to  
6 terms with diabetes; b) the complexity of managing diabetes in different contexts and alongside  
7 other demands; and c) fear of hypoglycaemia, high blood glucose values and complications. The  
8 HCPs workshops prioritised the following challenges as most important: a) balancing the clinical  
9 perspective (blood glucose regulation and prevention of long-term complications) with the  
10 perspective of the adult with new-onset T1D; b) overloading adults with new-onset T1D with  
11 information due to fear for their physical safety; and c) difficulties with how to address psychological  
12 and social issues. The highest rated priorities from the integrated workshops were: 1) *helping adults*  
13 *to come to terms with diabetes by addressing psychological, social, and emotional issues* and 2)  
14 *avoiding information overload and balancing the clinical perspective with the needs of the adult with*  
15 *new-onset T1D to facilitate a more positive adaptation to diabetes.*

### 17 **Solution themes**

18 The participants consistently suggested that diabetes care and support for adults with new-onset  
19 T1D needed to be phasic, firstly addressing the emotional, social, and physical impact of the  
20 diagnosis, and then how to adapt to life with diabetes. Adults with new-onset T1D and HCPs both  
21 recognised the benefits of addressing psychological and social needs to enhance engagement in self-  
22 management activities and consequently reduce the risk of diabetes complications (both physical  
23 and psychological). There was a high level of agreement in the suggested solutions and ideas stated  
24 by participants (both adults with new-onset T1D and HCPs) across the two countries although the

1 terminology used varied. Solutions to the prioritised challenges in relation to care priorities centred  
2 around four overarching themes: 1) provision of care which related to the interactions between the  
3 person with diabetes and the HCP; 2) ideal care content involved topics identified by participants as  
4 relevant and important to discuss in consultations following the diagnosis, 3) HCP care skillset, which  
5 concerned ways to support and improve HCPs skills sets and 4) organisation of care including  
6 availability and consistency of staff, timing of and mode of consultations and structure of electronic  
7 records. The themes are described in table 3 with illustrative quotes/excerpts from workshop  
8 discussions and information on how they fed into the co-designed interventions.

9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

For peer review only

Table 3 Description of themes including illustrative quotes and ways the theme informed the co-design process

Overarching theme	Brief description of theme	Illustrative quotes/excerpts from workshop discussions	Impact on co-design process
<b>Content of care</b>	<p>Signposting and normalising the difficult emotions related to the diagnosis were considered highly important in supporting adults in coming to terms with diabetes. Likewise, participants suggested signposting and discussing the common physical, emotional, and social issues that occur following diagnosis to help adults address these aspects of living with diabetes. People need to process information on diabetes, treatment, and the implications of these for daily life; but this processing can be challenging, so the information needs to be reinforced and repeated. Providing information about what adults with new-onset T1D can expect from their diabetes care, including a timeline of relevant appointments and contacts with HCPs, would help the person to see the bigger picture of their diabetes trajectory.</p>	<p><i>“it’s going to be an emotional journey going forward. So, in the same consultation you’re getting ‘and here’s your pen and this is how you inject it. You’ve got diabetes da-da-da’ - part of that initial consultation should be ‘and you are going to go on an emotional journey. You’re going to feel this, you’re going to feel that, to a greater or lesser degree’.” (PWD UK)</i></p> <p><i>“It’s the whole process [of being diagnosed] they need to ask more about. In my case I saw myself as a strong and healthy guy and then suddenly the doctor admitted me to A&amp;E. The feeling of having the rug pulled out from under you is still very real and present (PWD DK)</i></p> <p><i>“So why I’m here is because as a diabetes specialist nurse, getting the balance right between giving the information and being mindful of where people are at emotionally, we want to be able to think how we can do that in a way that’s safe and consistent throughout that journey. So, I do like this idea of the roadmap that we can use to try to ensure that can happen in a very busy clinic.” (HCP UK)</i></p>	<p>Specific and detailed ideas and solutions related to content of care were used to ensure that the conversation tools address challenges participants found important</p>
<b>Provision of care</b>	<p>Participants highlighted the importance of HCPs acknowledging that adjustment to the diagnosis is an ongoing and lengthy process. Personalising information in relation to the person’s attitudes, needs and life context in line with their journey of adaptation would increase relevance and transformation of knowledge into self-management skills. Using non-judgmental and empathetic language to explain glucose targets and</p>	<p><i>“If the HCP gave you a little bit of a kick and a little bit of a nudge so we could get closer to the emotional issues, because that takes up a lot of space. So does the practical stuff but also the emotional impact. So, you shouldn’t be allowed <u>not</u> to talk about it, I think.” (PWD DK)</i></p> <p><i>“Treating and managing diabetes isn’t just about keeping your blood sugars in check. It’s about understanding what it does to you as a person, understanding what it does to your life, and taking that whole system</i></p>	<p>The discussions in the workshops suggested that more than one tool would be useful to support both people with</p>

	<p>levels in a realistic and relative sense was recommended. Highlighting the difficulty of maintaining blood glucose values in the recommended range all the time would help improve self-efficacy and prevent adults with new-onset T1D developing a sense of failure.</p>	<p><i>approach, which brings in the emotional side. So, considering all those aspects and making that part of the medical care.” (PWD UK)</i></p> <p><i>“I think we’re very much driven by target blood glucose, you know, 4 to 7. I haven’t said it before, but somebody said to me, “It would have been really good to hear if somebody had told me actually it’s not bad or don’t worry about it if the blood sugar goes to 12 or 13. We don’t give them that level of assurance in terms of what’s going to happen.” (HCP UK)</i></p>	<p>diabetes and the HCPs in building their relationship</p>
<p><b>HCP skill set</b></p>	<p>Participants recommended providing HCPs with simple strategies and tools to enhance their skills and confidence in engaging with psychological and social issues to help support adults with new-onset T1D deal with these issues. Improving HCPs’ communication skills and maintaining these skills through regular supervision with a psychologist was also highlighted.</p>	<p><i>“I want to have a cupboard where I can just pull-out phrases and also reassurance so that I’m not patronizing the patient. And some workshops where I have to attend mandatory training.” (HCP UK)</i></p> <p><i>“Even though I think I’m very open and asking about things, but do I actually ask in a good way – am I sure the [the person with T1D] will open up to the questions even if they would like to?” (HCP DK)</i></p>	<p>The need to support both adults with new-onset T1D and HCPs to discuss psychological and social issues were considered in the co-design process</p>
<p><b>Organisation of care</b></p>	<p>Participants identified a need to allocate enough time in consultations to provide more support around the time of diagnosis. Continuity of care during the initial phase was considered essential. Small teams of HCPs providing care specifically for adults with new-onset T1D would enhance consistency in the information provided. The electronic patient record should prompt HCPs to ask questions about psychological and social issues. Provision of support groups were identified as additional opportunities for support. Participants also suggested that there should be opportunities to involve family members in their care.</p>	<p><i>“I really needed to talk to someone who not only had 10 minutes to tell me about how to use that[insulin] pen.” (PWD DK)</i></p> <p><i>“It’s having a relationship with someone else where you can say ‘how do you do (such and such)?’. Imagine getting the support of each other that we are in the same boat and we might be able to get new ideas, because we do things differently.” (PWD UK)</i></p> <p><i>“It is bad [not having enough time] and it must be something that we can do better. And it involves organisation, and it is about resources and prioritising to a great extent” (HCP DK)</i></p>	<p>The conversation tools do not specifically address organisation of care. However, the value of making the tool useful in both individual and group consultations was recognised.</p>

bmjopen-2021-05-140 on 2 November 2021. Downloaded from http://bmjopen.bmj.com/ on April 16, 2024 by guest. Protected by copyright.



## 1 Prototypes of tools to support adaptation

2 Through several cycles of feedback from adults with new-onset T1D (via email) and HCPs (via email  
3 and feedback at multidisciplinary team meetings) the co-design process resulted in the development  
4 of three prototypes of conversation tools that could be used flexibly in the care of adults with new-  
5 onset T1D.

6 Tool 1: *The diabetes roadmap* -the aim of this tool is to express how adapting to diabetes is an on-  
7 going biomedical, psychological, and social process. It lays out what the person with diabetes can  
8 expect from their diabetes care during the first year. It signposts and normalises emotional and  
9 social responses that the person with diabetes might encounter when adapting to life with T1D. The  
10 tool is visual depicting a winding road starting from the point of diagnosis. Images of different types  
11 of HCPs who adults with new-onset T1D will meet during the first year are placed on one side of the  
12 road map, and on the other side examples of thoughts and questions people might have to support  
13 them in expressing their experience of living with T1D.

14 Tool 2: *Living with diabetes* - this tool focusses on the way diabetes might affect the person's body,  
15 their thoughts and emotions and their everyday life with the aim of facilitating a dialogue on the  
16 person with T1D's own issues and emotions. It uses visual prompts with images developed from  
17 previous research, and speech bubbles signposting various ways of adapting to diabetes. The tool  
18 also involves some specific open questions to give adults with new-onset T1D the opportunity to  
19 express and process the biomedical, psychological, and social impacts of diabetes relevant to them.

20 Tool 3: *Adapting to diabetes* - through a combination of illustrations depicting common experiences  
21 at the time of diagnosis and quotes relating to such experiences developed in an earlier study (22),  
22 this tool aims to serve as a conversation starter. Adults with new-onset T1D are encouraged to reflect  
23 on their experiences of living with diabetes, explore their own values and support them in making  
24 decisions related to self-management based on these.

25 Participants suggested these tools could be used independently or in combination in both one-to-one  
26 consultations and group sessions. The advantage of one-to-one sessions was the ability to personalise  
27 the tools to reflect the life situation and specific issues of the individual. In group sessions the tools  
28 would provide space for reflection on common challenges, sharing of experiences and normalising the  
29 adaptive process. A training manual to guide HCPs in facilitating the conversation tools will be  
30 developed to increase their skills prior to future feasibility trials.

31

32

## 1 DISCUSSION

2 This co-design study included a diverse sample of adults with new-onset T1D and a broad range of  
3 HCPs from Denmark and the UK. Participants identified support related to coming to terms with  
4 diabetes and integrating clinical demands of treatment with the individual's life situation as their top  
5 priorities for developing interventions to support early adaptation. The study showed that  
6 organisation, provision of and content of care along with HCP care skills were important features of  
7 optimal care. The study's output were three visual prototype tools to support physical, psychological,  
8 and social adaptation to T1D in adults. The aims of the tools are to enable reflections on the impact  
9 of the diabetes diagnosis and establishing self-management routines that will improve health  
10 outcomes long term and enhance mental, physical, and social well-being for adults with new-onset  
11 T1D.

12 In line with previous research,(7, 26, 27) this study has highlighted the necessity of providing  
13 psychological and social support early. The lack of such support in the period after diagnosis can  
14 impact and increase the risk of long-term complications,(28) and might cause diabetes-related distress  
15 in the longer term.(27, 29) A key concept here is that early psychological and social intervention may  
16 help ameliorate or prevent the development of longer-term maladaptive coping mechanisms  
17 (avoidance or disengagement), diabetes distress and psychological morbidities (fear and anxiety)  
18 which will increase the risks for physical complications.

19 The ideas and solutions suggested for improving care processes at diagnosis across the participating  
20 countries were almost identical among the adults with new-onset T1D and HCPs participants. Previous  
21 research has identified commonalities between UK and DK in relation to the experiences and needs  
22 of adults with new-onset T1D(4) and the barriers of attending to these needs experienced by HCPs.  
23 (9) The resemblance in health care service provision for people with T1D (free access paid through  
24 taxation, corresponding clinical roles for HCPs) might explain the similar perception and experiences  
25 of HCPs and adults with new-onset T1D across DK and UK. Another explanation for the convergence  
26 between the two countries might be the universality of the challenges people experience following  
27 being diagnosed with a chronic condition as an adult.(30) Older and recent studies involving adults  
28 with longer diabetes duration have demonstrated a common and persistent perception of challenges  
29 in life with T1D across a variety of settings.(10) Such challenges include for example illness  
30 perception,(31, 32) change in identity,(33, 34) and acceptance of and adjustment to T1D.(35, 36)

31 This study showed that need for continuity, consistency and personalisation in care delivery following  
32 diagnosis was of high importance to both the adults with T1D and HCP participants. Communication,  
33 emotional support, and the quality of the relationship between the person with diabetes and their

1  
2  
3 1 HCP has been associated with long-term impacts on diabetes self-management and quality-of-life.(10,  
4 37, 38) Studies have also shown that adults with diabetes value interactions with HCPs that consider  
5 2 their mental well-being(39) and acknowledge the complex multifaceted challenges of living with  
6 3 diabetes.(40) In addition, the value of getting emotional support through peer support has also been  
7 4 highlighted in existent literature.(41, 42)  
8  
9

10  
11  
12 6 Other studies have identified the difficulties and challenges faced by HCPs in providing emotionally  
13 7 therapeutic care, identifying the need to increase the awareness, skills, and opportunities of HCPs for  
14 8 delivering such care.(43, 44) A key challenge to overcome is the need to balance clinical priorities  
15 9 (introducing diabetes technologies safely and setting glucose levels) with the wider needs of the  
16 10 person with diabetes following the disruption of the diagnosis. Integrating these different agendas in  
17 11 consultations might improve the consultation experiences for both adults with T1D and HCPs.(45)  
18 12 Openness and awareness may in turn improve the trust that is paramount for the relationship, and  
19 13 which may enable the integration of adults' experiential knowledge with that of HCPs to the benefit  
20 14 of both parties.(10, 46, 47)  
21  
22  
23

24  
25  
26  
27  
28 15 The conversation tools developed in this study will not in isolation change practice. Tools need to be  
29 16 underpinned by common values and understanding in terms of what is necessary for their use and  
30 17 who can provide the support including change of practice and collaboration and what training is  
31 18 needed.(48, 49) Multidisciplinary teamwork with input from adults with new-onset T1D and time for  
32 19 discussions on approaches to care for adults with new-onset T1D are likely to increase common values  
33 20 and engagement with and use of the tools in clinical practise. A common approach to the tools may  
34 21 enhance the therapeutic interactions between HCPs and adults following diagnosis allowing for a  
35 22 more open dialogue in relation to how people navigate the physical, psychological, and social impact  
36 23 of developing T1D in adulthood.  
37  
38  
39  
40  
41  
42  
43

44 24 While the challenges identified and prioritised in our study are in line with previous research in adults  
45 25 with diabetes, this study is the first to explore and compare specific solutions to these challenges  
46 26 among a transnational group of both adults with new-onset T1D and HCPs. Our study highlights that  
47 27 challenges occur from the time of diagnosis and support is needed to address these challenges as early  
48 28 as possible to potentially prevent long term psychological consequences such as high levels of diabetes  
49 29 distress.(29, 50)  
50  
51  
52  
53

#### 54 30 **Study limitations**

55  
56  
57 31 While participants identified several support needs and optimal care features in relation to adult onset  
58 32 T1D, the outcome of the co-design process did not attend to all challenges identified in the study. In  
59  
60

1 part this was a result of the prioritisation exercises in which the focus for the development work was  
2 agreed by consensus. The result of this process was that some areas such care organisation were not  
3 considered to same extent as care content areas. The conversation tools, for example, mainly address  
4 the content and provision of care during consultations. However, while care organisation was not  
5 directly addressed by the conversation tools, the study did emphasise a wider focus on psychological  
6 and social challenges as part of care delivery and this was expressed in the roadmap which set a  
7 framework for care organisation. In addition, the identification of training for health care professionals  
8 and enhanced continuity are systemic interventions.

9 There were some differences in study design between sites. Due to different ethical approval  
10 requirements, participants were recruited differently in DK and the UK. The content of some HCP  
11 workshops was adapted due to time restrictions in terms of their availability. Involvement of people  
12 with diabetes as co-facilitators in the workshops was only possible in the UK part of the study. Another  
13 area of national divergence was in relation to some aspects of care delivery. While the health care  
14 systems in the UK and Denmark are similar, the UK offers structured evidence-based group education  
15 which is not provided in DK. However, despite these small differences, our study captured the views  
16 of a large sample of both adults with new-onset T1D and HCPs across several sites in both the UK and  
17 DK. There was a high level of convergence and connectivity between the views of the people with  
18 diabetes and the HCPs. Therefore, we are confident that emerging ideas from the co-design process  
19 will be recognisable in the wider population and will increase the transferability of findings and  
20 implementation of the tools if they are found effective in enhancing a more positive transition into  
21 life with T1D in future trials.

## 22 **CONCLUSIONS**

23 This co-design study has identified the care priorities for adults who develop T1D, along with some  
24 practical conversational tools that may help guide HCPs in attending to the disruptive experience of  
25 the diagnosis and support adults in adjusting into a life with diabetes. Providing more emotionally  
26 expansive support that recognises and attends to the psychological and social impact of the diagnosis,  
27 may help adults adapt more positively to their diabetes. It will be important to undertake future  
28 studies to ascertain whether such interventions will improve psychological and social outcomes,  
29 increase self-management activation and care engagement, alongside metabolic outcomes, in this  
30 understudied population.

1  
2  
3 1 Acknowledgements  
4

5 2 The authors would like to thank the people with diabetes who gave up their time to take part in the  
6 3 study. We also thank the health care professionals in the participating centres who were involved in  
7 4 the study.  
8  
9

10  
11 5 Competing interest  
12

13 6 None declared  
14  
15

16 7 Funding  
17

18 8 This project is funded by the National Institute for Health Research (NIHR) under its Research for  
19 9 Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0317-20012). The views  
20 10 expressed are those of the author(s) and not necessarily those of the NIHR or the Department of  
21 11 Health and Social Care.  
22  
23

24  
25 12 The work presented in this article is also supported by Novo Nordisk Foundation. Grant numbers  
26 13 NNF17OC0028274 and NNF18OC0052083.  
27  
28

29  
30 14 Foundation of European Nurses in Europe (FEND) has also supported the work. Grant number N/A.  
31

32 15 Contributors  
33

34 16 MD-C, AF, LJOE, IW and GR conceptualised the study. MD-C, AF, LJOE, SS, ER, GR, JLW and RF collected  
35 17 data. MD-C, AF, SS, JWL and ER analysed the data. MD-C, AF and LJOE drafted the manuscript. IW, GR,  
36 18 and SS made important intellectual contributions to the manuscript and all authors read and  
37 19 approved the final manuscript.  
38  
39

40  
41  
42 20 Data availability  
43

44 21 Data from workshops are available upon reasonable request. Please contact the corresponding  
45 22 author.  
46  
47

48 23  
49

50 24  
51

52 25  
53

54 26  
55

56 27  
57

58 28  
59  
60

1  
2  
3 1  
4  
5  
6 2 **REFERENCES**  
7

- 8 3 1. Thomas NJ, Jones SE, Weedon MN, et al. Frequency and phenotype of type 1 diabetes in the  
9 4 first six decades of life: a cross-sectional, genetically stratified survival analysis from UK Biobank.  
10 5 *Lancet Diabetes Endocrinol.* 2017;6(2):122-9.
- 11 6 2. Thunander M, Petersson C, Jonzon K, et al. Incidence of type 1 and type 2 diabetes in adults  
12 7 and children in Kronoberg, Sweden. *Diabetes Res Clin Pract.* 2008;82(2):247-55.
- 13 8 3. Due-Christensen M, Zoffmann V, Willaing I, et al. The Process of Adaptation Following a New  
14 9 Diagnosis of Type 1 Diabetes in Adulthood: A Meta-Synthesis. *Qualitative Health Research.*  
15 10 2018;28(2):245-58.
- 16 11 4. Due-Christensen M, Willaing I, Ismail K, et al. Learning about Type 1 diabetes and learning to  
17 12 live with it when diagnosed in adulthood: two distinct but inter-related psychological processes of  
18 13 adaptation A qualitative longitudinal study. *Diabet Med.* 2019;36(6):742-52.
- 19 14 5. Grant L, Lawton J, Hopkins D, et al. Type 1 diabetes structured education: what are the core  
20 15 self-management behaviours? *Diabet Med.* 2013;30(6):724-30.
- 21 16 6. Beran D. Developing a hierarchy of needs for Type 1 diabetes. *Diabet Med.* 2014;31(1):61-7.
- 22 17 7. Rane K, Wajngot A, Wandell PE, et al. Psychosocial problems in patients with newly diagnosed  
23 18 diabetes: number and characteristics. *Diabetes Res Clin Pract.* 2011;93(3):371-8.
- 24 19 8. Kampling H, Petrak F, Farin E, et al. Trajectories of depression in adults with newly diagnosed  
25 20 type 1 diabetes: results from the German Multicenter Diabetes Cohort Study. *Diabetologia.* 2016.
- 26 21 9. Due-Christensen M, Sarre S, Joensen L, et al. Barriers and enablers to providing psycho-social  
27 22 support for adults with new onset Type 1 diabetes. *Diabetic Medicine.* 2020;37(S1):90-118.
- 28 23 10. Beran D, Golay A. Initial versus ongoing education: Perspectives of people with type 1 diabetes  
29 24 in 13 countries. *Patient Educ Couns.* 2017;100(5):1012-8.
- 30 25 11. Snow R, Sandall J, Humphrey C. Use of clinical targets in diabetes patient education:  
31 26 qualitative analysis of the expectations and impact of a structured self-management programme in  
32 27 Type 1 diabetes. *Diabet Med.* 2014;31(6):733-8.
- 33 28 12. Young-Hyman D, de Groot M, Hill-Briggs F, et al. Psychosocial Care for People With Diabetes:  
34 29 A Position Statement of the American Diabetes Association. *Diabetes Care.* 2016;39(12):2126-40.
- 35 30 13. NICE. Type 1 diabetes in adults: diagnosis and management NICE guideline CG15 2015.  
36 31 Available from: <https://www.nice.org.uk/guidance/ng17>.
- 37 32 14. Holt RI, Nicolucci A, Kovacs Burns K, et al. Correlates of psychological care strategies for people  
38 33 with diabetes in the second Diabetes Attitudes, Wishes and Needs (DAWN2) study. *Diabet Med.*  
39 34 2016;33(9):1174-83.
- 40 35 15. Munro N, Holt RIG, Davies MJ, et al. DAWN2 study findings: psychosocial support and  
41 36 structured education need to be more widespread. *Practical Diabetes.* 2013;30(6):239-40.
- 42 37 16. Byrne JL, Davies MJ, Willaing I, et al. Deficiencies in postgraduate training for healthcare  
43 38 professionals who provide diabetes education and support: results from the Diabetes Attitudes,  
44 39 Wishes and Needs (DAWN2) study. *Diabet Med.* 2017:n/a-n/a.
- 45 40 17. Joensen L, Fisher L, Skinner T, et al. Integrating psychosocial support into routine diabetes  
46 41 care: perspectives from participants at the Self-Management Alliance meeting 2016. *Diabet Med.*  
47 42 2019;36(7):847-53.
- 48 43 18. Fredrix M, Byrne M, Dinneen S, et al. 'It's an important part, but I am not quite sure that it is  
49 44 working': educators' perspectives on the implementation of goal-setting within the 'DAFNE' diabetes  
50 45 structured education programme. *Diabet Med.* 2020;37(1):1-11.
- 51 46 19. Brown T, Wyatt J. Design thinking for social innovation. *Stanford Social Innovation Review*  
52 47 [Internet]. 2010.
- 53 48 20. Craig P, Dieppe P, Macintyre S, et al. Developing and evaluating complex interventions: the  
54 49 new Medical Research Council guidance. *BMJ.* 2008;337:a1655.
- 55 50  
56 51  
57 52  
58 53  
59 54  
60 55

- 1 21. Lister C, Payne H, Hanson CL, et al. The Public Health Innovation Model: Merging Private Sector  
2 Processes with Public Health Strengths. 2017;5(192).
- 3 22. Due-Christensen M. The experiences of bio-psycho-social adaptation following a diagnosis of  
4 type 1 diabetes in adulthood [PhD Thesis]: King's College London; 2017.
- 5 23. Humayun MA, Jenkins E, Knott J, et al. Intensive structured education for type 1 diabetes  
6 management using BERTIE: Long-term follow-up to assess impact on glycaemic control and quality of  
7 life indices. *Diabetes Res Clin Pract.* 2018;143:275-81.
- 8 24. Harris SM, Shah P, Mulnier H, et al. Factors influencing attendance at structured education for  
9 Type 1 diabetes in south London. *Diabet Med.* 2017:n/a-n/a.
- 10 25. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology.*  
11 2006;3(2):77-101.
- 12 26. Kampling H, Mittag O, Herpertz S, et al. Can trajectories of glycemic control be predicted by  
13 depression, anxiety, or diabetes-related distress in a prospective cohort of adults with newly  
14 diagnosed type 1 diabetes? Results of a five-year follow-up from the German multicenter diabetes  
15 cohort study (GMDC-Study). *Diabetes Res Clin Pract.* 2018;141:106-17.
- 16 27. Gafvels C, Rane K, Wajngot A, et al. Follow-up two years after diagnosis of diabetes in patients  
17 with psychosocial problems receiving an intervention by a medical social worker. *Soc Work Health  
18 Care.* 2014;53(6):584-600.
- 19 28. Hesse D, Boysen L, Ridderstrale M. Adult-onset type 1 diabetes: Predictors of glycaemic  
20 control. *Endocrinol Diabetes Metab.* 2018;1(4):e00038.
- 21 29. Fisher L, Hessler D, Polonsky W, et al. Diabetes distress in adults with type 1 diabetes:  
22 Prevalence, incidence and change over time. *J Diabetes Complications.* 2016;30(6):1123-8.
- 23 30. Akyirem S, Forbes A, Wad JL, et al. Psychosocial interventions for adults with newly diagnosed  
24 chronic disease: A systematic review. 0(0):1359105321995916.
- 25 31. Broadbent E, Donkin L, Stroh JC. Illness and treatment perceptions are associated with  
26 adherence to medications, diet, and exercise in diabetic patients. *Diabetes Care.* 2011;34(2):338-40.
- 27 32. Due-Christensen M, Borrild L, Larsen K. Perception and integration of people living with type  
28 1 diabetes -- an empirical study. *European Diabetes Nursing.* 2006;3(1):13-8.
- 29 33. Hartog I, Scherer-Rath M, Kruizinga R, et al. Narrative meaning making and integration:  
30 Toward a better understanding of the way falling ill influences quality of life. *J Health Psychol.*  
31 2020;25(6):738-54.
- 32 34. Oris L, Rassart J, Prikken S, et al. Illness Identity in Adolescents and Emerging Adults With Type  
33 1 Diabetes: Introducing the Illness Identity Questionnaire. *Diabetes Care.* 2016;39(5):757-63.
- 34 35. Ambrosio L, Senosiain García JM, Riverol Fernández M, et al. Living with chronic illness in  
35 adults: a concept analysis. *Journal of Clinical Nursing.* 2015;24(17-18):2357-67.
- 36 36. Abdoli S, Ashktorab T, Ahmadi F, et al. The empowerment process in people with diabetes: an  
37 Iranian perspective. *International Nursing Review.* 2008;55(4):447-53.
- 38 37. Fisher L, Hessler D, Polonsky W, et al. Emotion regulation contributes to the development of  
39 diabetes distress among adults with type 1 diabetes. *Patient Educ Couns.* 2018;101(1):124-31.
- 40 38. Fisher L, Polonsky WH, Hessler D. Addressing diabetes distress in clinical care: a practical  
41 guide. *Diabet Med.* 2019;36(7):803-12.
- 42 39. Hendrieckx C, Halliday JA, Russell-Green S, et al. Adults With Diabetes Distress Often Want to  
43 Talk With Their Health Professionals About It: Findings From an Audit of 4 Australian Specialist  
44 Diabetes Clinics. *Canadian Journal of Diabetes.* 2020;44(6):473-80.
- 45 40. Litterbach E, Holmes-Truscott E, Pouwer F, et al. 'I wish my health professionals understood  
46 that it's not just all about your HbA1c!'. Qualitative responses from the second Diabetes MILES –  
47 Australia (MILES-2) study. *Diabet Med.* 2020;37(6):971-81.
- 48 41. Dale JR, Williams SM, Bowyer V. What is the effect of peer support on diabetes outcomes in  
49 adults? A systematic review. *Diabet Med.* 2012;29(11):1361-77.
- 50 42. Due-Christensen M, Zoffmann V, Hommel E, et al. Can sharing experiences in groups reduce  
51 the burden of living with diabetes, regardless of glycaemic control? *Diabet Med.* 2012;29(2):251-6.

- 1  
2  
3 1 43. Craven M, Simons Z, de Groot M. Diabetes distress among healthcare providers: A qualitative  
4 2 study. *Diabetes Res Clin Pract.* 2019;150:211-8.  
5 3 44. Entwistle VA, Cribb A, Owens J. Why Health and Social Care Support for People with Long-  
6 4 Term Conditions Should be Oriented Towards Enabling Them to Live Well. *Health Care Anal.* 2016:1-  
7 5 18.  
8 5 45. Röttle N, Schöpf-Lazzarino AC, Becker S, et al. Agreement of physician and patient ratings of  
9 6 communication in medical encounters: A systematic review and meta-analysis of interrater  
10 7 agreement. *Patient Education and Counseling.* 2020.  
11 8 46. Storni C. Patients' lay expertise in chronic self-care: a case study in type 1 diabetes.  
12 9 *2015;18(5):1439-50.*  
13 10 47. Zoffmann V, Harder I, Kirkevold M. A person-centered communication and reflection model:  
14 11 sharing decision-making in chronic care. *Qual Health Res.* 2008;18(5):670-85.  
15 12 48. Pals RA, Olesen K, Willaing I. What does theory-driven evaluation add to the analysis of self-  
16 13 reported outcomes of diabetes education? A comparative realist evaluation of a participatory patient  
17 14 education approach. *Patient Educ Couns.* 2016;99(6):995-1001.  
18 15 49. Willaing I, Vallis M. Educating the Person with Diabetes. *Textbook of Diabetes: John Wiley &*  
19 16 *Sons, Ltd; 2017. p. 326-40.*  
20 17 50. Wylie TAF, Shah C, Connor R, et al. Transforming mental well-being for people with diabetes:  
21 18 research recommendations from Diabetes UK's 2019 Diabetes and Mental Well-Being Workshop.  
22 19 *2019;36(12):1532-8.*  
23 20  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

25 Legend Figure 1:

26 *Figure 1. Examples of illustrations depicting support needs and challenges*



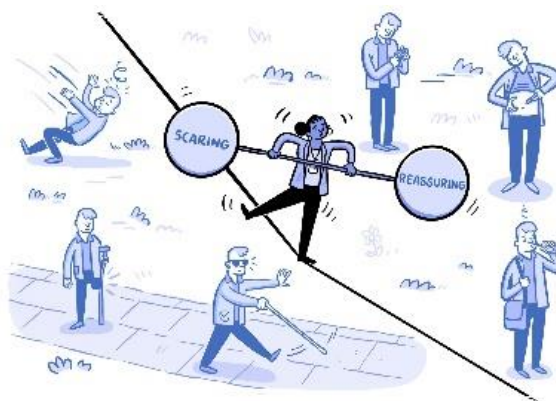
Support needs and challenges from the perspective of adults with new-onset T1D

Challenges in providing support from the perspectives of HCPs



*The complexity of managing diabetes*

*Difficulties with how to address psychological and social issues*



*Managing diabetes alongside other demands*

*Balancing information*

# Standards for Reporting Qualitative Research (SRQR)\*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

## Title and abstract

<p><b>Title</b> - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	<p>Page 1/lines 1-2</p>
<p><b>Abstract</b> - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	<p>Page 2/lines 1-29</p>

## Introduction

<p><b>Problem formulation</b> - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	<p>Page 4/lines 2-34 and Page 5/lines 1-4</p>
<p><b>Purpose or research question</b> - Purpose of the study and specific objectives or questions</p>	<p>Page 5/lines6-13</p>

## Methods

<p><b>Qualitative approach and research paradigm</b> - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	<p>Page 5/lines 16-25</p>
<p><b>Researcher characteristics and reflexivity</b> - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	<p>Page 6/lines 26-30</p>
<p><b>Context</b> - Setting/site and salient contextual factors; rationale**</p>	<p>Page 5/lines 31-34 and Page 6/lines 1-3</p>
<p><b>Sampling strategy</b> - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	<p>Page 6/lines 4-12</p>
<p><b>Ethical issues pertaining to human subjects</b> - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	<p>Page 7/lines 4-6</p>
<p><b>Data collection methods</b> - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	<p>Page 6/lines 21 to page 7 line 23 and table 1</p>

1 2 3 4 5	<b>Data collection instruments and technologies</b> - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 6/lines 24-26 and Page 7/lines 8-11 and figure 1
6 7 8 9	<b>Units of study</b> - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 9/lines 22-28 and table 2
10 11 12 13	<b>Data processing</b> - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Page 6/lines 24-26 Page 9/lines 2-20
14 15 16 17	<b>Data analysis</b> - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Page 9/lines 2-20
18 19 20 21	<b>Techniques to enhance trustworthiness</b> - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 9/lines 15-20

### Results/findings

22 23 24 25 26 27	<b>Synthesis and interpretation</b> - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pages 10 -14
28 29 30	<b>Links to empirical data</b> - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Table 3 Pages 12-13

### Discussion

31 32 33 34 35 36 37 38	<b>Integration with prior work, implications, transferability, and contribution(s) to the field</b> - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Pages 15-16
39 40 41 42	<b>Limitations</b> - Trustworthiness and limitations of findings	Page 16/lines 31-32 and Page 17/lines 1-8

### Other

43 44 45 46 47	<b>Conflicts of interest</b> - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Page 18/lines 5-6
48 49 50	<b>Funding</b> - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 18/lines 7-14

\*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

\*\*The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

**Reference:**

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014  
DOI: 10.1097/ACM.0000000000000388

For peer review only

# BMJ Open

## A co-design study to develop supportive interventions to improve psychological and social adaptation among adults with new-onset type 1 diabetes in Denmark and the United Kingdom

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2021-051430.R1
Article Type:	Original research
Date Submitted by the Author:	08-Sep-2021
Complete List of Authors:	Due-Christensen, Mette; Steno Diabetes Center Copenhagen, Health Promotion Research; King's College London, Faculty of Nursing, Midwifery and Palliative Care Joensen, Lene; Steno Diabetes Center Copenhagen, Sarre, Sophie; King's College London, Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care Romanczuk, Ewa; Odense Universitetshospital, Steno Diabetes Center Odense Wad, Julie; Steno Diabetes Center Copenhagen Forde, Rita; King's College London, Faculty of Nursing, Midwifery and Palliative Care Robert, Glenn; King's College London, Faculty of Nursing, Midwifery and Palliative Care Willaing, Ingrid; Steno Diabetes Center Copenhagen, Health Promotion Research Forbes, Angus; King's College London, Division of Care in Long-term Conditions
<b>Primary Subject Heading</b>:	Diabetes and endocrinology
Secondary Subject Heading:	Patient-centred medicine
Keywords:	DIABETES & ENDOCRINOLOGY, QUALITATIVE RESEARCH, General diabetes < DIABETES & ENDOCRINOLOGY

SCHOLARONE™  
Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

1  
2  
3 1 **Title:** *A co-design study to develop supportive interventions to improve psychological and social*  
4 *adaptation among adults with new-onset type 1 diabetes in Denmark and the United Kingdom*  
5  
6  
7 3  
8  
9

10 4 Corresponding author: Mette Due-Christensen, Steno Diabetes Center Copenhagen, Niels Steensens  
11 5 Vej 2, 2820 Gentofte, Denmark. E-mail: mdue0015@regionh.dk  
12

13 6 Lene Eide Joensen, Diabetes Management Research, Steno Diabetes Center Copenhagen, Gentofte,  
14 7 Denmark  
15

16 8 Sophie Sarre, Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, United  
17 9 Kingdom  
18

19 10 Ewa Romanczuk, Steno Diabetes Center Odense, Odense Universitets Hospital, Odense, Denmark  
20

21 11 Julie Lindberg Wad, Diabetes Management Research, Steno Diabetes Center Copenhagen, Gentofte,  
22 12 Denmark  
23

24 13 Rita Forde, Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, United  
25 14 Kingdom  
26

27 15 Glenn Robert, Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, United  
28 16 Kingdom  
29

30 17 Ingrid Willaing, Diabetes Management Research, Steno Diabetes Center Copenhagen, Gentofte,  
31 18 Denmark  
32

33 19 Angus Forbes, Faculty of Nursing, Midwifery and Palliative Care, King's College London, London, United  
34 20 Kingdom  
35

36 21 Word count: 4636  
37  
38  
39

40 22  
41

42 23  
43

44 24  
45

46 25  
47

48 26  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 1 **ABSTRACT**

4  
5 2 **OBJECTIVE**

6  
7  
8 3 To develop supportive interventions for adults with new-onset type 1 diabetes (T1D) to facilitate  
9 4 positive adaptive strategies during their transition into a life with diabetes.

10  
11 5 **DESIGN**

12  
13  
14 6 The study used a co-design approach informed by Design Thinking to stimulate participants'  
15 7 reflections on their experiences of current care and generate ideas for new supportive interventions.  
16  
17 8 Visual illustrations were used to depict support needs and challenges. Initial discussions of these needs  
18 9 and challenges were facilitated by researchers and people with diabetes in workshops. Data  
19 10 comprising transcribed audio recordings of the workshop discussions and materials generated during  
20 11 the workshops was analyzed thematically.

21  
22  
23  
24 12 **SETTINGS**

25  
26  
27 13 Specialized diabetes centers in Denmark and the United Kingdom.

28  
29 14 **PARTICIPANTS**

30  
31 15 Adults with new-onset T1D (n=24) and health care professionals (HCPs) (n=56) participated in six  
32 16 parallel workshops followed by four sequential workshops with adults (n=29) and HCPs (n=24)  
33 17 together.

34  
35  
36 18 **RESULTS**

37  
38  
39 19 The common solution prioritised by both adults with new-onset T1D and HCP participants was the  
40 20 development of an integrated model of care addressing the psychological and social elements of the  
41 21 diagnosis, alongside information on diabetes self-management. Participants also indicated a need to  
42 22 develop the organisation, provision, and content of care, along with the skills HCPs need to optimally  
43 23 deliver that care. The co-designed intervention included three visual conversation tools that could be  
44 24 used flexibly in the care of adults with new-onset T1D to support physical, psychological, and social  
45 25 adaptation to T1D.

46  
47  
48  
49  
50  
51 26 **CONCLUSION**

52  
53  
54 27 This co-design study has identified the care priorities for adults who develop T1D, along with some  
55 28 practical conversational tools that may help guide HCPs in attending to the disruptive experience of  
56 29 the diagnosis and support adults in adjusting into a life with diabetes.  
57  
58  
59  
60



1  
2  
3 1 Strength and limitations of this study  
4  
5

- 6 2 • The study included a diverse sample of adults with new-onset T1D from two countries  
7  
8 3 • A large number of health care professionals across multiple disciplines from two countries  
9  
10 4 took part in the study  
11  
12 5 • The broad approach including many different perspectives increases the transferability of the  
13  
14 6 results to other contexts  
15  
16 7 • Although we did not find any differences between perspectives across gender, a limitation of  
17  
18 8 the study is the relatively small number of male participants  
19  
20 9 • People with diabetes have been involved in the design and conduct of the study from  
21  
22 10 inception  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

## 1 INTRODUCTION

2 A diagnosis of Type 1 diabetes (T1D) can occur at any age, with around 50% of cases presenting in  
3 adulthood.(1, 2) Developing T1D as an adult can be very disruptive, as adults have already formed  
4 many aspects of their lives: employment, relationships, and lifestyle habits.(3, 4) The diagnosis  
5 introduces new responsibilities for acquiring and maintaining time-consuming self-management skills,  
6 and fears about hypoglycaemia and future diabetes complications, all of which may affect self-identity  
7 and life-plans.(5, 6) Previous research has identified that accommodating the demands of T1D into  
8 established life routines can lead to significant psychological and social challenges for adults with new-  
9 onset T1D.(7, 8) These challenges include difficulties in coming to terms with the diagnosis of T1D;  
10 experiencing added complexity and disruption of daily life due to managing diabetes alongside other  
11 demands; and feeling stigmatised and anxious about how the diagnosis will affect social relationships  
12 and employment.(3, 4)

13 During the disruptive period following diagnosis many adults feel that their psychological and  
14 emotional needs are not adequately addressed by health care professionals (HCPs).(9, 10) Adults with  
15 new-onset T1D perceive that the focus of their interactions with HCPs is on providing them with the  
16 technical skills needed for blood glucose management to achieve 'good' blood glucose levels.(4) This  
17 focus, when pursued without attending to the psychological and social challenges following the  
18 diagnosis of T1D, can create a sense of frustration and failure in the person with diabetes when  
19 optimal blood glucose levels are not achieved.(3, 4) Furthermore, the person may consequently be  
20 less likely to engage with their self-management behaviours, thereby increasing the risk of future  
21 burdensome and costly diabetes complications.(4, 11) Hence, early intervention to support adults in  
22 developing positive adaptive strategies and self-management routines in everyday life following  
23 diagnosis may reduce these problems and may improve long-term physical and mental health  
24 outcomes.

25 National and international guidelines(12, 13) highlight the importance of addressing the  
26 psychological and social needs of adults with diabetes, however, there are no specific  
27 recommendations for how to address these needs in the adult onset T1D population. While HCPs  
28 generally recognise the importance of providing psychological and social support for adults with  
29 diabetes,(14, 15) studies have reported minimal inclusion of such issues in routine diabetes care due  
30 to lack of training, tools and skills to engage in conversations about psychological and social  
31 aspects.(16-18) Furthermore, access to specialist psychology services is limited in most areas.  
32 Structural barriers such as consultation time constraints due to a focus on fulfilling the requirements  
33 set by clinical guidelines and an emphasis on glucose targets also limit the capacity for psychological  
34 and social support.(9, 17) Previous studies have reported that HCPs tend to overload people with

1 information on diabetes self-management, focusing on technical issues rather than providing  
2 psychological and social support due to a fear for the person's physical safety.(4, 9) Such studies  
3 have also found that this emphasis on diabetes treatment together with the risks of hypoglycaemia  
4 and long-term complications can induce a sense of anxiety in adults with new-onset T1D.(4, 9)

5  
6 Overall, existing evidence shows a disconnect between the needs of adults with new-onset T1D and  
7 current early-stage care, with potentially negative consequences in relation to the person's  
8 acceptance of and engagement with their diabetes; thereby, increasing the risks of future physical  
9 and psychological morbidity. To address this problem, we have undertaken a co-design study with  
10 adults with new-onset T1D and HCPs in Denmark (DK) and the United Kingdom (UK). The aim was to  
11 explore care priorities for adults with new-onset T1D and to develop supportive interventions to  
12 facilitate a more positive transition into life with diabetes- physically, emotionally, and socially - that  
13 could be tested in future feasibility trials.

## 14 15 **DESIGN AND METHODS**

16 The study used a co-design approach informed by Design Thinking to explore and develop  
17 interventions to support adults in adapting to T1D.(19) The co-design approach in the study was  
18 aligned with early stages of the Medical Research Council framework on developing and evaluating  
19 complex interventions to explicate mechanisms for intervention and to identify potential intervention  
20 components for future testing.(20) Design-thinking typically has three integrated phases centered on  
21 stakeholder engagement and participation.(21) The first phase (*Inspiration*) relates to exploring the  
22 target groups' physical, social, and emotional needs. The second phase (*Ideation*) includes a process  
23 for stimulating the target population to generate, develop, and test ideas that might be a solution to  
24 the needs defined in the ideation phase. In the third phase (*Implementation*) prototypes developed in  
25 the ideation phase are tested.

26 This paper presents our findings from the ideation phase, the inspiration element of the process has  
27 been reported elsewhere.(4, 9, 22) Prototypes that resulted from the ideation phase reported here  
28 will be tested in future feasibility trials.

### 29 30 **Study Settings and Participants**

31 The study participants were recruited from four specialist diabetes clinics in DK and two in the UK,  
32 with approximately 250 and 80 new cases of adult-onset T1D annually, respectively. The rationale for  
33 this was to consider the experiences of adults in different settings to enhance the transferability of  
34 the study outputs. T1D care in DK and the UK is similar in that it is provided by multidisciplinary

1  
2  
3 1 specialist diabetes teams, with the only major difference being the offer of group-based evidence-  
4 based structured self-management education programs in the UK from 6-12 months following  
5 diagnosis however, the uptake is low.(23, 24)  
6  
7

8  
9 4 Eligibility criteria for study participants included: adults ( $\geq 18$  years) diagnosed with T1D within the  
10 past five years to ensure recollection of diagnosis and HCPs with >1-year experience of providing care  
11 for adults with new-onset T1D. Of 82 adults with new-onset T1D invited to participate in the study, 36  
12 accepted the invitation, and 31 attended one or more workshops. Participants were recruited  
13 according to ethical approval in each country. In the UK potential participants were purposively  
14 sampled to achieve maximum variation in terms of age and gender and invited by letter. In DK eligible  
15 participants were approached by clinicians following out-patient appointments. All members of the  
16 multidisciplinary diabetes team in each clinic (ranging from 4-35 HCPs) were invited to participate via  
17 email.  
18  
19

### 20 **Patient and Public Involvement**

21 People with T1D have been involved in the design and conduct of the study. One person with T1D was  
22 a co-applicant on one of the grants. They were also part of the advisory group with four other people  
23 with T1D, a representative from a patient organisation and two health care professionals in addition  
24 to the research team. The advisory group have played a central role in making sure that the study and  
25 its outputs are patient centred.  
26  
27

### 28 **Data Collection**

29 We first conducted nine parallel workshops (adults with new-onset T1D in groups (n=24) and HCP in  
30 groups (n=56)) and then four integrated workshops (adults with new-onset T1D (n=29) and HCP (n=24)  
31 in a joint workshop) to stimulate the target populations to generate, develop, and test ideas for new  
32 supportive interventions. Workshops were conducted from June 2018 to October 2019. Data included  
33 audiotaped discussions from all workshops which were transcribed and sticky notes and flip charts  
34 with participants' feedback. (For an overview of the process see table 1). In the UK three adults with  
35 T1D from the study advisory board undertook training in group facilitation together with the UK  
36 research team to co-facilitate the parallel and integrated workshops. In DK workshops were facilitated  
37 by members of the research team. The research teams consisted of experienced clinicians and  
38 researchers.  
39  
40

41 Workshops for adults with new-onset T1D were conducted either in university or diabetes clinic  
42 rooms. Workshops for HCPs took place in the participating diabetes clinics. The parallel workshops  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

1  
2  
3 1 lasted two hours each. The integrated workshops were also conducted either in university (n=2) or  
4 2 diabetes clinic rooms (n=2), they were 3 hours long with breaks for food and refreshment.

### 3 Ethical considerations

4 Written consent was obtained from all participants. The study was approved by the Danish Data  
5 Protection Agency (VD-2018-196, I-Suite 6439) and The North West Research Ethics Committee  
6 (15/NW/0528) in the UK.

### 7 Workshop methods

8 The parallel workshops were structured to enable smaller group discussions to stimulate participants  
9 to reflect on their experiences. Illustrations depicting the common support needs and challenges  
10 expressed by adults with new-onset T1D and HCPs in the inspiration phase(4, 9, 22) were used to  
11 stimulate group discussions (see figure 1 for examples). Following these facilitated discussions,  
12 participants were asked to vote on the three challenges they considered the most important to  
13 address. Brain-storming exercises in smaller groups were then used to generate as many ideas and  
14 solutions as possible related to the prioritized challenges.

15 [insert figure 1 here]

16 In the integrated workshops adults with new-onset T1D and HCPs voted on their top two priorities  
17 and then worked together to develop interventions to address these. Ideas and solutions from  
18 previous workshops were summarised onto cards and combined with new ideas which were gradually  
19 refined to provide prototypes of tools to support adults with new-onset T1D. Preliminary prototypes  
20 were collated and integrated by the advisory board. The prototypes were circulated via email to  
21 workshop participants for verification, comments, and further suggestions for refinements. Over  
22 several iterations through emails and conversations the prototypes were further refined into a  
23 deliverable format for testing in future feasibility trials.

24

25

26

27

28

29

Table 1 Summary of study data types and collection points

Data collection point	Objective	Participants	Activities	Data types
<b>Inspiration phase (previous studies)</b>				
Interviews(4, 22)	To explore the experience of diagnosis, support needs and challenges	Adults with new-onset T1D	Longitudinal semi-structured individual interviews (two interviews over 6-8 months)	Transcribed interviews
Focus groups(9)	To explore preferences and needs in relation to providing support to adults with new-onset T1D. Identify barriers and enablers, reflections on current procedures, processes and care provision at diagnosis, HCPs' perceptions of issues relating to provision of support to adults with new-onset T1D and reflections on and the identification of dilemmas/challenges in current care.	HCPs	Exercises: Story dialogue (HCPs sharing their experience of a particular consultation) Presentation of experiences of adults with new-onset T1D using quotes and illustrations to facilitate discussion (from previous studies)	Transcriptions of discussion Notes from participants Field notes Story dialogue notes
<b>Ideation phase</b>				
Workshops for adults with new-onset T1D (n=3)	To validate findings from previous studies. To prioritise among identified challenges and generate preliminary ideas and develop solutions	Adults with new-onset T1D	Exercises: Prompt questions such as: <i>What do you think is the most important thing when supporting adults with new-onset T1D?</i> Illustrations and quotes of adults with new-onset T1D experiences from previous studies	Sticky notes with ideas and solutions Field notes Transcription of audio-recorded group discussions
Workshops for HCPs (=6)	To validate findings from previous studies. To prioritise among identified challenges from previous work To generate ideas and develop solutions to these challenges	HCPs	Illustrations depicting the identified challenges were used to encourage discussion before prioritising which were most important to focus on	Transcription from audio-recorded group discussions Preliminary ideas on sticky notes and field notes
Integrated workshops (n=4)	Prioritise among the identified challenges and the ideas from individual workshops Build on previous ideas and develop prototypes of support tools	Adults with new-onset T1D and HCPs	Presentation of priorities and ideas and solutions from previous workshops Alterations of solutions, design of prototypes	Transcription from audio-recorded group discussions Sticky notes Preliminary prototypes
Feedback	To obtain feedback from potential users of the prototype in relation to usability, relevance, and design	Adults with new-onset T1D and HCPs	Presentation of preliminary prototypes, structured feedback to specific questions via email or in meetings with HCPs	Revised prototypes ready for field testing

## 1 **Data analysis**

2 Anonymised data from the workshops were analysed thematically for common themes among the  
3 suggested ideas and solutions for each prioritised challenge across sites and countries. The analysis  
4 followed Braun and Clarke's(25) method, which is based on a five-step process:

5 1) becoming familiar with the data by reading and re-reading the outputs from workshops  
6 (transcriptions, post it notes, summary notes), and making notes of early impressions

7 2) generating initial codes, through looking across the dataset to compare challenges, ideas and  
8 solutions for similarities and differences within and across sites and countries

9 3) searching for common themes, by comparing the relationships between the ideas and solutions  
10 related to the prioritised challenges and organising them into broader themes

11 4) reviewing themes, by identifying patterns across the themes and labelling overarching themes for  
12 the challenges, ideas, and solutions

13 5) defining and naming themes through refining the relationships between the challenges and the  
14 suggested solutions and ideas.

15 The initial coding of workshop data was conducted by local members of the research team and  
16 discussed with the first author (MD-C). The coding was compared for similarities and differences  
17 between sites and countries in preparation for theme development. MDC developed preliminary  
18 themes in collaboration with SS and AF (UK) and ER and JLW (DK). These were then discussed with and  
19 refined by members of the research teams across the sites during the initial steps of the analysis  
20 process. Subsequently the whole team met to agree on the final themes and prototypes of tools.

## 22 **RESULTS**

23 Of the 31 adults with new-onset T1D participating in the study, 16 (52%) were from DK, 20 (64%) were  
24 women, median diabetes duration was 2.5 years (ranging from 1 to 4.5 years) and median age was 42  
25 years (ranging from 22 to 72 years). Of the 61 HCPs participating in the study, 44 were from DK (71%).  
26 Thirty-six were nurses (59 %), 14 doctors (23%), 8 dieticians (13 %) and 3 (5 %) others (i.e.,  
27 psychologists). They had a median of 15 years (ranging from 1 to 35 years) of experience of caring for  
28 adults with new-onset T1D (see Table 2). Ten HCPs (five from each country) were male, three of whom  
29 were nurses from the UK, the remaining were doctors. Most participants were Caucasian.

30 Twenty-eight participants (16 adults with new-onset T1D and 12 HCPs) took part in more than one  
31 workshop.

1 *Table 2 Participants in parallel and integrated workshops*

	<i>UK</i> <i>n=15</i>	<i>DK</i> <i>n=16</i>	<i>TOTAL</i> <i>n=31</i>
<b><i>Adults with new-onset T1D n (%)</i></b>			
Female	11 (73.3)	9 (56.2)	20 (64.5)
Male	4 (26.7)	7 (43.8)	11 (35.5)
Age median*	42 (32.5-57.5)	43.5 (35-46.8)	42 (34-51.5)
Years with diabetes*	3.5 (2-3.6)	2 (1.4-3)	2.5 (1.5-3.5)
<b><i>Health care professionals n (%)</i></b>	<b><i>n=17</i></b>	<b><i>n=44</i></b>	<b><i>n=61</i></b>
Dietician	2 (11.8)	6 (13.6)	8 (13.1)
Doctor	6 (35.3)	8 (18.2)	14 (23)
Nurse	7 (41.2)	29 (65.9)	36 (59)
Other**	2 (11.8)	1 (2.3)	3 (4.9)
Years in diabetes care*	12 (2.5-16.5)	16.8 (11-25)	15 (10-20)

\*Median, IQR (25%-75%) \*\*Other = researcher, psychotherapist, psychologist

Missing data on years in diabetes care for HCPs: UK=1, DK=2

### 2 **Prioritizations**

3 Top priorities differed slightly among the parallel workshops. The three challenges most commonly  
 4 given the highest priority across the workshops for adults with new-onset T1D were: a) coming to  
 5 terms with diabetes; b) the complexity of managing diabetes in different contexts and alongside  
 6 other demands; and c) fear of hypoglycaemia, high blood glucose values and complications. The  
 7 HCPs workshops prioritised the following challenges as most important: a) balancing the clinical  
 8 perspective (blood glucose regulation and prevention of long-term complications) with the  
 9 perspective of the adult with new-onset T1D; b) overloading adults with new-onset T1D with  
 10 information due to fear for their physical safety; and c) difficulties with how to address psychological  
 11 and social issues. The highest rated priorities from the integrated workshops were: 1) *helping adults*  
 12 *to come to terms with diabetes by addressing psychological, social, and emotional issues* and 2)  
 13 *avoiding information overload and balancing the clinical perspective with the needs of the adult with*  
 14 *new-onset T1D to facilitate a more positive adaptation to diabetes.*

### 17 **Solution themes**

18 The participants consistently suggested that diabetes care and support for adults with new-onset  
 19 T1D needed to be phasic, firstly addressing the emotional, social, and physical impact of the  
 20 diagnosis, and then how to adapt to life with diabetes. Adults with new-onset T1D and HCPs both  
 21 recognised the benefits of addressing psychological and social needs to enhance engagement in self-  
 22 management activities and consequently reduce the risk of diabetes complications (both physical  
 23 and psychological). There was a high level of agreement in the suggested solutions and ideas stated  
 24 by participants (both adults with new-onset T1D and HCPs) across the two countries although the



1 terminology used varied. Solutions to the prioritised challenges in relation to care priorities centred  
2 around four overarching themes: 1) provision of care which related to the interactions between the  
3 person with diabetes and the HCP; 2) ideal care content involved topics identified by participants as  
4 relevant and important to discuss in consultations following the diagnosis, 3) HCP care skillset, which  
5 concerned ways to support and improve HCPs skills sets and 4) organisation of care including  
6 availability and consistency of staff, timing of and mode of consultations and structure of electronic  
7 records. The themes are described in table 3 with illustrative quotes/excerpts from workshop  
8 discussions and information on how they fed into the co-designed interventions.

9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

For peer review only

Table 3 Description of themes including illustrative quotes and ways the theme informed the co-design process

Overarching theme	Brief description of theme	Illustrative quotes/excerpts from workshop discussions	Impact on co-design process
<b>Content of care</b>	<p>Signposting and normalising the difficult emotions related to the diagnosis were considered highly important in supporting adults in coming to terms with diabetes. Likewise, participants suggested signposting and discussing the common physical, emotional, and social issues that occur following diagnosis to help adults address these aspects of living with diabetes. People need to process information on diabetes, treatment, and the implications of these for daily life; but this processing can be challenging, so the information needs to be reinforced and repeated. Providing information about what adults with new-onset T1D can expect from their diabetes care, including a timeline of relevant appointments and contacts with HCPs, would help the person to see the bigger picture of their diabetes trajectory.</p>	<p><i>“it’s going to be an emotional journey going forward. So, in the same consultation you’re getting ‘and here’s your pen and this is how you inject it. You’ve got diabetes da-da-da’ - part of that initial consultation should be ‘and you are going to go on an emotional journey. You’re going to feel this, you’re going to feel that, to a greater or lesser degree’.” (PWD UK)</i></p> <p><i>“It’s the whole process [of being diagnosed] they need to ask more about. In my case I saw myself as a strong and healthy guy and then suddenly the doctor admitted me to A&amp;E. The feeling of having the rug pulled out from under you is still very real and present (PWD DK)</i></p> <p><i>“So why I’m here is because as a diabetes specialist nurse, getting the balance right between giving the information and being mindful of where people are at emotionally, we want to be able to think how we can do that in a way that’s safe and consistent throughout that journey. So, I do like this idea of the roadmap that we can use to try to ensure that can happen in a very busy clinic.” (HCP UK)</i></p>	<p>Specific and detailed ideas and solutions related to content of care were used to ensure that the conversation tools address challenges participants found important</p>
<b>Provision of care</b>	<p>Participants highlighted the importance of HCPs acknowledging that adjustment to the diagnosis is an ongoing and lengthy process. Personalising information in relation to the person’s attitudes, needs and life context in line with their journey of adaptation would increase relevance and transformation of knowledge into self-management skills. Using non-judgmental and empathetic language to explain glucose targets and</p>	<p><i>“If the HCP gave you a little bit of a kick and a little bit of a nudge so we could get closer to the emotional issues, because that takes up a lot of space. So does the practical stuff but also the emotional impact. So, you shouldn’t be allowed <u>not</u> to talk about it, I think.” (PWD DK)</i></p> <p><i>“Treating and managing diabetes isn’t just about keeping your blood sugars in check. It’s about understanding what it does to you as a person, understanding what it does to your life, and taking that whole system</i></p>	<p>The discussions in the workshops suggested that more than one tool would be useful to support both people with</p>

	<p>levels in a realistic and relative sense was recommended. Highlighting the difficulty of maintaining blood glucose values in the recommended range all the time would help improve self-efficacy and prevent adults with new-onset T1D developing a sense of failure.</p>	<p><i>approach, which brings in the emotional side. So, considering all those aspects and making that part of the medical care.” (PWD UK)</i></p> <p><i>“I think we’re very much driven by target blood glucose, you know, 4 to 7. I haven’t said it before, but somebody said to me, “It would have been really good to hear if somebody had told me actually it’s not bad or don’t worry about it if the blood sugar goes to 12 or 13. We don’t give them that level of assurance in terms of what’s going to happen.” (HCP UK)</i></p>	<p>diabetes and the HCPs in building their relationship</p>
<p><b>HCP skill set</b></p>	<p>Participants recommended providing HCPs with simple strategies and tools to enhance their skills and confidence in engaging with psychological and social issues to help support adults with new-onset T1D deal with these issues. Improving HCPs’ communication skills and maintaining these skills through regular supervision with a psychologist was also highlighted.</p>	<p><i>“I want to have a cupboard where I can just pull-out phrases and also reassurance so that I’m not patronizing the patient. And some workshops where I have to attend mandatory training” (HCP UK)</i></p> <p><i>“Even though I think I’m very open and asking about things, but do I actually ask in a good way – am I sure the [the person with T1D] will open up to the questions even if they would like to?” (HCP DK)</i></p>	<p>The need to support both adults with new-onset T1D and HCPs to discuss psychological and social issues were considered in the co-design process</p>
<p><b>Organisation of care</b></p>	<p>Participants identified a need to allocate enough time in consultations to provide more support around the time of diagnosis. Continuity of care during the initial phase was considered essential. Small teams of HCPs providing care specifically for adults with new-onset T1D would enhance consistency in the information provided. The electronic patient record should prompt HCPs to ask questions about psychological and social issues. Provision of support groups were identified as additional opportunities for support. Participants also suggested that there should be opportunities to involve family members in their care.</p>	<p><i>“I really needed to talk to someone who not only had 10 minutes to tell me about how to use that[insulin] pen.” (PWD DK)</i></p> <p><i>“It’s having a relationship with someone else where you can say ‘how do you do (such and such)?’. Imagine getting the support of each other that we are in the same boat and we might be able to get new ideas, because we do things differently.” (PWD UK)</i></p> <p><i>“It is bad [not having enough time] and it must be something that we can do better. And it involves organisation, and it is about resources and prioritising to a great extent” (HCP DK)</i></p>	<p>The conversation tools do not specifically address organisation of care. However, the value of making the tool useful in both individual and group consultations was recognised.</p>

bmjopen-2021-05-140 on 2 November 2021. Downloaded from http://bmjopen.bmj.com/ on April 16, 2024 by guest. Protected by copyright.

## 1 Prototypes of tools to support adaptation

2 Through several cycles of feedback from adults with new-onset T1D (via email) and HCPs (via email  
3 and feedback at multidisciplinary team meetings) the co-design process resulted in the development  
4 of three prototypes of conversation tools that could be used flexibly in the care of adults with new-  
5 onset T1D.

6 Tool 1: *The diabetes roadmap* -the aim of this tool is to express how adapting to diabetes is an on-  
7 going biomedical, psychological, and social process. It lays out what the person with diabetes can  
8 expect from their diabetes care during the first year. It signposts and normalises emotional and  
9 social responses that the person with diabetes might encounter when adapting to life with T1D. The  
10 tool is visual depicting a winding road starting from the point of diagnosis. Images of different types  
11 of HCPs who adults with new-onset T1D will meet during the first year are placed on one side of the  
12 road map, and on the other side examples of thoughts and questions people might have to support  
13 them in expressing their experience of living with T1D. (Supplementary file 1)

14 Tool 2: *Living with diabetes* - this tool focusses on the way diabetes might affect the person's body,  
15 their thoughts and emotions and their everyday life with the aim of facilitating a dialogue on the  
16 person with T1D's own issues and emotions. It uses visual prompts with images developed from  
17 previous research, and speech bubbles signposting various ways of adapting to diabetes. The tool  
18 also involves some specific open questions to give adults with new-onset T1D the opportunity to  
19 express and process the biomedical, psychological, and social impacts of diabetes relevant to them.  
20 (Supplementary file 2)

21 Tool 3: *Adapting to diabetes* - through a combination of illustrations depicting common experiences  
22 at the time of diagnosis and quotes relating to such experiences developed in an earlier study (22),  
23 this tool aims to serve as a conversation starter. Adults with new-onset T1D are encouraged to reflect  
24 on their experiences of living with diabetes, explore their own values and support them in making  
25 decisions related to self-management based on these. (Supplementary file 3)

26 Participants suggested these tools could be used independently or in combination in both one-to-one  
27 consultations and group sessions. The advantage of one-to-one sessions was the ability to personalise  
28 the tools to reflect the life situation and specific issues of the individual. In group sessions the tools  
29 would provide space for reflection on common challenges, sharing of experiences and normalising the  
30 adaptive process. A training manual to guide HCPs in facilitating the conversation tools will be  
31 developed to increase their skills prior to future feasibility trials.

32

## 1 DISCUSSION

2 This co-design study included a diverse sample of adults with new-onset T1D and a broad range of  
3 HCPs from Denmark and the UK. Participants identified support related to coming to terms with  
4 diabetes and integrating clinical demands of treatment with the individual's life situation as their top  
5 priorities for developing interventions to support early adaptation. The study showed that  
6 organisation, provision of and content of care along with HCP care skills were important features of  
7 optimal care. The study's output were three visual prototype tools to support physical, psychological,  
8 and social adaptation to T1D in adults. The aims of the tools are to enable reflections on the impact  
9 of the diabetes diagnosis and establishing self-management routines that will improve health  
10 outcomes long term and enhance mental, physical, and social well-being for adults with new-onset  
11 T1D.

12 While optimal care is a global challenge and essential for all people with diabetes, the early phase of  
13 living with type 1 diabetes provides a window of opportunity for adults to help them understand and  
14 come to terms with diabetes. This may assist them in adapting more positively to their condition from  
15 the outset in a way that will help them live well with diabetes in the future. In line with previous  
16 research,(7, 26, 27) this study has highlighted the necessity of providing psychological and social  
17 support related to the disruption caused by the diagnosis and the impact this may have on identity,  
18 relationships and everyday activities for adults who develop T1D. The lack of such support in the period  
19 after diagnosis can impact and increase the risk of long-term complications,(28) and might cause  
20 diabetes-related distress in the longer term.(27, 29) A key concept here is that early psychological and  
21 social intervention may help ameliorate or prevent the development of longer-term maladaptive  
22 coping mechanisms (avoidance or disengagement), diabetes distress and psychological morbidities  
23 (fear and anxiety) which will increase the risks for physical complications.

24 The ideas and solutions suggested for improving care processes at diagnosis across the participating  
25 countries were almost identical among the adults with new-onset T1D and HCPs participants. Previous  
26 research has identified commonalities between UK and DK in relation to the experiences and needs  
27 of adults with new-onset T1D(4) and the barriers of attending to these needs experienced by HCPs.  
28 (9) The resemblance in health care service provision for people with T1D (free access paid through  
29 taxation, corresponding clinical roles for HCPs) might explain the similar perception and experiences  
30 of HCPs and adults with new-onset T1D across DK and UK. Another explanation for the convergence  
31 between the two countries might be the universality of the challenges people experience following  
32 being diagnosed with a chronic condition as an adult.(30) Older and recent studies involving adults  
33 with longer diabetes duration have demonstrated a common and persistent perception of challenges

1  
2  
3 1 in life with T1D across a variety of settings.(10) Such challenges include for example illness  
4 2 perception,(31, 32) change in identity,(33, 34) and acceptance of and adjustment to T1D.(35, 36)

7 3 This study showed that need for continuity, consistency and personalisation in care delivery following  
8 4 diagnosis was of high importance to both the adults with T1D and HCP participants. Communication,  
9 5 emotional support, and the quality of the relationship between the person with diabetes and their  
10 6 HCP has been associated with long-term impacts on diabetes self-management and quality-of-life.(10,  
11 7 37, 38) Studies have also shown that adults with diabetes value interactions with HCPs that consider  
12 8 their mental well-being(39) and acknowledge the complex multifaceted challenges of living with  
13 9 diabetes.(40) In addition, the value of getting emotional support through peer support has also been  
14 10 highlighted in existent literature.(41, 42)

21 11 Other studies have identified the difficulties and challenges faced by HCPs in providing emotionally  
22 12 therapeutic care, identifying the need to increase the awareness, skills, and opportunities of HCPs for  
23 13 delivering such care.(43, 44) A key challenge to overcome is the need to balance clinical priorities  
24 14 (introducing diabetes technologies safely and setting glucose levels) with the wider needs of the  
25 15 person with diabetes following the disruption of the diagnosis. Integrating these different agendas in  
26 16 consultations might improve the consultation experiences for both adults with T1D and HCPs.(45)  
27 17 Recently, the use of diabetes related patient reported outcome measures (PROMS) has been  
28 18 suggested as a way to incorporate psychological and social issues into consultations(46). To our  
29 19 knowledge, a diabetes related PROM focusing on the psychosocial impact of a diagnosis of T1D has  
30 20 not yet been developed. Due to their limited experience with living with T1D, a reliance solely on  
31 21 PROMs would be limited in terms of meaningfully informing future practice and care. Alongside the  
32 22 refinement of better measures, developing tools specifically aimed at improving patient experiences  
33 23 following diagnosis by raising openness and awareness about potential challenges may help integrate  
34 24 adults' experiential knowledge with that of HCPs to the benefit of both parties.(10, 47, 48)

45 25 The conversation tools developed in this study will not in isolation change practice. Tools need to be  
46 26 underpinned by common values and understanding in terms of what is necessary for their use and  
47 27 who can provide the support including change of practice and collaboration and what training is  
48 28 needed.( 49,50) Multidisciplinary teamwork with input from adults with new-onset T1D and time for  
49 29 discussions on approaches to care for adults with new-onset T1D are likely to increase common values  
50 30 and engagement with and use of the tools in clinical practise. A common approach to the tools may  
51 31 enhance the therapeutic interactions between HCPs and adults following diagnosis allowing for a  
52 32 more open dialogue in relation to how people navigate the physical, psychological, and social impact  
53 33 of developing T1D in adulthood.

1  
2  
3 1 While the challenges identified and prioritised in our study are in line with previous research in adults  
4 2 with diabetes, this study is the first to explore and compare specific solutions to these challenges  
5 3 among a transnational group of both adults with new-onset T1D and HCPs. Our study highlights that  
6 4 challenges occur from the time of diagnosis and support is needed to address these challenges as early  
7 5 as possible to potentially prevent long term psychological consequences such as high levels of diabetes  
8 6 distress(29, 51).

### 7 **Study limitations**

8 While participants identified several support needs and optimal care features in relation to adult onset  
9 T1D, the outcome of the co-design process did not attend to all challenges identified in the study. In  
10 part this was a result of the prioritisation exercises in which the focus for the development work was  
11 agreed by consensus. The result of this process was that some areas such as care organisation were  
12 not considered to same extent as care content areas. The conversation tools, for example, mainly  
13 address the content and provision of care during consultations. However, while care organisation was  
14 not directly addressed by the conversation tools, the study did emphasise a wider focus on  
15 psychological and social challenges as part of care delivery and this was expressed in the roadmap  
16 which set a framework for care organisation. In addition, the identification of training for health care  
17 professionals and enhanced continuity are systemic interventions.

18 There were some differences in study design between sites. Due to different ethical approval  
19 requirements, participants were recruited differently in DK and the UK. The content of some HCP  
20 workshops was adapted due to time restrictions in terms of their availability. Involvement of people  
21 with diabetes as co-facilitators in the workshops was only possible in the UK part of the study. Another  
22 area of national divergence was in relation to some aspects of care delivery. While the health care  
23 systems in the UK and Denmark are similar, the UK offers structured evidence-based group education  
24 which is not provided in DK. However, despite these small differences, our study captured the views  
25 of a large sample of both adults with new-onset T1D and HCPs from the multidisciplinary teams across  
26 several sites in both the UK and DK.

27 It is important to acknowledge that we did not have any inclusion criteria or collect data relating to  
28 the ethnicity of participants. Previous research has highlighted the lack of representation from people  
29 with non-White ethnicity in T1D research(52). This mission may have meant our sample lacked  
30 representation of people with Black or Asian ethnicity. In part this reflects the fact that T1D is more  
31 prevalent in Caucasians(53) and the relative homogeneity of the Danish population. Therefore, we  
32 acknowledge that while the study did include perspectives of a wide range of participants across  
33 multiple settings in two countries, the perspectives of other ethnic populations or cultural settings

1  
2  
3 1 were not addressed in the study. Future studies should address this deficit as the experiences and  
4  
5 2 perspectives of people from other ethnicities may be socially and culturally nuanced.  
6  
7

8 3 There was a potential gender bias in the study, with more female participants in both the people with  
9  
10 4 T1D and HCPs. In terms of adults with T1D more women than men participated in the study. Previous  
11  
12 5 studies of people with established T1D indicate that women and men may have different experiences  
13  
14 6 of diabetes and perceptions of how diabetes impacts on their lives.(54,55) However, it is not  
15  
16 7 established how divergent gender based experiences are at the point of diagnosis, indeed in our  
17  
18 8 previous research which included both men and women in relation to their experiences of a T1D  
19  
20 9 diagnosis found that areas of impact were common.(4) While we did not systematically map  
21  
22 10 perspectives according to gender in adults with T1D, our sample included both gender perspectives  
23  
24 11 and the proposed solutions were consensus based, following the co-design methods outlined. Among  
25  
26 12 the HCPs, nurses were the most common professional group, this partly reflects the fact that nurses  
27  
28 13 formed the largest proportion of HCPs in the multidisciplinary teams of the participating centres. In  
29  
30 14 the Danish centre a further factor was that the nurses had greater availability at the time of conducting  
31  
32 15 the workshops. It may also be that the psychosocially based subject matter of the research have  
33  
34 16 seemed more relevant to nurses, however, studies have shown psychosocial issues are considered to  
35  
36 17 be important challenges by both diabetes nurses and doctors.(56-58) However, while there were more  
37  
38 18 nurses who participated in the study, there was a broad consensus across disciplines in relation to the  
39  
40 19 identified themes and solutions. It is also important to note that a tenant of this research model is  
41  
42 20 that all perspectives are considered relevant, as it is the ideas that they contribute rather than the  
43  
44 21 volume of contribution that informs the co-design process.  
45  
46  
47  
48  
49

50 22 Despite these limitations, we believe that due to the high level of convergence and connectivity  
51  
52 23 between the views of the people with diabetes and the HCPs, the emerging ideas from the co-design  
53  
54 24 process will be recognisable in the wider population and will increase the transferability of findings.  
55  
56 25 Thus, the implementation of the tools is likely to be more successful if they are found effective in  
57  
58 26 enhancing a more positive transition into life with T1D in future trials.  
59  
60

## 50 27 **CONCLUSIONS**

51  
52 28 This co-design study has identified the care priorities for adults who develop T1D, along with some  
53  
54 29 practical conversational tools that may help guide HCPs in attending to the disruptive experience of  
55  
56 30 the diagnosis and support adults in adjusting into a life with diabetes. Providing more emotionally  
57  
58 31 expansive support that recognises and attends to the psychological and social impact of the diagnosis,  
59  
60 32 may help adults adapt more positively to their diabetes. It will be important to undertake future



1  
2  
3 1 studies to ascertain whether such interventions will improve psychological and social outcomes,  
4  
5 2 increase self-management activation and care engagement, alongside metabolic outcomes, in this  
6  
7 3 understudied population.

#### 8 9 4 Acknowledgements

10  
11 5 The authors would like to thank the people with diabetes who gave up their time to take part in the  
12  
13 6 study. We also thank the health care professionals in the participating centres who were involved in  
14  
15 7 the study.

#### 16 17 8 Competing interest

18  
19 9 None declared

#### 20 21 22 10 Funding

23  
24 11 This project is funded by the National Institute for Health Research (NIHR) under its Research for  
25  
26 12 Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0317-20012). The views  
27  
28 13 expressed are those of the author(s) and not necessarily those of the NIHR or the Department of  
29  
30 14 Health and Social Care.

31  
32 15 The work presented in this article is also supported by Novo Nordisk Foundation. Grant numbers  
33  
34 16 NNF17OC0028274 and NNF18OC0052083.

35  
36 17 Foundation of European Nurses in Europe (FEND) has also supported the work. Grant number N/A.

#### 37 38 18 Contributors

39  
40 19 MD, AF, LJ, IW and GR conceptualised the study. MD, AF, LJ, SS, ER, GR, JW and RF collected data. MD,  
41  
42 20 AF, SS, JW and ER analysed the data. MD, AF and LJ drafted the manuscript. IW, GR, and SS made  
43  
44 21 important intellectual contributions to the manuscript and all authors read and approved the final  
45  
46 22 manuscript.

#### 47 48 23 Data availability

49  
50 24 Data from workshops are available upon reasonable request. Please contact the corresponding  
51  
52 25 author.

53  
54 26

55  
56 27

57  
58 28

59  
60

1  
2  
3 **1 REFERENCES**  
4

- 5  
6 2 1. Thomas NJ, Jones SE, Weedon MN, et al. Frequency and phenotype of type 1 diabetes in the  
7 3 first six decades of life: a cross-sectional, genetically stratified survival analysis from UK Biobank.  
8 4 *Lancet Diabetes Endocrinol.* 2017;6(2):122-9.
- 9 5 2. Thunander M, Petersson C, Jonzon K, et al. Incidence of type 1 and type 2 diabetes in adults  
10 6 and children in Kronoberg, Sweden. *Diabetes Res Clin Pract.* 2008;82(2):247-55.
- 11 7 3. Due-Christensen M, Zoffmann V, Willaing I, et al. The Process of Adaptation Following a New  
12 8 Diagnosis of Type 1 Diabetes in Adulthood: A Meta-Synthesis. *Qualitative Health Research.*  
13 9 2018;28(2):245-58.
- 14 10 4. Due-Christensen M, Willaing I, Ismail K, et al. Learning about Type 1 diabetes and learning to  
15 11 live with it when diagnosed in adulthood: two distinct but inter-related psychological processes of  
16 12 adaptation A qualitative longitudinal study. *Diabet Med.* 2019;36(6):742-52.
- 17 13 5. Grant L, Lawton J, Hopkins D, et al. Type 1 diabetes structured education: what are the core  
18 14 self-management behaviours? *Diabet Med.* 2013;30(6):724-30.
- 19 15 6. Beran D. Developing a hierarchy of needs for Type 1 diabetes. *Diabet Med.* 2014;31(1):61-7.
- 20 16 7. Rane K, Wajngot A, Wandell PE, et al. Psychosocial problems in patients with newly diagnosed  
21 17 diabetes: number and characteristics. *Diabetes Res Clin Pract.* 2011;93(3):371-8.
- 22 18 8. Kampling H, Petrak F, Farin E, et al. Trajectories of depression in adults with newly diagnosed  
23 19 type 1 diabetes: results from the German Multicenter Diabetes Cohort Study. *Diabetologia.* 2016.
- 24 20 9. Due-Christensen M, Sarre S, Joensen L, et al. Barriers and enablers to providing psycho-social  
25 21 support for adults with new onset Type 1 diabetes. *Diabetic Medicne.* 2020;37(S1):90-118.
- 26 22 10. Beran D, Golay A. Initial versus ongoing education: Perspectives of people with type 1 diabetes  
27 23 in 13 countries. *Patient Educ Couns.* 2017;100(5):1012-8.
- 28 24 11. Snow R, Sandall J, Humphrey C. Use of clinical targets in diabetes patient education:  
29 25 qualitative analysis of the expectations and impact of a structured self-management programme in  
30 26 Type 1 diabetes. *Diabet Med.* 2014;31(6):733-8.
- 31 27 12. Young-Hyman D, de Groot M, Hill-Briggs F, et al. Psychosocial Care for People With Diabetes:  
32 28 A Position Statement of the American Diabetes Association. *Diabetes Care.* 2016;39(12):2126-40.
- 33 29 13. NICE. Type 1 diabetes in adults: diagnosis and management NICE guideline CG15 2015.  
34 30 Available from: <https://www.nice.org.uk/guidance/ng17>.
- 35 31 14. Holt RI, Nicolucci A, Kovacs Burns K, et al. Correlates of psychological care strategies for people  
36 32 with diabetes in the second Diabetes Attitudes, Wishes and Needs (DAWN2() ) study. *Diabet Med.*  
37 33 2016;33(9):1174-83.
- 38 34 15. Munro N, Holt RIG, Davies MJ, et al. DAWN2 study findings: psychosocial support and  
39 35 structured education need to be more widespread. *Practical Diabetes.* 2013;30(6):239-40.
- 40 36 16. Byrne JL, Davies MJ, Willaing I, et al. Deficiencies in postgraduate training for healthcare  
41 37 professionals who provide diabetes education and support: results from the Diabetes Attitudes,  
42 38 Wishes and Needs (DAWN2) study. *Diabet Med.* 2017:n/a-n/a.
- 43 39 17. Joensen L, Fisher L, Skinner T, et al. Integrating psychosocial support into routine diabetes  
44 40 care: perspectives from participants at the Self-Management Alliance meeting 2016. *Diabet Med.*  
45 41 2019;36(7):847-53.
- 46 42 18. Fredrix M, Byrne M, Dinneen S, et al. 'It's an important part, but I am not quite sure that it is  
47 43 working': educators' perspectives on the implementation of goal-setting within the 'DAFNE' diabetes  
48 44 structured education programme. *Diabet Med.*0(ja).
- 49 45 19. Brown T, Wyatt J. Design thinking for social innovation. *Stanford Social Innovation Review*  
50 46 [Internet]. 2010.
- 51 47 20. Craig P, Dieppe P, Macintyre S, et al. Developing and evaluating complex interventions: the  
52 48 new Medical Research Council guidance. *BMJ.* 2008;337:a1655.
- 53 49 21. Lister C, Payne H, Hanson CL, et al. The Public Health Innovation Model: Merging Private Sector  
54 50 Processes with Public Health Strengths. 2017;5(192).

- 1 22. Due-Christensen M. The experiences of bio-psycho-social adaptation following a diagnosis of  
2 type 1 diabetes in adulthood [PhD Thesis]: King's College London; 2017.
- 3 23. Humayun MA, Jenkins E, Knott J, et al. Intensive structured education for type 1 diabetes  
4 management using BERTIE: Long-term follow-up to assess impact on glycaemic control and quality of  
5 life indices. *Diabetes Res Clin Pract.* 2018;143:275-81.
- 6 24. Harris SM, Shah P, Mulnier H, et al. Factors influencing attendance at structured education for  
7 Type 1 diabetes in south London. *Diabet Med.* 2017:n/a-n/a.
- 8 25. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology.*  
9 2006;3(2):77-101.
- 10 26. Kampling H, Mittag O, Herpertz S, et al. Can trajectories of glycemic control be predicted by  
11 depression, anxiety, or diabetes-related distress in a prospective cohort of adults with newly  
12 diagnosed type 1 diabetes? Results of a five-year follow-up from the German multicenter diabetes  
13 cohort study (GMDC-Study). *Diabetes Res Clin Pract.* 2018;141:106-17.
- 14 27. Gafvels C, Rane K, Wajngot A, et al. Follow-up two years after diagnosis of diabetes in patients  
15 with psychosocial problems receiving an intervention by a medical social worker. *Soc Work Health*  
16 *Care.* 2014;53(6):584-600.
- 17 28. Hesse D, Boysen L, Ridderstrale M. Adult-onset type 1 diabetes: Predictors of glycaemic  
18 control. *Endocrinol Diabetes Metab.* 2018;1(4):e00038.
- 19 29. Fisher L, Hessler D, Polonsky W, et al. Diabetes distress in adults with type 1 diabetes:  
20 Prevalence, incidence and change over time. *J Diabetes Complications.* 2016;30(6):1123-8.
- 21 30. Akyirem S, Forbes A, Wad JL, et al. Psychosocial interventions for adults with newly diagnosed  
22 chronic disease: A systematic review.0(0):1359105321995916.
- 23 31. Broadbent E, Donkin L, Stroh JC. Illness and treatment perceptions are associated with  
24 adherence to medications, diet, and exercise in diabetic patients. *Diabetes Care.* 2011;34(2):338-40.
- 25 32. Due-Christensen M, Borrild L, Larsen K. Perception and integration of people living with type  
26 1 diabetes -- an empirical study. *European Diabetes Nursing.* 2006;3(1):13-8.
- 27 33. Hartog I, Scherer-Rath M, Kruizinga R, et al. Narrative meaning making and integration:  
28 Toward a better understanding of the way falling ill influences quality of life. *J Health Psychol.*  
29 2020;25(6):738-54.
- 30 34. Oris L, Rassart J, Prikken S, et al. Illness Identity in Adolescents and Emerging Adults With Type  
31 1 Diabetes: Introducing the Illness Identity Questionnaire. *Diabetes Care.* 2016;39(5):757-63.
- 32 35. Ambrosio L, Senosiain García JM, Riverol Fernández M, et al. Living with chronic illness in  
33 adults: a concept analysis. *Journal of Clinical Nursing.* 2015;24(17-18):2357-67.
- 34 36. Abdoli S, Ashktorab T, Ahmadi F, et al. The empowerment process in people with diabetes: an  
35 Iranian perspective. *International Nursing Review.* 2008;55(4):447-53.
- 36 37. Fisher L, Hessler D, Polonsky W, et al. Emotion regulation contributes to the development of  
37 diabetes distress among adults with type 1 diabetes. *Patient Educ Couns.* 2018;101(1):124-31.
- 38 38. Fisher L, Polonsky WH, Hessler D. Addressing diabetes distress in clinical care: a practical  
39 guide. *Diabet Med.* 2019;36(7):803-12.
- 40 39. Hendrieckx C, Halliday JA, Russell-Green S, et al. Adults With Diabetes Distress Often Want to  
41 Talk With Their Health Professionals About It: Findings From an Audit of 4 Australian Specialist  
42 Diabetes Clinics. *Canadian Journal of Diabetes.* 2020;44(6):473-80.
- 43 40. Litterbach E, Holmes-Truscott E, Pouwer F, et al. 'I wish my health professionals understood  
44 that it's not just all about your HbA1c!'. Qualitative responses from the second Diabetes MILES –  
45 Australia (MILES-2) study. *Diabet Med.* 2020;37(6):971-81.
- 46 41. Dale JR, Williams SM, Bowyer V. What is the effect of peer support on diabetes outcomes in  
47 adults? A systematic review. *Diabet Med.* 2012;29(11):1361-77.
- 48 42. Due-Christensen M, Zoffmann V, Hommel E, et al. Can sharing experiences in groups reduce  
49 the burden of living with diabetes, regardless of glycaemic control? *Diabet Med.* 2012;29(2):251-6.
- 50 43. Craven M, Simons Z, de Groot M. Diabetes distress among healthcare providers: A qualitative  
51 study. *Diabetes Res Clin Pract.* 2019;150:211-8.

- 1  
2  
3 1 44. Entwistle VA, Cribb A, Owens J. Why Health and Social Care Support for People with Long-  
4 2 Term Conditions Should be Oriented Towards Enabling Them to Live Well. *Health Care Anal.* 2016;1-  
5 3 18.  
6 4 45. Röttele N, Schöpf-Lazzarino AC, Becker S, et al. Agreement of physician and patient ratings of  
7 5 communication in medical encounters: A systematic review and meta-analysis of interrater  
8 6 agreement. *Patient Education and Counseling.* 2020.  
9 7 46. Skovlund SE, Lichtenberg TH, Hessler D, et al. Can the Routine Use of Patient-Reported  
10 8 Outcome Measures Improve the Delivery of Person-Centered Diabetes Care? A Review of Recent  
11 9 Developments and a Case Study. *Curr Diab Rep.* 2019;19(9):84.  
12 10 47. Storni C. Patients' lay expertise in chronic self-care: a case study in type 1 diabetes.  
13 11 2015;18(5):1439-50.  
14 12 48. Zoffmann V, Harder I, Kirkevold M. A person-centered communication and reflection model:  
15 13 sharing decision-making in chronic care. *Qual Health Res.* 2008;18(5):670-85.  
16 14 49. Pals RA, Olesen K, Willaing I. What does theory-driven evaluation add to the analysis of self-  
17 15 reported outcomes of diabetes education? A comparative realist evaluation of a participatory patient  
18 16 education approach. *Patient Educ Couns.* 2016;99(6):995-1001.  
19 17 50. Willaing I, Vallis M. Educating the Person with Diabetes. *Textbook of Diabetes: John Wiley &*  
20 18 *Sons, Ltd; 2017. p. 326-40.*  
21 19 51. Wylie TAF, Shah C, Connor R, et al. Transforming mental well-being for people with diabetes:  
22 20 research recommendations from Diabetes UK's 2019 Diabetes and Mental Well-Being Workshop.  
23 21 2019;36(12):1532-8.  
24 22 52. Spanakis EK, Golden SH. Race/ethnic difference in diabetes and diabetic complications. *Curr*  
25 23 *Diab Rep.* 2013;13(6):814-23.  
26 24 53. Maahs DM, West NA, Lawrence JM, et al. Epidemiology of type 1 diabetes. *Endocrinol Metab*  
27 25 *Clin North Am.* 2010;39(3):481-97  
28 26 54. Castellano-Guerrero AM, Guerrero R, Ruiz-Aranda D, et al. Gender differences in quality of life  
29 27 in adults with long-standing type 1 diabetes mellitus. *Diabetol Metab Syndr.* 2020;12:64-  
30 28 55. Sturt J, Dennick K, Due-Christensen M, et al. The detection and management of diabetes  
31 29 distress in people with type 1 diabetes. *Curr Diab Rep.* 2015;15(11):101.  
32 30 56. Peyrot M, Rubin RR, Siminerio LM, et al. Physician and nurse use of psychosocial strategies in  
33 31 diabetes care - Results of the cross-national Diabetes Attitudes, Wishes and Needs (DAWN) study.  
34 32 *Diabetes Care.* 2006;29(6):1256-62.  
35 33 57. Pouwer F, Beekman AT, Lubach C, et al. Nurses' recognition and registration of depression,  
36 34 anxiety and diabetes-specific emotional problems in outpatients with diabetes mellitus. *Patient Educ*  
37 35 *Couns.* 2006;60(2):235-40.  
38 36 58. Haugstvedt A, Hernar I, Graue M, et al. Nurses' and physicians' experiences with diabetes  
39 37 consultations and the use of dialogue tools in the DiaPROM pilot trial: A qualitative study. *Diabet Med.*  
40 38 2021;38(6):e14419  
41 39  
42 40  
43 41  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

42 Legend Figure 1:

43 *Figure 1. Examples of illustrations depicting support needs and challenges*

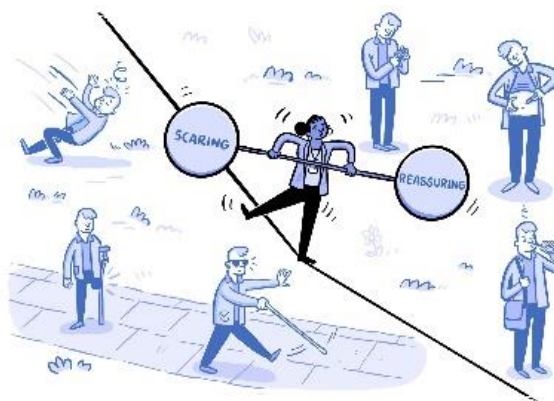
Support needs and challenges from the perspective of adults with new-onset T1D

Challenges in providing support from the perspectives of HCPs



*The complexity of managing diabetes*

*Difficulties with how to address psychological and social issues*

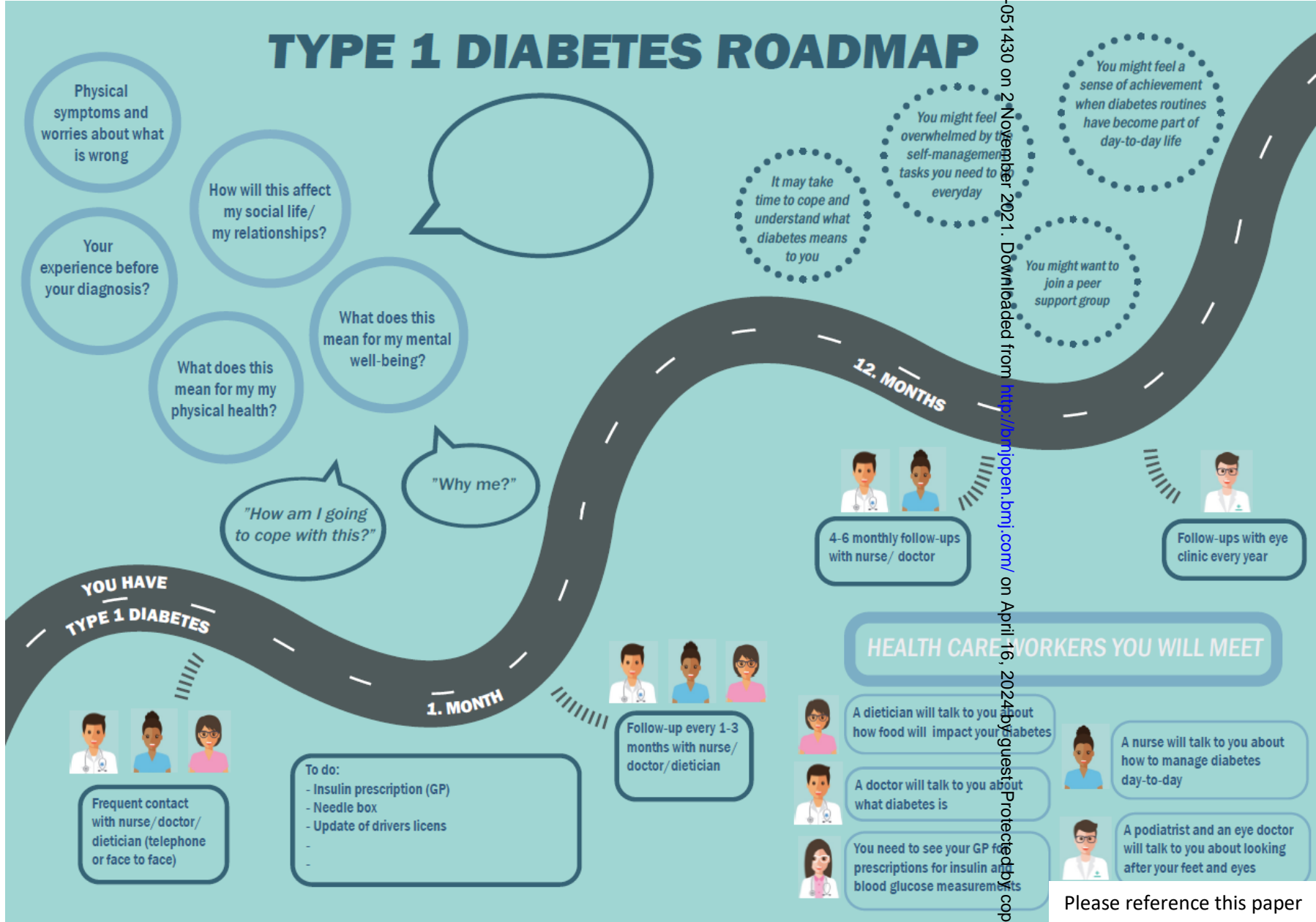


*Managing diabetes alongside other demands*

*Balancing information*

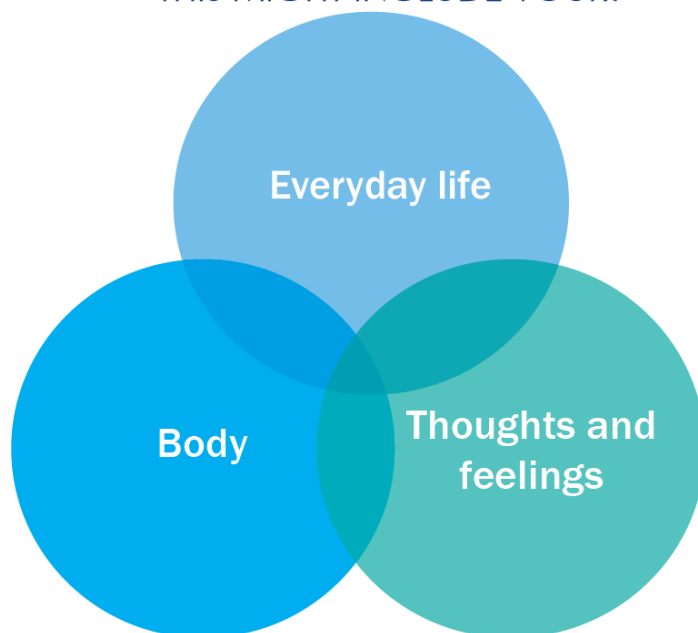
bmjopen-2021-051430 on 2 November 2021. Downloaded from <http://bmjopen.bmj.com/> on April 16, 2024 by guest. Protected by copyright.

1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46

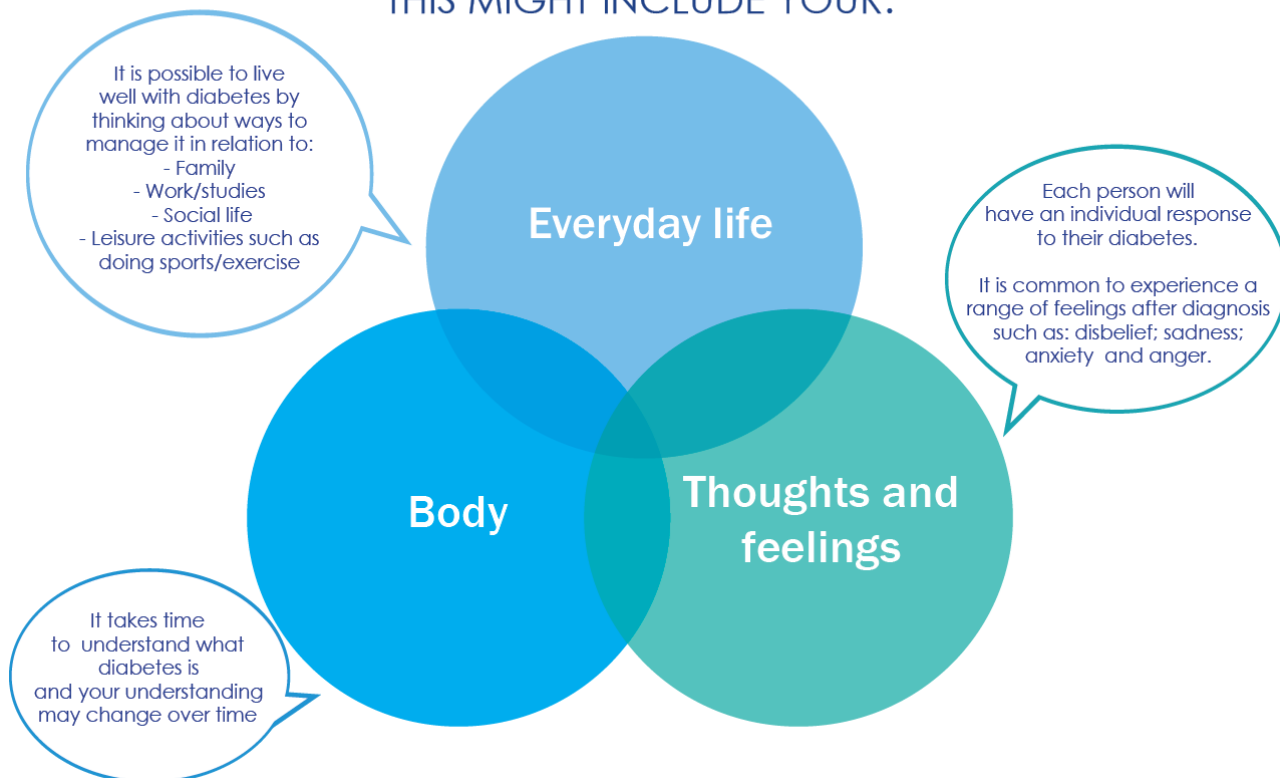


1  
2  
3  
4  
5  
6  
7  
8  
9  
10  
11  
12  
13  
14  
15  
16  
17  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60

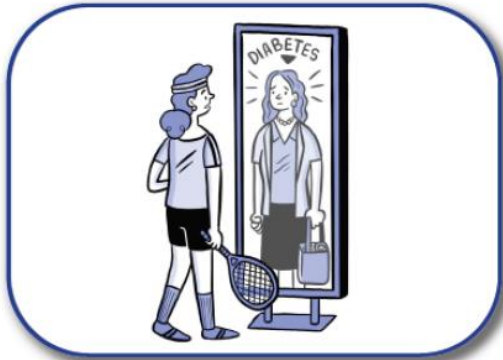
TYPE 1 DIABETES CAN AFFECT MANY PARTS OF YOUR LIFE.  
THIS MIGHT INCLUDE YOUR:



TYPE 1 DIABETES CAN AFFECT MANY PARTS OF YOUR LIFE.  
THIS MIGHT INCLUDE YOUR:



Please reference this paper



*"I feel stupid that this feels so hard because you almost feel like it feels a bit silly to say, 'This is really hard,' because what is hard about it? It's difficult to explain what is hard."*

*(Julie, twenties)*



*"Sometimes it just feels really tedious. When you're tired and just want to have to not think about something, and you just still have to think about diabetes?"*

*(Eric, forties)*

Please reference this paper



## Standards for Reporting Qualitative Research (SRQR)\*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

### Title and abstract

<p><b>Title</b> - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	<p>Page 1/lines 1-2</p>
<p><b>Abstract</b> - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	<p>Page 2/lines 1-29</p>

### Introduction

<p><b>Problem formulation</b> - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	<p>Page 4/lines 2-34 and Page 5/lines 1-4</p>
<p><b>Purpose or research question</b> - Purpose of the study and specific objectives or questions</p>	<p>Page 5/lines6-13</p>

### Methods

<p><b>Qualitative approach and research paradigm</b> - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**</p>	<p>Page 5/lines 16-25</p>
<p><b>Researcher characteristics and reflexivity</b> - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	<p>Page 6/lines 26-30</p>
<p><b>Context</b> - Setting/site and salient contextual factors; rationale**</p>	<p>Page 5/lines 31-34 and Page 6/lines 1-3</p>
<p><b>Sampling strategy</b> - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	<p>Page 6/lines 4-12</p>
<p><b>Ethical issues pertaining to human subjects</b> - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	<p>Page 7/lines 4-6</p>
<p><b>Data collection methods</b> - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	<p>Page 6/lines 21 to page 7 line 23 and table 1</p>

1 2 3 4 5	<b>Data collection instruments and technologies</b> - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 6/lines 24-26 and Page 7/lines 8-11 and figure 1
6 7 8 9	<b>Units of study</b> - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 9/lines 22-31 and table 2
10 11 12 13	<b>Data processing</b> - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Page 6/lines 24-26 Page 9/lines 2-20
14 15 16 17	<b>Data analysis</b> - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Page 9/lines 2-20
18 19 20 21	<b>Techniques to enhance trustworthiness</b> - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 9/lines 15-20

### Results/findings

22 23 24 25 26 27	<b>Synthesis and interpretation</b> - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Pages 9 line 23 - 14
28 29 30 31 32	<b>Links to empirical data</b> - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Table 3 Pages 12-13, supplementary file 1-3

### Discussion

33 34 35 36 37 38 39 40 41	<b>Integration with prior work, implications, transferability, and contribution(s) to the field</b> - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Pages 15-17 line 6
42 43 44	<b>Limitations</b> - Trustworthiness and limitations of findings	Page 17 line 8 to page 18/line 26

### Other

45 46 47 48 49	<b>Conflicts of interest</b> - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Page 19/lines 8-9
50 51 52	<b>Funding</b> - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 19/lines 10-17

1 \*The authors created the SRQR by searching the literature to identify guidelines, reporting  
2 standards, and critical appraisal criteria for qualitative research; reviewing the reference  
3 lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to  
4 improve the transparency of all aspects of qualitative research by providing clear standards  
5 for reporting qualitative research.  
6  
7

8 \*\*The rationale should briefly discuss the justification for choosing that theory, approach,  
9 method, or technique rather than other options available, the assumptions and limitations  
10 implicit in those choices, and how those choices influence study conclusions and  
11 transferability. As appropriate, the rationale for several items might be discussed together.  
12

13  
14 **Reference:**

15 O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative**  
16 **research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014  
17 DOI: [10.1097/ACM.0000000000000388](https://doi.org/10.1097/ACM.0000000000000388)  
18  
19  
20  
21  
22  
23  
24  
25  
26  
27  
28  
29  
30  
31  
32  
33  
34  
35  
36  
37  
38  
39  
40  
41  
42  
43  
44  
45  
46  
47  
48  
49  
50  
51  
52  
53  
54  
55  
56  
57  
58  
59  
60