The co-design of a reactive chatbot to support young people's self-management of type 1 diabetes mellitus.

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The co-design of a reactive chatbot to support young people's self-management of type 1 diabetes mellitus

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Abstract

This study co-designed a reactive chatbot to support self-management of young people and young adults with type 1 Diabetes Mellitus, during transition to adult healthcare services. Qualitative focus groups and interviews were undertaken with 38 young people and young adults aged 11–25 years at 4 study sites across England, to inform chatbot co-design. Data were analysed using Framework Analysis, the Behaviour Change Wheel and COM-B approach. The reactive chatbot includes messaging dialogues and additional materials considerate of the lived experiences of participants, barriers and enablers to self-management, behaviour change theory and techniques. As far as possible, participant recommendations for content, function, and aesthetics of the prototype were implemented. Mechanisms of action for self-management are considered in the developed chatbot. Further research is needed to explore prototype feasibility including the fidelity of the messaging content.

Keywords

digital health, diabetes, young people, young adults, qualitative

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Data Availability Statement included at the end of the article

Background

Research aim: The study aims to co-design a youth centred, NHS approved chatbot to support 11–25 year-olds with type 1 Diabetes Mellitus during their transition to adult care.

Type 1 diabetes (T1DM) is a long-term condition diagnosed in childhood leading to dependence on exogenous insulin across the lifespan. The prevalence of T1DM in young people and young adults (YP/YA) is increasing globally; >98,000 YP under 15 years are diagnosed with T1DM each year (Ogle et al., 2022). Paediatric diabetes care is family-centred, focussing on medical management and psychosocial adjustments impacting child and family. Adult services are more self-directed. Because transition to adult services begins in adolescence (⩾11 years), encouraging self-management early is imperative. Self-management theories highlight the key role of family in managing T1DM (Grey et al., 2015) and suggest the trajectory towards self-management is influenced by individual, family, and clinical factors including developmental stage and clinical characteristics. The self-management of T1DM impacts upon quality of life (QOL), short- and long-term health (Tuohy et al., 2023). Navigating developmental, illness and other contextual factors can present challenges for YP/YA, leading to deterioration of glycaemic control. Poor management can result in diabetic ketoacidosis, severe hypoglycaemia, cognitive decline, visual impairment and blindness, kidney failure, loss of consciousness, and death (Leocadio et al., 2023). Supporting a smooth transition and mastery over self-management can reduce complications and improve health outcomes in this population.

Healthcare professionals (HCPs), YP/YA, and families increasingly use digital health technologies to improve management of long-term conditions. A global literature review on the use of digital health technologies through transition to adult healthcare for YP with long-term conditions, focussing on T1DM (19 studies) identified a range of digital and web-based interventions to support YP; however, few studies included those with T1DM, and none included chatbots, suggesting research is needed to understand challenges and how communication technology could support transition (Orpin et al., 2025).

YP/YA are digital citizens; they seek health information and connectivity via digital technology but unfortunately their perspectives are not always included in the technology design or decision making. Patient centred approaches are needed to support the development of T1DM digital support tools as recent studies report available digital support is underutilised or not aligned with the needs of YP/YA (Mancone et al., 2024; Rohatgi, 2025). The World Health Organisation's (WHO) youth centred digital framework advocates co-design to support the acceptability and effectiveness of interventions for diverse users and contexts. It is suggested that digital interventions are more effective for users if they support personalisation, anonymity and continuous monitoring influenced by behaviour change theory (World Health Organisation [WHO], 2024).

An umbrella review reports on the effectiveness of mobile phone-based interventions for youth users with 10 different long-term conditions (Sun et al., 2024). Thirty-four meta-analyses reporting 235 randomised controlled trials with almost 50,000 participants from 52 countries were included. Apps with text messaging were found to help with managing blood glucose levels for those with type 2 diabetes and medication adherence for people with HIV or cardiovascular disease. However, few studies reported on moderators, risks, ethical needs, or potential adverse effects. Telehealth and digitally mediated care are promoted to improve adherence, clinical outcomes, and diet related behaviours. In diabetes care its use has grown since the pandemic with remote options for YA/YP being preferred to support independence and bridge care from child to adult services (Suratham and Klainin-Yobas, 2025). Healthcare professionals emphasise the need for evidence-based design, tools that can be operated by both patients and professionals, with features supporting behaviour change. Communication technologies are needed to meet patient expectations and assist with healthcare workload pressures (Singh et al., 2023).

In response to the need for high quality, youth centred tools, preferences for apps, text messaging and telehealth to support adherence and self-management, this project seeks to fill a gap in T1DM transition support by developing an accessible, safe, developmentally appropriate and clinically validated chatbot intervention. Chatbots are conversational apps that simulate human-like conversation through text or voice interactions, providing a safe space for interacting with YP/YA to promote health behaviours (Laymouna et al., 2024).

Study design and method

A descriptive qualitative design (Creswell and Creswell, 2017) facilitated the co-design of the chatbot. Primary objectives included:

1. To obtain views of YP/YA with T1DM to determine information required in a chatbot to support safe transition to adult healthcare.
2. To develop a chatbot and additional multi-media transition resources on an established platform (UK-wide digital diabetes information resource).

The UK Medical Research Council recommends complex interventions are based on evidence and theory to support the intervention's process of change (Skivington et al., 2021). The self-management framework of Corbin and Strauss (1985) and Behaviour Change Wheel (BCW) of Michie et al. (2014) underpinned the research.

The BCW uses a Capability, Opportunity, Motivation, and Behaviour (COM-B) model and Theoretical Domains Framework (TDF) to consider how interventions can include functions and behaviour change techniques (BCTs) to change behaviour. The three-stage (eight-step process) of the BCW helped us to understand barriers and enablers of T1DM self-management in YP/YA (Figure 1). We added stage 4 to the analytic process, considering the digital development needs of the chatbot.

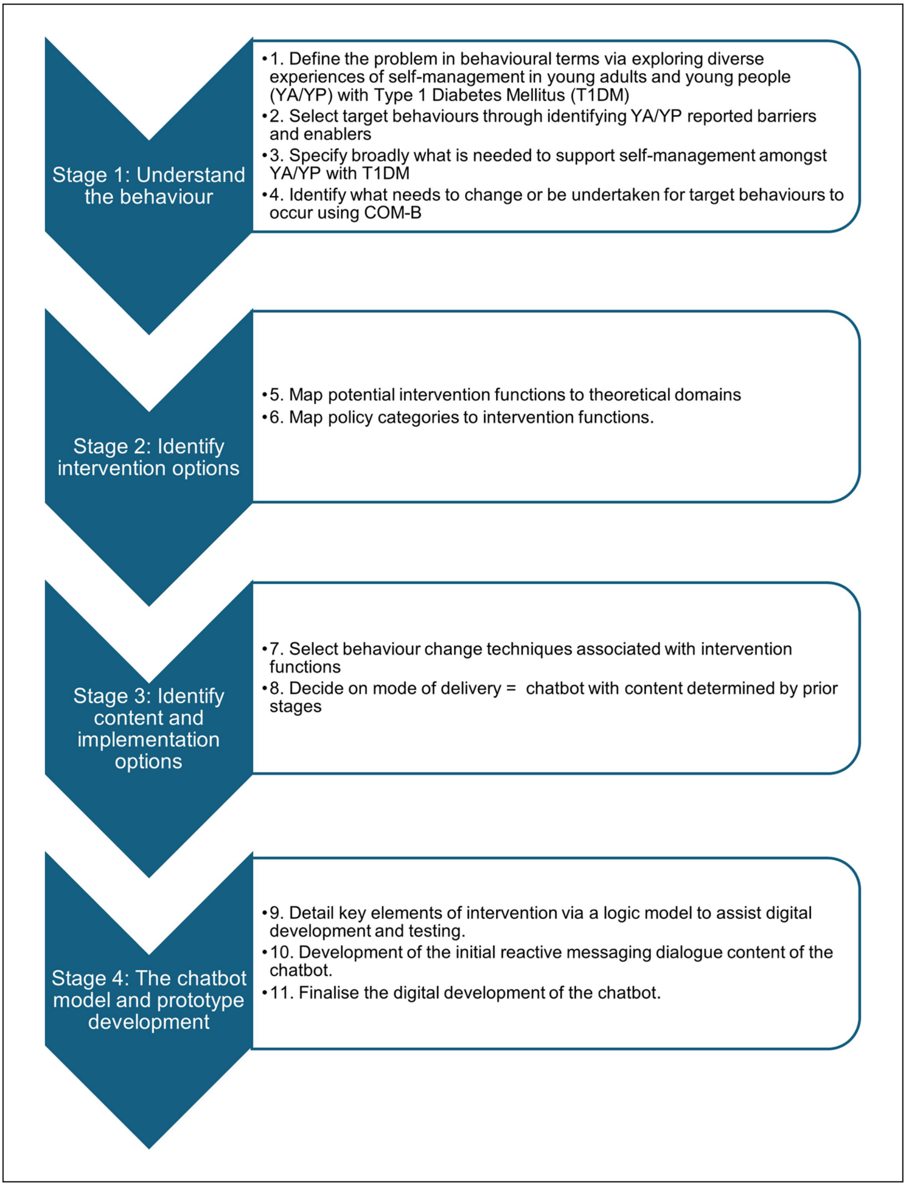
To overcome the potential 'research-practice gap' a user-oriented co-design approach was adopted (Kickbusch et al., 2021). Combining theory-based and co-design methodology, is proposed to increase intervention efficacy, overcome barriers to YP/YA T1DM self-management and support engagement. Several teams worked together on the project:

1. Researchers: academics and healthcare professionals (HCP) from medical, nursing and psychology backgrounds, with collaboration from 'Thrive by Design' (TbD; an NHS co-design digital inclusion and innovation team).
2. Digital experts: content designers and developers working with a social enterprise that offers diabetes support–a digital informational resource platform that the chatbot will integrate, supported by IBM Watson.
3. Diabetes experts: Health care professionals who reviewed, advised, and clinically approved intervention content.
4. Expert User Group (EUG): YP/YA with T1DM, parents and youth worker. The EUG was engaged in all study stages. Virtual meetings were held quarterly; ⩾5 young people attended each meeting. Views were collated on live documentation (using Padlet, an online tool for engagement and collaboration (Fisher, 2017)). The EUG was instrumental in designing the chatbot's content.

Reporting follows the COREQ Checklist (Tong et al., 2007).

Sampling and recruitment

A purposive sampling strategy was used to recruit YP/YA aged 11–25 years living with T1DM. Each participant had a formal physician-confirmed



- 1. Define the problem in behavioural terms via exploring diverse experiences of self-management in young adults and young people (YA/YP) with Type 1 Diabetes Mellitus (T1DM)
- 2. Select target behaviours through identifying YA/YP reported barriers and enablers
- 3. Specify broadly what is needed to support self-management amongst YA/YP with T1DM
- 4. Identify what needs to change or be undertaken for target behaviours to occur using COM-B

- 5. Map potential intervention functions to theoretical domains
- 6. Map policy categories to intervention functions.

- 7. Select behaviour change techniques associated with intervention functions
- 8. Decide on mode of delivery = chatbot with content determined by prior stages

- 9. Detail key elements of intervention via a logic model to assist digital development and testing.
- 10. Development of the initial reactive messaging dialogue content of the chatbot.
- 11. Finalise the digital development of the chatbot.

Figure 1. Stages of the chatbot co-design to support young people and young adults with their type 1 diabetes mellitus self-management.

diagnosis documented in their NHS medical records. Participants were recruited from four NHS Diabetes Clinical Teams–two paediatric/pre-transition and two adult/post-transition services. This supported participant representation across the transition pathway. Eligible participants needed to be receiving ongoing NHS diabetes care, be fluent in spoken English, and familiar with using a PC, smartphone, or tablet, so they could engage in the co-design activities. For individuals in paediatric services eligibility also included being expected to transfer to adult NHS diabetes service. For individuals using adult services, eligibility required confirmed transition from a paediatric NHS diabetes service. Principal Investigators (Consultant Paediatric or Adult Diabetologists) at each site were responsible for screening electronic patient records to verify formal diagnosis, confirm all inclusion criteria and identify a diverse group of eligible participants (including those digitally/socially excluded). Sites opened to recruitment January/February 2022 and continued until adequate thematic depth and variation were achieved across age groups and transition stages (October 2022). This was an initial phase of a multiphase project.

Participants ⩾16 years gave written informed consent. Those aged 11–15 years provided assent following parent/legal guardian informed consent.

Ethical considerations

The study was ethically approved by the NHS Research Ethics Committee (IRAS Reference:292053) and the Lead NHS Trust Research and Innovation Department approved this study.

Data collection

We conducted 5 focus groups (FG) with 19 participants (FG1n = 4, FG2n = 6, FG3n = 3, FG4n = 2, FG5n = 4) and 19 interviews with YP/YA with T1DM. Data collection was undertaken in private rooms at hospital sites at times convenient to participants, facilitated by experienced researchers. Each Interview/Focus group lasted on average 60 minutes. Semi-structured topic guides were used to explore YP/YA experiences of T1DM self-management and chatbot preferences, considering self-management theory (Corbin and Strauss, 1985) and the COM-B model (Michie et al., 2014).

Focus groups and interviews were audio recorded, transcribed verbatim and anonymised. Electronic data were stored securely on NHS or University password-protected computers and transferred using encrypted devices. Paper files were stored securely in locked filing cabinets. Participants were given a pseudonym to maintain anonymity.

Analysis

Stage 1: Understanding the behaviour (YP/YA's T1DM self-management in context)

1. A Framework Analysis approach (Smith and Firth, 2011; supported by NVivo (version 12.6, 2021) enabled an in-depth investigation of YP/YA T1DM self-management experiences. All transcripts were first coded by AR to ensure consistency. To enhance rigour, half of the transcripts were independently double coded by VS and JH, providing an opportunity to compare coding outputs and refine thematic boundaries. Throughout the analysis process, the coding team (AR, VS, and JH) met regularly to review coded data, discuss interpretations, and consider the developing framework. NVivo facilitated this process by enabling comparison of coding, organising analytic memos, and tracking coding queries to support intercoder reliability.
2. Target behaviours were selected by determining YP/YA experiences of barriers and enablers to self-management, adding COM-B coding to the analytic framework.
3. Exploring the experiences of YP/YA, we determined broadly what was needed to achieve self-management behaviours.
4. Mapping specified target behaviours from step 3 to the COM-B model we considered in more detail what needed to be undertaken for target behaviours to occur (remove barriers and encourage enablers), linking behaviours to TDF domains.

Stage 2: Identifying Intervention options

5. Intervention functions were mapped onto theoretical domains identified in step 4 and evaluated using the APEASE (acceptability, practicability, effectiveness, affordability, side effects, and equity) criteria of the BCW framework.

Decisions were informed by understanding context and technological considerations (detailed in stage 4 findings).

6. Policy categories include communication/marketing, guidelines, fiscal measures, regulation, legislation, environmental/social planning, and service provision. We mapped relevant policy categories onto the intervention functions identified in step 5.

Stage 3: Identifying content and Implementation options

7. Based on identified intervention functions (step 5), we selected BCTs from the behaviour change technique taxonomy (BCTTv1; Michie et al., 2013) which details techniques standardised to determine active components of behaviour change interventions.
8. The mode of delivery was pre-determined by the study's purpose to co-design a chatbot. The content, however, was guided by the taxonomy and intervention functions to support effective communication.

Stage 4: The chatbot prototype development

9. A logic model was developed to represent the T1DM self-management chatbot.
10. Stage 1–3 analyses with the logic model, provided developers with information about behavioural support needs and user preferences. Message dialogues were curated based on this knowledge with links to additional materials such as PDF informational resources, videos, and virtual links approved by the clinical team and expert user group (EUG). In addition, EUG members participated in the creation of some multi-media materials. Messaging dialogues were coded to intents, categorised by conversational topics (a topic library was created based on participants and EUG suggestions).
11. The reactive chatbot prototype was finalised, using IBM Watson as the AI platform, constructed on two levels:

Level 1: A generic transition platform providing information about managing holistic health needs during adolescence and young adulthood.

Level 2: A platform that provides relevant T1DM-specific information for YP/YA.

In Initial testing of the chatbot's functionality, the release of messages was evaluated against user utterances (request for support and information messages) to ensure software was picking up reactive content appropriately.

It is Important to note that at key stages of the analytic process, for example when determining thematic structures and at coding decisions, details were shared with members of the EUG. These sessions served to provide opportunity for members to bring further lived experience and contextual insights to validate or challenge interpretations. This ensured analytic and intervention content decisions were influenced by the realities YP/YA face in navigating their T1DM self-management.

Results

The final study sample included 38 young people and young adults (YP/YA) each with a formal diagnosis of type 1 Diabetes Mellitus (T1DM). Twenty-four participants were pre-transition (11–17 years) and 12 were post transition (18–25 years). Table 1 details participant demographic characteristics. There was diversity across the sample reflecting differences in experiences of digital access, time since diagnosis and exposure to diabetes related technologies. These factors impacted a variety of transition and self-management experiences.

The Framework Analysis uncovered three inter-related aspects of self-management for YP/YA. These included: (1) Medical self-management (MSM): taking medication, adhering to advice, using supportive devices and safety; (2) Behavioural self-management (BSM), learning

Table 1. Participant characteristics.

Age	Self-identified gender	Pseudonym	Service	Interview/focus group
13	M	Noah	Child	FG
16	F	Shannon	Child	FG
16	M	Joseph	Child	FG
14	M	Mathew	Child	FG
13	F	Freya	Child	IV
11	F	Ellie	Child	FG
13	F	Katie	Child	FG
17	F	Abigail	Child	FG
13	F	Emma	Child	FG
12	F	Molly	Child	FG
14	F	Grace	Child	FG
22	F	Lucy	Adult	FG
20	F	Georgia	Adult	FG
20	M	Joshua	Adult	FG
11	F	Amelia	Child	FG
13	M	Max	Child	IV
11	M	Ethan	Child	IV
22	F	Rebecca	Adult	IV
22	M	Daniel	Adult	FG
19	F	Isabelle	Adult	FG
20	F	Amy	Adult	IV
11	F	Jade	Child	FG
14	F	Leah	Child	FG
12	M	William	Child	FG
18	M	James	Adult	IV
20	F	Sophie	Adult	IV
17	M	Samuel	Child	IV
17	F	Chloe	Child[a]	IV
25	F	Olivia	Adult	IV
23	F	Hannah	Adult	IV
15	F	Courtney	Child	IV
13	F	Holly	Child[a]	IV
16	M	Jack	Child[a]	IV
21	F	Megan	Adult[a]	IV
19	M	Thomas	Adult[a]	IV
21	F	Jessica	Adult[a]	IV
16	F	Evie	Child[a]	IV
17	F	Lauren	Child[a]	IV

[a] Digitally/socially excluded.

to integrate T1DM into everyday contexts and roles influenced; and (3) Emotional self-management (ESM), maintaining emotional equilibrium, managing fears and distress associated with T1DM and impacts on identity. These aspects of self-management were found to be interconnected; medical needs influenced emotions, emotions influenced behavioural routines and behavioural contexts facilitated or acted as barriers to good medical practices. Table 2 details the themes and subthemes of the Framework Analysis.

Table 2. Themes and subthemes of young peoples and young adults' self-management of type1 diabetes mellitus.

First level/ overarching theme	Second level subtheme
1. 1. Medical self-management (MSM)	1.1 Everyday demands How everyday life affects self-management.
	1.2 Fears and concerns Sources of stress around medical management.
	1.3 Support Sources of support for medical regimens and adherence to advice.
4. 3. Behavioural self-management (BSM)	3.1 Competing demands Competing demands of self-managing.
	3.2 Inclusivity Ways YP/YA feel more included and how others can be more inclusive.
	3.3 Practical considerations Issues YP/YA need focus/support on to modify or adopt health behaviours.
3. Emotional self-management (ESM)	3.1 Communication about emotions Heightening awareness, being open about experiences, help to better manage emotions.
	3.2 Support Emotional support for reassurance, acceptance, encouragement, and care – assisting coping.
	3.3 The interplay of emotions, cognitions, and behaviours in coping with T1DM Coping strategies to reduce unpleasant emotions.

Medical self-management (MSM)

Overview. Participants discussed MSM as a continuous element of their day to day lives. It was viewed often as a burden with the constant need to plan, monitor and find ways to adapt. Participants highlighted contexts they would find difficult, but perceived others could navigate easily, leading to them wishing they could 'live normally'. Medical needs could disrupt plans, especially for social or unfamiliar situations. Participants had diverse levels of self confidence in medically managing and over time had experienced an increase in risk awareness. There was variability in terms of access to support for MSM.

Everyday demands. YP/YA reflected on their everyday activities, describing situations at school or work, issues in engaging with sports and socialising. These experiences influenced how well they felt they were able to manage. A diagnosis of T1DM for YP/YA and their families was reported to be a 'shock', and it had taken most participants time to adjust to the long-term nature of the condition and their medical intervention needs. *'Within the* first and second *year of having it, I used to go through a lot of stress'* (William, 12). Participants suggested coping with MSM was supported by engagement in physical activity such as going to the *'gym', 'skating', 'swimming' and 'martial arts.* Physical activity, although supportive of health and wellbeing inflicted worries related to needing diet/insulin adjustments. Some participants were more aware than others of actions needed to maintain good MSM in these contexts, with several finding sports anxiety provoking because of the unpredictability in glucose levels and self-consciousness associated with the visibility of their medical devices. There were also difficulties expressed in using assistive devices when undertaking physical activities, for example keeping blood glucose monitoring stickers in place. This had led to some participants avoiding sports because their device made them feel awkward. Confidence decreased in MSM when YP/YA were needing to manage multiple contextual demands. This highlighted their need for anticipatory guidance and context driven support, where any behaviour normalising messaging would be important.

Fears and concerns. Several participants discussed how they would frequently mentally prepare for what they would consider as frightening (and rare) scenarios. Although there was a desire to reach independence from family, the potential and reality of this was experienced as risky. YP/YA require guidance to achieve a liveable balance among the demands of T1DM and their desire for a *'normal'* lifestyle. Participants mentioned how they might cope in certain situations for example, eating out or being away from home.

> *'Worrying about my self-care and my diabetes increases when I'm doing something different. . . If I'm going on holiday, that will make me quite worried because you can never take enough supplies on holiday . . . or if you're going out for a walk, I get super paranoid that I'll have like five hypos and need loads of glucose sweets. . . it's the preparing for the very rare situation all the time. . .'.* (Lucy, 22).

Participants fears and concerns were heightened through transition where adult services were reported less supportive. YP/YA wanted reassurance that it is ok to experience a struggle with their self-management needs.

> *'Everybody tries to promote like, look what you can do with diabetes. . . but nobody ever really turns around and goes it's OK to feel that way'* (Olivia, 25).

Support. Participants reported different experiences of support from family and healthcare professionals. Some suggested they had received lots of support and guidance whereas others said advice could be conflicting or outdated, especially with respect to the use of technology. Understanding side effects was paramount to enabling participants to feel in control of their condition. There was discussion around needs changing when getting older:

> *'But when I get older. . . like going out. . . if you're like at university or something. . .how you could deal with like, alcohol and stuff.'* (Courtney, 15).

Despite a few hesitancies, digital health devices were perceived as helpful. However, there was variance in support received from HCP to use them, for example:

> 'He said 'Georgia, I'm not entirely sure we want to continue funding your pump because you have very good control, so you can go back and have a different diet because I'm not up-to-date with technology and I think that you can do well by yourself" (Georgia, 20).

MSM challenges were influenced by an array of factors including developmental readiness, perception of risk, level of social reassurance and continuity of care across services and sources of support. These factors support chatbot considerations for example, the need for normalising messages to lower feelings of stress, anticipatory support, device management advice, and broader emotional validation.

Table 3 details barriers and enablers to MSM mapped to COM-B, illustrating how capability, opportunity, and motivation shape medical adherence and device use, alongside identified intervention functions to support behavioural modifications.

Behavioural self-management (BSM)

Overview. In discussing BSM participants talked about how they needed to learn to integrate T1DM into routines, manage social situations and their broader responsibilities. This sometimes-led participants to feel that the behavioural load of T1DM would conflict with their developmental needs. For example, being or becoming independent, being able to be spontaneous and feeling that they socially belonged with peers. Behavioural expectations were

Table 3. Barriers and enablers to medical self-management (MSM).

COM	Barriers	Enablers	Intervention functions
Psychological capability	• Difficulty integrating MSM into routines • T1DM novelty. Embarrassment/ difficulties managing devices.	• Establishing/maintaining routines. • Using apps.	• Enablement–increase capability through encouragement/access to support. • Persuasion - influence user action/training, show users how skills can be performed/ managed. • Training – how to use informational resources and supportive devices.
Physical capability	• Lack of awareness of impaired glucose levels • Limited access to support for understanding symptoms.	• Knowledge of symptoms to act on triggers	• Training – T1DM information and benefits of MSM, guidance on performing MSM and goal setting.
Physical opportunity	• Lack of access to support/monitoring equipment. • Undertaking new activities/in new situations.	• Support of T1DM knowledgeable peers.	• Environmental restructuring – guidance on communicating with peers about T1DM. • Training - encouraging dialogue with HCP and support for digital monitoring.
Social opportunity	• Support in child versus adult services. • Difficult to communicate about T1DM.	• Support available/ received from HCP, education, and workplaces.	• Persuasion – encouragement to access various support.
Reflective motivation	• Lack of accountability. • Uncertainty about the benefits of digital interventions. • Lack of awareness of poor MSM. • Reluctance to overburden/access HCP.	• Support of digital devices/applications. T1DM Informational support. • Knowledge to motivate action. • Awareness of and access to HCP support/other networks of support.	• Enablement and persuasion – to consider adherence needs, consequences, MSM targets, set goals. • Education – information about T1DM and consequences of good/ poor MSM.

harder to manage through transition as adult services were reported to offer less guidance.

Competing demands. YP/YA discussed behavioural demands as time consuming, *'constant'* and *'exhausting'* and were sometimes seen to be incompatible with their daily lives. YA reflected on how they had received more behavioural support in paediatric services to manage competing life demands and how hard it is now to be supported by adult services which are more self-directed:

> *'Paediatrics was amazing, I wish I'd never left. . . as soon as you move to adults, you're left. You're lost.'* (Hannah, 23).

Inclusivity. Managing T1DM demands an openness that can be uncomfortable for some YP/YA, especially in new contexts. It could be difficult to know what to say when talking through their needs to teachers, employers, or peers: '. . .*when I changed schools it was really hard for me to go up to a new teacher and tell them'* (Freya, 13). Where YP/YA were in receipt of support and encouragement from friends this was highly valued, especially those T1DM informed. But this was not always available.

A constant of T1DM is the focus on behaviour. A YP/YA must enact behaviours to undertake treatment tasks/regimens, attend clinic, or take actions to reduce distress. Help from others is highly appreciated:

> *'I find it quite difficult sometimes to do my insulin just because it is a lot of pressure. . .my mum sometimes reminds me to do it. . .I find it quite a big challenge to click the button in to do it'* (Leah, 14).

Knowledge, past experiences, feelings, attitudes, and beliefs each were found to impact on T1DM behaviours and be influenced by the YP/YA age/developmental status.

Practical considerations. Disruptions in routine could set YP/YA back in terms of their confidence to self-manage effectively. For example, unplanned delays to eat could lead to stress. Digital technologies were viewed as helpful when they could provide real-time feedback, but some were not also without barriers, for example skin discomfort or reactions to devices. Where there were more challenges to BSM, the challenge would often relate to habit formation, with more assertiveness needed for checking and taking control.

Good BSM promoted YP/YA involvement in peer activities but there was an awareness that friends would benefit from more knowledge about T1DM to support the YP/YA: '. . .*they've known me have a hypo, they've known me have a high. So, they know what to look out for*' (Samuel, 17). This may be especially important to avoid/limit the experimental/risky behaviours adolescents may consider engaging in.

Interventions focus on adherence to blood glucose monitoring, insulin, and oral medications. However, participants reported many YP/YA have difficulties with diet. Joshua reflected on how he was grateful for digital health support using a continuous glucose monitoring system to monitor his glucose levels:

> *'I went to a Libre training session. . .I was the first person to go on a Libre before I switched to a Dexcom . . .there was a 70-year-old man . . . talking about how he was still on two injections a day, and with that of course it's a really controlled strict diet that he had to follow. . .I just thought wow how fortunate are we. . .'.* (Joshua, 20).

Recommendations to change eating behaviour are difficult to implement. It is important therefore to consider behavioural issues around eating that may disrupt BSM, for example:

> *'I'm a person who really enjoys a routine. . .I can get quite stressed out if something happens that breaks the routine. . . If all of a sudden, I have to go an extra two hours without eating that wasn't planned, I'm now worrying is my blood sugar going to get too low*' (Georgia, 20).

Parental worries regarding poor adherence in YP/YA can also lead to overprotective parenting and parents taking a lead in managing their child's condition. There is a balance to be achieved from providing YP/YA with support and enabling independence. Practical insights can help guide chatbot considerations and the inclusion of behavioural prompts, with content offering messages they can model and goal setting/planning tools.

Table 4 details BSM barriers and enablers in relation to COM-B, highlighting the significant role of social and environmental opportunity in shaping behavioural consistency alongside identified intervention functions to support behavioural modifications.

Emotional self-management (ESM)

Overview. All participants suggested T1DM was emotionally draining upon them. They had experienced stress from the stigma of others

Table 4. Barriers and enablers to behavioural self-management (BSM).

COM	Barriers	Enablers	Intervention functions
Psychological capability	• Participating in peer activities when feeling unwell. • Feeling unwell/challenged inhibits BSM monitoring. • Forgetting BSM targets/lack of BSM skills.	• Technological support to assist health monitoring. • Visual/audible reminders to action BSM, e.g., pump alarms/ vibrations. • Confidence in skill acquisition. • Families supporting BSM independence. • BSM routines.	• Environmental restructuring –prioritising BSM. • Enablement – supporting discussions around behavioural barriers and solutions. • Training – practice BSM skills, enable BSM routines.
Physical capability	• Feeling ill can inhibit T1DM monitoring.	• Social support.	• Enablement – support problem solving and awareness of T1DM consequences.
Physical opportunity	• Lack of support. • Complex/non-routine lifestyles impacting BSM.	• T1DM informed peers supporting non-engagement with risky behaviours and help to BSM.	• Environmental restructuring –understanding BSM in different settings.
Social opportunity	• Inappropriate social influences. • Peer pressure. • Independence anxiety. • Hesitancy to declare T1DM status to teachers/employers. • Need for advice on how to communicate to receive support.	• Peers who understand T1DM can support positive decision-making. • Being comfortable to communicate about needs and experiences to peers. • BSM is better actioned with support from family.	• Enablement – access social support from HCP/other sources to understand holistic benefits of BSM. • Persuasion – share experiences with others, to gain support for BSM.
Automatic motivation	• Difficult to engage in BSM behaviours in public. • Need for sense of reward for BSM efforts; day-to-day managing can feel tough/unfair.	• When good BSM routines are established, behaviours become habitual. • Being less conscious of the judgements of others. • Support from education/workplace.	• Training – understand/learn how to integrate BSM routines. Guidance and support to practice BSM skills. • Incentivisation – congratulate oneself on BSM adherence.
Reflective motivation	• Lack of confidence in undertaking BSM. • Prioritising life events/ challenges over BSM. • Lack of readiness to change. • Lack of control/ independence over BSM behaviours because HCP/family inhibits independence.	• HCP and family promote independence. • Seeing other YP/YA managing T1DM well and sharing experiences. • Clear and achievable targets. • Guidance to goal set.	• Enablement – access and understand guidelines for BSM and access social support. • Incentivisation – commit to BSM goals and identify how to become a role model for others.

and self-stigma, worries about their future health, anxiety in feeling the need to constantly check their blood glucose and a lot of concern about transitioning to adult services and feeling pressured to cope. ESM challenges were influenced by both MSM and BSM, especially through adolescence and emerging adulthood.

Communication about emotions. There was a reluctance amongst participants to share with others their worries or to ask for help. Not feeling understood by teachers or healthcare professionals further heighted their avoidance to talk about the emotional impact of their T1DM. T1DM frequently conflicts with other issues faced by YP/YA including their social identity, cognitive, and physiological development needs, and in parallel, the YP/YA is learning to take over responsibility for the management of their T1DM from parents. T1DM distress is an outcome; emotional difficulties, stressors and frustrations can result from managing the condition.

A range of sources of distress were identified by participants, including stigma/self-consciousness; concerns about maintaining health and wellbeing; day-to-day management difficulties; struggles with healthcare including navigating transition, and fears about the future including concerns about being or living away from home.

> *'I do get stressed just with diabetes in general, because I'm always in the back of my mind, I'm thinking what's gonna be the next complication.'* (Sophie, 20).

Fears about the future can undermine YP/YA's life plans and career aspirations.

Support. There was some talk around a need for stronger trusting relationships with healthcare professionals to receive more emotion focussed support. A few participants added that their schools were not understanding of their condition and school rules/policies made their days harder, for example, toilet restrictions impacted their glucose-related needs and privacy.

YP/YA can feel uncomfortable in asking for help and support: *'I figure it just gives me more stress on my shoulders and I can manage myself'.* (Max, 13). Participants alluded to issues of distress when they have felt restricted. Several examples were shared including times when they were unable to join in with peers in activities, when they have been unable to eat what they would like or when they have needed to catch up on schoolwork due to missing lesson time for medical needs:

> *'If we're doing PE, it'll often take you out of PE or if we're doing English it'll take you out of English and then I will miss the entire lesson, and I'll come back and will have to write a full page of English.'* (Jade, 11).

Many participants found the continuous need to monitor and be conscious of their T1DM to be emotionally difficult:

> *'You can sit there, and you can be doing your work and it's all silent and then your alarm starts going off* (Emma, 13).

There was several YP/YA who conveyed their awkwardness in medically managing their diabetes around others, in fear of others being alarmed or denoting them as *'different*'.

Interplay of emotions, cognitions, and behaviours in coping with T1DM. The negative emotions linked with worry about complications, fear of judgement, stigma and burnout influenced self-management behaviours. Through adolescence there is an acute awareness of bullying behaviours if perceived as different. The anxiety around the possibility of *'not fitting in'* impacted participants psychological wellbeing and could impact help seeking behaviours and overall T1DM self-management. Coping strategies that were highlighted as helpful included social media engagement and the distraction achieved from engagement with digital apps/games. Social media also offers YP/YA a way to seek and receive support for ESM and provides opportunity to network with others with T1DM.

Several participants commented on how they *'follow'* influencers who are coping well, to learn and share experiences.

ESM difficulties could be interpreted as associated with a need for increased emotional skills and motivation. This reinforces the need for interventions that help YP/YA to acknowledge stress/distress as something that is prevalent in their patient group, provide coping strategies, model healthy responses, and promote help seeking behaviours.

Table 5 details ESM barriers and enablers mapped to COM-B, highlighting how emotional needs integrate with social support, identity, and behavioural regulation, alongside identified intervention functions to support behavioural modifications.

Chatbot needs

Overview. YP/YA and EUG members evaluated the functional, aesthetic, and relational needs of a chatbot intervention. Some participants stated they viewed existing diabetes apps as

'boring' or burdensome and they would not want more of the same. There were comments around a lack of interest in engagement especially for those aged 16–18 years. Whereas others were more encouraging saying they wanted a supportive tool. This was expressed dominantly by those who perceived themselves as isolated or needing more support during transition:

> *'I think it's brilliant to be honest, yeah. . .when you're younger, your parents sort of deal with most of it. . .I probably didn't have like a touch phone or internet on my phone, something like that, but obviously kids do now'.* (James, 18).

Key preferences. Participants suggested how the chatbot should be:

- Relatable
- Not overly clinical
- Responsive to emotional needs with rapport building to encourage openness
- Not too complex or difficult to use – the chatbot should give clear and easy to follow messaging content
- Not burdensome
- Acknowledge how some users may have experienced digital exclusion or limitations on device use.

Both research participants and EUG members said they would require the chatbot to cover several topics including: communication, relationships, school, employment, , understanding T1DM, medication, technological support/failure, diet and food, alcohol, exercise, festivals, holidays, illness, pregnancy, glucose regulation and emergency situations, driving safety, transition and adult care, emotional states, loneliness, procedural anxiety, diabetes related stress, intimate relationships and psychological support.

These preferences have been used to influence the chatbots messaging tone, reactive message triggers, avatar design and have helped to develop the topic library:

> *'I think on the app you could have like a like a document's library. . . it could be like advice leaflets you've saved or the most commonly asked for.'* (Hannah, 23).

It is acknowledged that content needs to be mindful of how emotional relevance, personalisation, age calibration, and the need for anticipatory guidance are central features needed to engage user trust and their engagement, especially at times of difficulty transitioning.

APEASE analysis. The APEASE analysis confirmed chatbot co-design decision-making, highlighting which content and functions were deemed feasible with the current technical ability and which will need future development. Recommendations were drawn from participant and EUG suggestions, related literature exploring how to improve the therapeutic relationship (Noyce and Simpson, 2018) and recommendations based on the five characteristics of effective messaging for behaviour change (Cavanaugh

Table 5. Barriers and enablers to emotional self-management (ESM).

COM	Barriers	Enablers	Intervention functions
Psychological capability	• Disruption of 'routine' can cause anxiety. • Lack of ESM awareness and skills can impact perceived control of heightening worries.	• Time and support to develop ESM. • Confidence to deal with routine deviations. • Emotionally able to manage health experiences/ outcomes. • Family supports independence from diagnosis/ early age.	• Enablement – support daily routines. • Training – ESM skills.
Social opportunity	• Lack of contact with others with T1DM reinforces feelings of isolation/being 'different'. • Wanting to 'fit in' with peers. • Social and self-stigma, influencing embarrassment. • Lack of emotional support in adult services. • Anxiety around being independent. • Not relying on family. • Independence anxiety impacted by need to be assertive with employers/teachers.	• Access to others with T1DM – hearing about others ESM experiences and coping, corroborating their own feelings. • Positive social media influencers. • Peer support to reassess risky behaviours. • Learning how others cope. • Support from HCP. • Peers without T1DM helping YP/YA navigate their everyday worlds. • Family, education, and workplaces understanding emotional toil of T1DM.	• Persuasion – helping to identify how others benefit from support. • Enablement – prompting contact with HCP and sharing stories of ESM to improve overall happiness and life satisfaction. • Training – techniques to improve self-belief.
Automatic motivation	• Anxiety around risks and complications of T1DM, dietary needs, exercise, travel, taking drugs, smoking, alcohol, sex, puberty, attending festivals and driving. • Feeling defined by T1DM. • Realisation of what diagnosis means and struggle to accept. • Discomfort in sharing diagnosis and maintaining self-management in public places. • T1DM can cause loneliness, anxiety, depression, and stress. Feeling burnt out and not coping.	• Awareness of ESM needs. • Sharing and hearing about other experiences. • Understand own limitations, limitations of self-monitoring and natural consequences to ease self-pressure. • Support to achieve a good life balance. • Time to establish routines and skill acquisition. • Reaching out for help (this sometimes feels too difficult to do). • Engagement in activities with people to maintain a positive outlook and internal locus of control (understanding not everything can always be controlled).	• Persuasion and enablement – providing information on T1DM risks and complications, allaying unfounded fears. • Support and advice around condition-related anxieties. • Training – recognising and monitoring emotional consequences, to improve self-management skills, acknowledging YP/YA can struggle with feeling they are doing things wrong/not good enough.
Reflective motivation	• Lack of confidence. • Lack of motivation to change daily routines. • Limited individual decision making.	• Being more proactive. • Establishing routines for ESM. • Reducing pressure on selves to be perfect. • Where HCP/families provide support for self-management, this releases emotional pressure about managing everything. • Learning from others who are effectively managing their emotions.	• Persuasion to access information about the emotional consequences of T1DM. • Enablement – help YP/YA access support, set goals. • Incentivisation – support YP/YA to see the benefits of ESM and accept praise to bolster confidence.

Table 6. Chatbot logic model.

Element	Description
Intervention functions	Enablement, persuasion, training, education, environmental restructuring, incentivisation
Inputs – chatbot components	- Goal setting & action planning - Behaviour monitoring - Motivational messaging - Informational support - Stress management & self-talk - Social support prompts - Personalisation (avatar, tone) - Safety and routine establishment - Multimedia tools (videos, links, guidelines)
Behaviour change techniques (BCTs; Michie et al., 2013)	- Goal setting, commitment - Feedback and self-monitoring - Social support - Instructions & antecedents - Health/emotional consequences - Behaviour comparison, prompts - Practice/rehearsal, habit formation - Credible source - Rewards and incentives
Mechanisms of impact (COM-B; Michie et al., 2014)	- Psychological Capability: Decision-making, attention, memory - Physical Capability: Skills and practice - Social Opportunity: Social norms and support - Physical Opportunity: Context and access - Reflective Motivation: Beliefs, goals, intentions - Automatic Motivation: Emotions, reinforcement
Mechanisms of change (TDF; Michie et al., 2014)	Informed by behavioural regulation, beliefs about capabilities, social role identity, skills, emotional appraisal, and decision-making processes
Short-term outcomes	- Increased SM knowledge - Improved self-efficacy - Greater perceived support - Routine development - Enhanced emotional reflection - Increased confidence in device use and health planning
Long-term outcomes	- Improved medical adherence - Behavioural consistency (e.g., diet, checking blood sugar) - Emotional regulation and reduced distress - Improved glycaemic control - Enhanced QOL and autonomy - Increased social engagement and peer support

et al., 2009). The analysis provided support for messaging content that is simple, motivational, and reactive to user input. Desired features including retaining user preferences and customising conversational styles were not deemed feasible at this stage of development.

The chatbot logic model. Table 6 presents the integrated logic model showing how behavioural theory, qualitative evidence, COM-B mapping, and BCTs informed the chatbots content, mechanisms of action and proposed short and long-term outcomes.

The logic model assisted developers to build behaviour change messages into chatbot conversations. This required initially developing knowledge databases of topics of interest using T1DM self-management guidelines. Behaviour change theories/techniques were used to generate theme dialogue modules based on the study findings (behaviour change messaging content aligned with topics). An initial set of questions around transitioning to adult services were put to the chatbot to guide a foundation for the conversation themes and structures. These were further enhanced during the co-design process as research team members and EUG posed more questions to the chatbot. These rounds of questioning were vital as they provided the digital team with further insight into the topic coverage required and how users may phrase their messages. This enabled the digital team to develop further behavioural messaging content and resources to help answer future questions.

Discussion

Digital health interventions are an effective way to deliver information and support self-management in YP/YA with T1DM (Skivington et al., 2021). The chatbot intervention is the first we are aware of in the UK NHS that is co-designed to address the lack of personalised and supported SM tools for YP/YA as they transition from child to adult services with T1DM (Orpin et al., 2025). The chatbot is theory (Corbin and Strauss, 1985; Michie et al., 2013, 2014) and evidence based, offering informational support through messaging content that draws upon the T1DM clinical evidence base, facilitating knowledge of T1DM and self-management skills relevant to the medical, behavioural, and emotional needs of its users. The chatbot aims to complement individuals' transition experiences supporting users' confidence in navigating their self-management journey.

The behavioural analysis uncovered key barriers and enablers to the medical, behavioural, and emotional self-management of T1DM in YP/YA across their transition from child to adult services. We determined the necessary mechanisms of action for a self-management supportive reactive chatbot:

1. To achieve good Medical self-management (MSM), YP/YA need physical capability/physical skills to engage in MSM behaviours. YP/YA need to be provided with opportunities to medically manage, assisted by physical resources and behavioural cues in their environment. The social opportunity to medically manage is also required. The YP/YA social environment, their relationships with others, and support from others influence how they perceive MSM and its importance in their lives. Reflective motivation, involving YP/YA in action planning, evaluating the pros and cons of good MSM behaviours is needed to engage YP/YA in behaviour change.
2. To achieve good Behavioural self-management (BSM), YP/YA need the physical skills, ability, and competence to self-assess and practice their T1DM self-management behaviours. Skills are enhanced by behavioural regulation processes such as action planning and self-monitoring, drawing on knowledge of T1DM, and positive social influences and resources available to them in their physical environments. Outside resources can enable behavioural learning. Social support, modelling, and positive feedback can impact motivation. Beliefs about capabilities, consequences of actions, goals and implementation intentions are promoted by developing self-confidence and perceived behavioural control. When the YP/YA is at a stage whereby they can recognise through self-assessment their behaviours that support their self-management against those that do not, then they have increased readiness to engage in behavioural change.
3. To achieve good Emotional self-management (ESM), YP/YA need psychological

> skills, memory, attention, and decision-making capabilities. Such are supported by positive social influences including social support, positive social comparisons, and a social identity relatable to their wider age/developmental stage group. They need the opportunity to engage in learning, modelling, and positive feedback. Motivation to engage in ESM is further enhanced by improving levels of self-confidence and perceived behavioural control. Beliefs about consequences (outcome expectancies, anticipated regret, consequents), goals (goal setting, action planning), implementation intentions (conscious decisions to perform a behaviour in a certain way), and the stability of their intentions can all impact positively or negatively on their emotional regulation. Knowledge of T1DM and behavioural regulation can support the emotional impact of T1DM.

To achieve good integration of each area of self-management need, the chatbot includes messaging and additional multimedia (videos, links, guidelines) offering goal setting and action planning guidance, encouraging the establishment of routines, giving tips to assist personal behaviour monitoring, using motivational messaging, and providing informational support to improve T1DM knowledge and supportive strategies. Topic libraries include advice and resources on stress management and self-talk, and social support prompts enable T1DM conversations and connections with others. The avatar can be personalised by users to enhance comfort in use, and all messaging content adopts a supportive and encouraging tone. Communication with the chatbot priorities safety, signposting and encouraging dialogue with HCP where relevant.

Strengths and limitations of the study

A major strength of this study is in its co-design. EUG members reported how it was motivating to see their ideas coming together in developing a tool of real-world value. Their involvement led to a shared appreciation of how a chatbot will be received and managed in the real world with day-to-day distractions. A collaborative, longitudinal relationship was established to support in-depth feedback. The chatbot is responsive to a whole host of topics relevant to YP/YA with T1DM that address the three inter-related aspects of T1DM self-management. The UK based sample however Impacts the generalisability of findings because health systems, digital and cultural norms and expectations differ across countries. The prototype was also shaped amidst digital constraints which impacted some of our APEASE decisions. These constraints reflect the challenge of developing digital health tools that are desired, theory and evidence based and technologically feasible. Further development of the chatbot may require bespoke technology.

Participants made suggestions for chatbot content including messaging tone and functionality. However, these stated preferences may not translate to engagement or behaviour change. Using the chatbot will be influenced by emotional state, level of motivation and context demands. This study does offer insight into potential user needs and preferences, but an understanding of real-world use is needed to explore the chatbots efficacy in practice and how it can support self-management for YP/YA over time.

Ethical considerations were paramount in the development of the chatbot. YP/YA need developmentally appropriate messaging and clear information detailing what a chatbot is, how it will store information and safeguard wellbeing. Importantly, the co-designed chatbot is hosted within a platform already NHS England approved. It is clinically governed and developed in line with strict safety data protection standards. The platform is accessed by all NHS Diabetes clinics that support YP/YA in the UK; the chatbot will be introduced alongside the platform to users by specialist clinicians. The chatbot messaging content is replete with signposting to human interaction/support, especially where users share messages that implicate risk to their holistic wellbeing. Any behaviour change technique content is supportive and not coercive.

Future study considerations include developing the chatbot to consider affective states. Distress can interfere with understanding, and the YP/YA may need advice to seek help and support over other health behaviour change needs. The chatbot could screen and record psychological factors that may impact the chatbot's ability to implement and sustain behaviour change recommendations. These include considerations of low mood, disordered eating or eating disorder, anxiety symptoms, and diabetes distress. One other key functionality in the future will be the ability to store user preferences so they can easily return to where they left off with the chatbot.

Conclusion

We have created the first NHS prototype reactive chatbot for YP/YA with T1DM transitioning to adult healthcare services. Future studies will assess its feasibility. The reactive messaging and additional materials delivered by the chatbot aim to support YP/YA T1DM medical, behavioural, and emotional self-management by increasing users:

1. Capability–through information and feedback on goal setting and achievement.
2. Opportunity–through educational and training content and self-management prompts so that YP/YA can become more aware of opportunities.
3. Motivation–through motivational messages offering support, encouragement, empathy, and affirmation.

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Ethical considerations

The study was ethically approved by the NHS Research Ethics Committee (IRAS Reference:292053) and the Lead NHS Trust Research and Innovation Department approved this study.

Consent to participate

All participants aged 16 years and above provided informed written consent via a signed electronic consent form. For participants aged 11–15 years, the parent/legal guardian of the YP was asked to provide informed written consent and asked to sign an electronic consent form. YP aged 11–15 years were asked to sign an electronic assent form to confirm that they were interested in taking part in the research.

Consent for publication

Consent for publication is not applicable to this article as it does not contain any identifiable data

Author contributions

PD conceived and planned the study with input from MJ, VS, FC, AS, RZ, and AR. **AR** designed Interview and Focus Group schedules. **JO, JH and VS** undertook the data collection. **AR, JH and VS** analysed the data. **MJ and RJ** led the digital development. **AR, LS** drafted the article and **PD, JH, JB, FC, MJ,**

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Data availability statement

Data access will remain with the current research team due to ethical approval restrictions. Participants consented to the use of brief anonymised excerpts from their data to be included in reports and publications.

Supplemental material

Supplemental material for this article is available online.

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