# Connected Health And Telemedicine

# **Original Research Article**



# A qualitative study for co-designing the future of technology to support physical activity for adolescents living with type 1 diabetes

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# Abstract

**Aim:** The aims of this study were to (i) understand what adolescents (and their parents) identify as positive and negative experiences with technology for engaging in physical activity (PA) when living with type 1 diabetes (T1D) and (ii) identify possible future design considerations for supporting or enabling technologies for this population.

**Methods:** Nine online collaborative workshops (n = 25 people) were held over a month with participants who were either adolescents attending with (n = 22) or without (n = 3, aged 16 and over) parents. Each workshop involved (1) a training activity, (2) a design task involving describing a good day vs. a bad day, and (3) a design task asking people to consider future design changes for technology to support them in engaging with physical activity.

**Results:** The following key themes emerged from the first design task: (1) Wearable factors; (2) Social acceptance & identity; (3) Negative emotions; (4) Glycaemic stability offers positive emotions and PA Enjoyment; and (5) Presence, preparation & prevention. The second design task identified the following additional key themes: (6) Improve attachment experiences; (7) Connected devices reduce user burden; (8) Improve accuracy; (9) Personalisation of devices; (10) Funding and policy changes – health equity.



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**Conclusion:** Technology can reduce the burden and improve PA support, but there are still gaps in how these technologies can be better designed to consider the psychosocial and emotional factors of both adolescents and their parents as co-users.

Keywords: Type 1 diabetes, technology, adolescent, co-design, digital health, user-centred design

# INTRODUCTION

Type 1 diabetes (T1D) is a serious life-long, life-threatening autoimmune condition<sup>[1]</sup>. Physical complications and acute medical requirements can be complex. Technologies and interventions are being developed which reduce the human burden and support self-management behaviours. Over 400,000 people currently live with T1D in the UK, and over 10% of these are under the age of  $19^{[1]}$ .

A diagnosis of T1D in youth is known to be accompanied by deteriorations in mood and mental health<sup>[2]</sup>. Depression in youth living with T1D is known to be double that of reported data from the general population<sup>[3]</sup>. Adolescents often share the burden of self-management of their condition with parents/ caregivers while navigating their journey to independence and young adulthood<sup>[4]</sup>. There is evidence that Physical Activity (PA) can improve physical and psychological well-being<sup>[5-7]</sup>. However, research still shows that many fears are associated with the fear of hypoglycaemia<sup>[8]</sup>. There is also a lack of understanding of how technology can be best used to support PA among adolescents with T1D<sup>[6,7,9]</sup>.

Traditionally, medical provision has been perceived as being more passive and can result in a disempowered patient experience<sup>[10,11]</sup>. This can also result in disengaged adolescents who do not attend clinics or other health service appointments. Currently, many adolescents living with T1D generate their own health data (for example, glucose information) using diabetes technology<sup>[12,13]</sup>. The availability of this data could enable adolescents to critically interpret and evaluate their health and well-being. This shift towards person-centred and user-driven data can also lead to better shared decision making and treatment. Adolescents often wear technology on the skin, and experience alarms, vibrations, skin irritation and interruptions to their daily routines, including during PA participation.

Empowering patients to share their ideas for change offers agency in health and care. Co-design practices with people living with T1D - especially adolescents, could help improve self-esteem and confidence<sup>[14]</sup>. Collaborative arts-based participatory methods, which position the adolescent and their parents/caregivers as "insider-experts", have been used successfully in research<sup>[15]</sup>. Direct benefits include translatable, acceptable, and culturally relevant research for the youth population and indirect benefits include a sense of empowerment and ownership. Self-management is considered a core strategy in coping with this lifelong, life-threatening autoimmune condition<sup>[16]</sup>. Similar to experience labs, whereby participants use design tools to identify and voice their needs, using online virtual whiteboard space can create an environment that supports participation and collaboration<sup>[17]</sup>. Using collective discussion and co-design to prompt out-of-thebox, or divergent thinking towards future change is often considered as an ethical approach when interviewing adolescents and their parents<sup>[18,19]</sup>.

This study invited participants to use creative and innovative design thinking tools to identify what needs to change between present technology and preferred future technology in the context of engagement with PA while living with T1D.

#### **METHODS**

The study was approved through University departmental ethics (ID 1086).

#### Participants and recruitment

Adolescents living with T1D and their primary caregiver/parent(s) were invited to participate in an online design workshop. Participants were recruited through email after taking part in a pre-selection criteria survey. Eligibility criteria were established via a self-reported online survey to establish the diagnosis of T1D, age of participants, technology literacy and access. Participants were made aware that to take part, they must currently use technology for T1D and/or PA.

Recruitment adverts were posted on social media (Facebook and Twitter), using targeted hashtags, including #T1D and #gbdoc. Inclusion criteria included adolescents aged 10-18 + years, diagnosed with T1D, residing in the U.K., able to read and write in English and have access to the internet for the online workshop. The participant information sheet and consent form were emailed to participants, and electronic signatures of consent as opt-in were gathered. For adolescents under the age of 16, a parent was invited to accompany them for online security and safeguarding purposes.

#### Design

This was a qualitative study designed using participatory research methods involving user-centred design approaches and design thinking tools. The design of the participant activities is described in Table 1, including the time allocated. The timing of tasks was piloted with researchers and lay people before conducting the workshop sessions with participants. Included in the pilot trials were people who had never used the software to allow for a thorough investigation of barriers to use.

Experience mapping and Rose, Thorn, Bud tasks (https://conceptboard.com/blog/design-thinking-tools-activities/) were developed using online whiteboard software called MURAL (www.mural.co). MURAL was used in this study as it is a freely accessible tool that facilitates interactions during collaborative participatory research and is remotely accessed<sup>[20]</sup>. Using the Rose, Thorn, Bud design tool, bud data (ideas relating to technological change) were dragged onto a prioritisation grid using Must Have, Should Have, Could Have, and Won't Have (MoSCoW) methodology [see Table 2].

A total of 9 workshops were conducted with a maximum of 6 people each<sup>[21]</sup>. Participant age was considered when grouping people together. Older adolescents who attended without parents were often grouped together. The researcher was sensitive to age-specific details when inviting younger adolescents (10-13 years) to the workshop. Two workshops were held as one-to-one with the researcher due to parent requests and a cancellation.

#### Workshop procedures

Nine design workshops were held over a one-month period with participants who were either adolescents attending without parents (16 years and over) or adolescents and parents together (n = 25).

The first whiteboard activity was a training session for the participants in the use of the software and to introduce icebreakers for relationship building and trust. Initial warm-up and welcome exercises provided space and time for co-design practices to form. After a break period, participants were then welcomed to whiteboard activity 2. In whiteboard activity 2, swim lane prompts, and "before, during and after" areas helped participants understand research question 1: What current experiences do adolescents and parents identify as important (both positive and negative) with technology when engaging in physical activity?

Information Gathering		Activity 2 (MURAL board 2)	Activity 3 (MURAL board 3)
What?	Whiteboard title: "Welcome and warm up"	Whiteboard title: "Experiences - Bad day vs. Good Day": Activity type - Experience mapping. Participants map	Whiteboard title: "Room 101"
	Introduction to MURAL activity Time allocated: 20 min	as "Bad day" vs. "Good day" in terms of PA with T1D and technology. Time allocated: 30-35 min	Activity type - Rose, Thorn, Bud, and MoScoW) to illustrate potential features of technology for supporting PA in T1D. Time allocated: 30-35 min
Why?	To induce engagement and introduce; ice breaker tasks grounding in the research aim	To help participants to think about their own experiences, open discussion, deepen participants' understanding of the driving forces, and connections and relationships between tech interactions, and PA engagement (Identify current challenges and opportunities) before talking about the future	Identifying socio-technical needs and requirements for PA engagement in the future (identify what needs to change between the present and the preferred future)

#### Table 1. Design of whiteboard activities

#### Table 2. Data examples collected using the MoSCoW prioritization tool

Must have	Should have	Could have	Won't have
"Would like pump to be lighter/slimmer"	"Improve to reduce delay between devices"		
"Can be inaccurate"	"Delay in reacting to hypos - end up overtreating"		
"Dexcom app alerts with BG numbers"	"If my watch could display constant BG"		
	"Lag in sensing LOW BG changes"		
	"be good to have watch link to CGM"		
"When alarms don't give your BG numbers"			

Finally, to facilitate creating constructs of the future, divergent thinking design tools were used in whiteboard activity 3 using visual prompts of current technology [see Table 1]. These prompts helped participants to answer research question 2: What do adolescents and parents construct and illustrate as potential design considerations (social and technical) with regards to digital/technology support for engaging in physical activity when living with type 1 diabetes?

#### Data collection and analysis

Data collection was facilitated through a group/collaborative approach with images and text using MURAL [see Table 2 for data excerpt examples]. Workshops were hosted by the lead author, who has lived experience of parenting a child with T1D. This tacit knowledge and having a dual position helped to expand and strengthen critical analysis of the data alongside literature reviewing.

On all whiteboards, participants were encouraged to add opinions and experiences via post-it notes and/or images for each timed task. Investigative questions allowed the researcher to prompt discussion and initiate participant self-reflective thinking during data collection. After completion, PDF file formats of the whiteboard were immediately transferred to a secure University password-protected server location. Audio discussions (during workshop sessions) were recorded with consent for transcription. No participant video data was captured or recorded, and only whiteboard data was imported for analysis. One interview provided by two male adolescents, both aged 16, with their mothers present, was not recorded due to human error. Researcher field notes were taken using journal methods.

During workshops, a chat function was enabled between the researcher and participants for ease of communicating one-to-one should sensitive issues arise. Participants were not able to use the chat function between each other for safeguarding. Participants were also made aware that the researcher would be taking

written field notes to help with analysis which would not include any personal identifiable information.

Reflexive thematic analysis began with the sole researcher's familiarisation with data, included reading and labelling data (MURAL board data and interview transcript data) with highlighter pens<sup>[22]</sup>. Data from online whiteboards was transferred to physical post-it notes to organise and group data. Informal note taking (similar to a scientific lab logbook) during interviews was performed to supplement audio recordings; these notes were taken to assist with analysis<sup>[23]</sup>. Table 2 below provides an informative layout of data excerpts from whiteboard activity 3 - Rose, Thorn, Bud using the MoSCoW prioritization design tool. Bud data was representative of the technological changes an adolescent would like to see happening in the future.

Transcription of verbatim audio interview data was carried out by the lead author. Revisiting the data in several iterations was carried out, with time away for reflection and review. This was conducted until iterations concluded central core concepts in the data, and no new themes were found<sup>[22]</sup>. This approach is termed inductive. Grounded analysis of the data allowed the researcher to be recursive in approaches to iterate between reading, reflecting, wondering and critically questioning by visiting the data repeatedly<sup>[23]</sup>. Regarding reflexive thematic analysis, the process requires positioning from the research study on the chosen epistemology, ontology, and assumptions. This study is underpinned by the fact that the technique was creative and explorative from a realist epistemological viewpoint. The assumption is that adolescents would enjoy being creative in a sensitive, emotional context in relation to their health. Ontologically, the study was designed to create new data from participants' world view in the way that co-design allows agency and voice to be central to the generation of novel findings.

During the first cycle of data coding in response to the research question, the underlying ideology was concerned with - what is this data about? Notes and characterisations of the data followed this line of interpretation. During the second cycle of data coding in response to the second research question, the underlying ideology focused on the latent meaning in the data - is it possible to categorise the initial codes? Finally, third cycle data processing and coding was directed by the underlying ideology - Can I look for patterns and relationships within all categories to determine if a central concept is driving the data into a higher-level theme? This process is shown in Figure 1 with examples of post-it notes data and interview transcript:Data were coded and analysed by the lead author. This was discussed with the research team, using several data examples of the above coding structure in line with methodology published by Braun, Clarke<sup>[22]</sup>.

# RESULTS

Out of 88 responses to the recruitment survey, 25 people agreed to take part. Table 3 shows details of the participants who took part.

The average age of the adolescents was 14.07 years (SD 2.26), and years since diagnosis were 5.07 years (SD2.69). Most participants were residing in Scotland, UK, with only one parent and adolescent from England, UK. As participants were recruited from social media, it was not evident if they knew each other. Reflexive thematic analysis of the data generated themes relating to whiteboards 2 and 3. Whiteboard 1 was designed to train the participants in the use of the software. No data was collected for analysis from this board. Each whiteboard were analysed to answer each of the research questions. The results section includes a discussion of results in alignment with themes.

Participant description	Adolescent age	Age at diagnosis	N
Female	18	16	1
Mother & son	12	10	2
Mother & daughter	14	10	2
Mother & son	11	8	2
Mother & daughter	13	3	2
Mother & daughter	13	12	2
Mother & son	11	4	2
Female	17	12	1
Female	16	12	1
Mother & daughter	13	8	2
Mother & son	16	10	2
Mother & son	16	10	2
Mother & daughter	12	7	2
Mother & daughter	15	11	2

#### **Table 3. Participant descriptions**

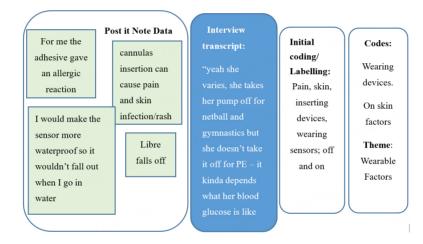


Figure 1. Generating theme 1: Wearable factors: Data analysis process example. Showing stages of labelling and data examples involved in the interpretation of the theme.

# Research question 1: what current experiences do adolescents and parents identify as important (both positive and negative) with technology when engaging in physical activity? [MURAL Activity 2, see Table 1]

Data was interpreted to generate the following five themes: (1) Wearable factors; (2) Social acceptance & identity; (3) Negative emotions; (4) Glycaemic stability offers positive emotions and PA enjoyment; (5) Presence, preparation & prevention. Whiteboard data analysis was supplemented by also using interview transcript data. Results are presented below with a discussion on theme interpretation.

#### Theme 1: wearable factors

Narrative typed on post-it notes referred to wearing technology with respect to cannula issues "*dodgy cannula*", and the impending glycaemic variation due to this wearable device. Frequent mentions of carrying around equipment and wearing technology physically on the skin produced factors involving skin irritation, pain, adhesion issues and visibility of diabetes. Participants' experiences on a bad day reported frequent, heavy interaction, with a narrative reflecting a sense of overwhelm and constant demand. Paradoxically, on a good day, participants reported that less interaction with technology felt like a positive

experience. This data was interpreted to reflect similarities known in research topics such as alarm fatigue, user burden, and diabetes distress <sup>[24-26]</sup>.

#### Excerpt:

"We've had a few dodgy cannulas going into swimming pools, coming off and issues with that. Tired because even highs do the same thing as well, because he's been active, and maybe there's a treatment and then he's high and then he gets grumpy (asks teen – teen agrees). So, there can be definite mood changes as well. And yeah, definitely at nighttime like what [anon] said, then you're left maybe 24 / 48 h afterwards then you're left having to deal with the consequences of that technology and that exercise. So, you end up having to put on temp basals during the day and it changes everything really, and you're having to try and figure out everything the next day and what's going to happen with it all." Participant ID15.

#### Theme 2: social acceptance & identity

This theme relates to identity factors when using technology in public spaces and the related emotional effects experienced by participants. Participants felt that managing T1D and PA in front of others might induce unwanted questions and societal influence. Discretion of devices and choices to scan and view data on Smartphones was one way in which adolescents felt they could cope with technology interactions that they perceived affected their identity.

#### Excerpt:

"It's so irritating... sometimes when I'm at college I'm getting my pen and it's fiddly and I'm trying to inject under the table, I don't want everyone to look, if I'm in a lecture, I don't want to be the centre of attention. Also, if I'm wearing a long sleeve t-shirt, I have to do my belly. It's awkward to inject. You get to college, and you've realised you're wearing tights and long sleeves and there's nowhere to inject and it's so awkward." Participant ID 16.

#### Theme 3: negative emotions

Participants used post-it notes to convey emotional language such as "grumpy, frustrated, annoyed, stressful" etc. in the "Bad Day" area of the whiteboard. A collaborative submission between a parent and a male participant aged 13 (diagnosed at age 10) provided this data in the excerpt. Experiences related to negative emotions were provided using post-it note text, and imagery. This included negative emotions in relation to using smartphone apps, scanning glucose with devices such as Freestyle Libre, and having to carry equipment. Participants often reported frustration when technology failures occurred either before, during, and/or after PA. This troubleshooting with technical issues caused participants to experience interruption when having fun participating in PA or impeding their PA completely.

#### Excerpt:

"I actually found that quite interesting talking with H there. I thought he was being objectionable, but he really wasn't (laughs). So, he always wasn't (laughs). So, he always has to have the equipment on him and do the carbs before and after and all that stuff, but when he was talking about his feelings he's fed up before he does any exercise because he knows he needs to prepare and for what he's going to do." Participant ID 11 (parent).

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# Theme 4: glycaemic stability offers positive emotions and PA enjoyment

When discussing experiences as "good and bad", participants often reflected that the comparison, for them, between good and bad relates to the stability of blood glucose. The excerpt example provided was taken from a female participant aged 12, diagnosed at age 7 years. This participant spoke of enjoying PA and feeling positive emotions when glucose remained stable before, during, and after PA. Happiness was the emotional word choice used on the whiteboard, which the participant described as often felt before PA. The participant wanted to show that on a bad day, they start off feeling "happy" - in relation to their love of PA. However, as the day progresses, the participant offers data relating to a decline in mood, blood glucose variability, and negative emotions. Moving onto the good day area of the whiteboard, this participant (and many others) populated post-it notes and images to suggest happiness, restfulness, and peace of mind, all in relation to stable blood glucose.

# Excerpt:

"So, I enjoy being active! I usually have lunch first, then I have activity. It might be that my insulin set falls off, and the Libre falls (sighs) and then I go hypo, and then afterwards, I go up. But then I go back down.

(mum) ...normally all our sporty mishaps have been when there's been too much active insulin on board, so it's that unannounced activity, it's that, jumping on a trampoline at a friend's house or whatever erm that just sets things, and it kinda ruins the fun because it's, yeah, it ruins the fun." Participant ID 29.

# Theme 5: presence, preparation & prevention

This theme represents reports of experiences in predicting, preventing, and organising practical aspects of self-management. The effects of PA on glycaemia were aligned with these tasks. Participants reflected on aiming to be proactive and preparing for PA. They also shared experiences of the paradoxical effects of not being prepared. When PA was unannounced or spontaneous, the participants experienced negative emotions, and felt a sense of greater glucose variability. In the excerpt (female age 17, diagnosed at age 5), participant data provides evidence of positive emotional experiences when participants felt able to be present and prepared for PA.

Awareness of the somatic sensations of the body's glucose levels was discussed by some participants in the study. A sense that when one is aware of how they physically feel, either before, during, or after activity, this can act as a felt sense to prompt interaction with technology to adjust the insulin dose. In this space of cognisance, participants spoke of the need to be prepared for PA and the paradoxical experiences which follow consequently when awareness is absent (hypoglycaemic unawareness), or PA is unplanned.

The negative emotional effects felt in congruence with this were a sense that spontaneity was not achievable without life risk. In some data, participants spoke of positive emotions when they had prepared their equipment and medication with enough time to be active. This data captures direct new insights into the effects of temporal considerations with awareness. Questions that participants ask themselves to predict a safe experience. One parent participant expressed a sense of guilt in not predicting well enough to reduce risk "*pressure to get it right for child*" (typed on a post-it note on the Bad day area of MURAL board 2). On the same board, the same participant spoke of "predicting" and "worrying" at night after a day of PA. In contrast with this, the participant expressed a feeling of "peace of mind" in the Good day area of MURAL board 2. This emotive reflection of the awareness, prediction, and prevention of risk was populated by some participants in their wish to communicate that current technology does not negate risk or worry. Furthermore, this participant's adolescent currently wears the most up-to-date closed-loop technology with

algorithm-controlled glucose sensor devices (Medtronic 780g with Guardian sensor 3 system).

#### Excerpt:

"probably that if you've done exercise that you have awareness to not take as much insulin because on a bad day you might have dismissed it, or not realised the effect of exercise on your bloods, and you've not decreased the insulin, because you didn't have awareness...like to say if you're prepared, you know what kind of activities you're going to be doing, so you know how to prepare, that's a good day and you can judge it." Participant ID 7.

# Research question 2: what do adolescents and parents construct and illustrate as potential design considerations (social and technical) with regards to digital/technology support for engaging in physical activity when living with type 1 diabetes? [MURAL Activity 3, see Table 1]

In relation to research question 2, the data were interpreted to generate a further five themes: (6) Improve attachment experiences; (7) Connected devices reduce user burden; (8) Improve accuracy; (9) Personalisation of devices; (10) Funding and policy changes - health equity. Table 2 provides examples of completed whiteboard data in relation to theme 8.

#### *Theme 6: improve attachment experiences*

Many participants experienced barriers related to "wearable factors". Regarding wearable factors, this participant expressed a desire for the adhesive to be changed on the Freestyle Libre device to prevent allergy. Many other participants reported issues related to skin experiences and attaching devices in situ. This data became the foundation for the theme Improve attachment experiences. In the audio transcript, it was shown that this barrier caused a following disengagement with technology due to skin irritation.

#### Excerpt:

"I had the Libre for a few months, and it was fine, but I started to get an allergic reaction to the adhesive, so I had to stop using it, which was so annoying, and it was a really bad allergic reaction - like my skin was so bad. And then I tried again a couple of months ago and the same thing happened, which is so annoying, and it was pain because I almost had a taste of like, how good it was and how easy it was and then they were like "no you can't have it because of how allergic I got with it" which was understandable but really annoying at the same time. For me it was really frustrating because I didn't have to pay anything on the NHS but all the other ones I would have to pay for and obviously for me they weren't really, I don't have the money every month for the Dexcom, but the only one available on the NHS is the one that I can't use. Because it's gonna be like a massive rash on my arm." Participant ID 16.

#### Theme 7: connected devices reduce user burden

Data from participants' experiences were interpreted to report barriers associated with many different interactions and different devices. This was interpreted as a fragmented experience (many different devices performing different tasks). There were reports of new technology that currently exists to offer a more streamlined experience. However, participants felt this area for development requires improvement in connectivity, with signal disruption being prevalent. Participants spoke of the connection of devices in terms of reducing burdens or making their lives easier.

Excerpt:

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"we were talking about insulin pumps – we were saying they're good but they still do need a lot of, they need a lot of input and interactions from the users and erm in an ideal world we would love something like the iLET which requires less user interaction, from our side, erm cause even with an insulin pump, you're constantly having to make adjustments, constantly having to enter carbs and connect with other things." Participant ID 15.

# Theme 8: improve accuracy

Participants who were using technology to quantify and communicate blood glucose levels found current technology to be inaccurate. Some participants prioritised this data as a "Must have" future change using the MoSCoW tool. The theme Improve accuracy reports a perceived sense that, although there is a range of glucose sensing devices, without connectivity features (to other devices) and trust, participants were still reverting to finger prick blood tests using a blood glucose meter (glucometer). This relates to MURAL whiteboard 2 "Experiences - Bad day Vs Good day" data where participants spoke of carrying equipment. On-skin technology, without accuracy, requires carrying equipment around to have a sense of trustworthy, fallback options when accuracy is compromised. Furthermore, this data also highlights a relationship between accuracy and negative emotions such as frustration and annoyance.

# Excerpt:

"Sometimes they'll show me I'm low and I'm not actually though, I'm like 5.0, I mean it's annoying, they're really good for a general sense of direction but, I still have to do a blood test." Participant ID 6.

# *Theme 9: personalisation of devices*

Utilising the Rose, Bud, Thorn tool, many participants pointed towards making a change to visual, sound, and alert functions of current technology. This created the basis for the theme Personalisation of devices. Descriptions of changing the size and weight were also reported "*smaller and tubeless* (pump)" [ID40]; "*would like pumps to be slimmer*" [ID6]; "make volume louder and connect by Bluetooth (BGM); if it was significantly smaller, he would think about it (Pump); ...*carrying about heavy tech, needs to be lighter* (pumps)" [ID11]. These were found to be personalisable attributes that appeared to be individual when looking across the data. For example, participants who used insulin pens offered data about changing the needle guard shape to accommodate the insulin pen lid when travelling or storing the pen in their bags. Experiences of technology that vibrates, alerts, and prompts were shared. Data also showed a desire for a change to a specific type of insulin pump. This pump was chosen because it was smaller than other pumps on the market. The participants expressed a feeling that it lacks important functions, which causes the participant considerable effort each day "*bolus calculator not on pump and takes longer to work out for food correction - would be good to have this on the pump* (pump)," participant ID 20.

#### Excerpt:

"The annoying thing about that pump is that fact that she's got to have her phone to type in carbs which is annoying, you know, if she was able to do boluses without having to, like she has to work it out on the phone but then has to type it out into the pump - yeah it's the bolus calculator." Participant ID 11.

#### Theme 10: funding and policy changes - health equity

Data representing participants' access to technology, and improvements to the cost of current options contributed to the generation of the final theme Funding and policy changes - health equity.

When participants had populated MURAL board 3 with their preferred future experiences with technology, many mentioned a lack of funding or access issues related to technology - "Don't use it as it isn't funded (Dexcom CGM)". They felt that if they did begin to self-fund technology, it would cause a health inequity and financial burden for their adolescent and others: "Better support for CGM technology, limited by price (CGM); government policy should change to allow hybrid closed loop (sensor & pump), would self-fund but when teen becomes independent - the cost may be a burden. Also got to fight for others!" Participant ID 48.

# DISCUSSION

This study involved the use of co-design with adolescents living with T1D and their parents as co-users of technology which is used to assist, treat, and monitor the condition. The intention behind the study was to use collaborative co-design methods to share experiences of T1D and PA and to identify future possibilities for the role of technology in this management. Working with families in a space where there are high emotions, life risks, and daily use of technology requires sensitivity, neutral positioning, and appropriate design prompts. Value was placed on person-centred approaches in health self-management in this study.

In terms of inclusion and representation, this study provides evidence that adolescents and families are capable of sharing their understanding and discussing the need to support PA through the use of assistive technology to monitor and manage T1D. The requirement for promoting PA in this population has been neglected for many years<sup>[7]</sup>. Participants' data in this study reflected if and how people currently interact with technology, which is sometimes worn on the skin, and carried in backpacks when out of the house. Frequent mentions of carrying around equipment and wearing technology physically on the skin revealed issues involving skin irritation, pain, adhesion issues and visibility of diabetes. Barriers in relation to "onbody" wearing of devices were voiced in line with previous research highlighting age-specific factors<sup>[26]</sup>. Participants' experiences on a bad day reported frequent, heavy interaction, reflecting a sense of being overwhelmed and placing constant demands on the user. On a good day, participants reported less interaction with technology felt like a positive experience. This is similar to other existing research which reports alarm fatigue, user burden, and diabetes distress<sup>[24-26]</sup>.

This study revealed that preparation, prevention strategies and pre-planning are important in the context of PA for people living with diabetes. Previous research also showed that spontaneity can be a barrier to meaningful PA in this population<sup>[27]</sup>. Further aligned with previous research, coping strategies to reduce life risk in PA, including overcompensation with glucose (pre-exercise), do not always provide safety from exercise-induced hypoglycaemia<sup>[28]</sup>. Therefore, with adolescent-specific groups, wearing technology and carrying around weighted items while managing life risk from the addition of PA introduces additional human burden and does not negate life risk. Frustration and negative emotion were key themes from this study, and people used language describing annoyance, inaccuracy of devices and data, multiple adjustments being required and a clear lack of enjoyment when engaging with PA when technology was involved. Although technology is moving towards reducing human burden, this was clearly not evident yet from the findings of this study<sup>[29]</sup>.

A strength of this study was the ability to facilitate meaningful participant discussion and sharing of real lived experience. The study confirms some of the findings from previous research but additionally shows that adolescents taking ownership and feeling heard throughout such design studies is essential. The online and collaborative design thinking methods used developed a space for agency for those living with T1D. Parents also reported that this was the first time they heard their child "open up" about some issues. We recommend that future research applies similar design approaches to this population and others managing conditions where technology is expected to continue to play a role in self-management.

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Our study showed that participants were able to share their comparison of good and bad days with T1D and PA through their interaction with technology. In response to research question 3.1 (*What current experiences do adolescents and parents identify as important (both positive and negative), with technology when engaging in physical activity?*), results showed a desire for changes to future digital technology to support PA for T1D. These ranged from psychosocial to technologically specific factors, i.e., support to process negative emotions linked to visibility of device usage in public spaces, to size, colour, weight, and connectivity with other devices. Imagery and metaphorical language were used by participants to discuss sensitive health issues which can cause distress, burden, and negative emotional experiences. Allowing parent involvement as co-users also gave inclusion to caregivers who often use technologies to share the health burden with adolescents living with T1D.

The lack of time to produce prototypes of devices was considered an area for future research. This may involve creating lo-fidelity models designed by adolescents and their caregivers through to prototypes, as discussed in MURAL activity 3 of this study. Furthermore, to represent more adolescents, a larger study would perhaps strengthen the argument for funding policy change in relation to technologies for supporting physical activity for this population.

In conclusion, the aim of this study was to understand what adolescents (and their parents) identify as positive and negative experiences with technology for engaging with PA when living with T1D, and to articulate shared meaning for actionable and appropriate future technology design. Technology currently has good intentions to reduce the burden of self-management of T1D. As the potential benefits of technology are realised, research must continue to look at issues relating to equity of access and potential barriers to the use of this technology. In terms of support for PA specifically, digital interventions also need to focus on psychosocial needs and connectivity, not only across devices, but also across the supporting human network.

# DECLARATIONS

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This paper is written from empirical research held through doctoral studies in which participants were kind enough to offer their lived experiences to progress academic understanding.

#### Authors' contributions

Made substantial contributions to the conception and design of the study and performed data analysis and interpretation: Morrow D, Kirk A, Lennon M, Muirhead F

Performed data acquisition, as well as provided administrative, technical, and material support: Morrow D, Kirk A, Lennon M, Muirhead F

# Availability of data and materials

Not applicable.

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# **Conflicts of interest**

All authors declared that there are no conflicts of interest.

#### Ethical approval and consent to participate

This research was conducted with written consent and approval from participants with ethical approval from the University of Strathclyde, Department of Computer and Information Sciences (Ethics ID 1086).

#### **Consent for publication**

Not applicable.

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