diabetesresearchandclinicalpractice 202 (2023) 110830

Contents lists available at ScienceDirect

Diabetes Research and Clinical Practice

journal homepage: www.journals.elsevier.com/diabetes-research-and-clinical-practice

"Empowering Us": A community-led survey of real-world perspectives of adults with type 1 diabetes using insulin pumps and continuous glucose monitoring to manage their glucose levels

Meaghan Read [a], Kim N. Henshaw [a], Dessi P. Zaharieva [a,b], Tim C. Brown [a,c], Andrea E. Varga [a], Christine Bray [a], Michelle Cox [a], Pär-Johan Goody-Rohdin [a], Kim Hider [a], Paul Jelleyman [a], Alicia Jenkins [d,e,f,g], Carolyn Jones [a], Peggy Kerr [a], Rob Leach [a], Kim Martin [a], Natalie Oreskovic [a], Grant O'Sullivan [a], Jasmin Rucioch [a], Catriona Sims [d], Carmel Smart [h,i], Jane Speight [j,k,l], Jamie Stanistreet [a], Michael Tippett [a], Ioaga Tivalu [a], Tania Withers [a], David N. O'Neal [d,e,f,*]

[a] Diabetes Victoria, Carlton, Victoria, Australia
[b] Division of Endocrinology, Department of Pediatrics, Stanford University School of Medicine, Stanford, CA, USA
[c] School of Mathematics, Monash University, Clayton, Victoria, Australia
[d] Department of Medicine, The University of Melbourne, Parkville, Victoria, Australia
[e] Department of Endocrinology, St Vincent's Hospital Melbourne, Victoria, Australia
[f] Australian Centre for Accelerating Diabetes Innovations, The University of Melbourne, Parkville, Victoria, Australia
[g] The Baker Heart and Diabetes Institute, Melbourne, Victoria, Australia
[h] John Hunter Children's Hospital, Newcastle, New South Wales, Australia
[i] School of Health Sciences, University of Newcastle, Newcastle, New South Wales, Australia
[j] School of Psychology, Institute of Health Transformation, Deakin University, Geelong, Victoria, Australia
[k] The Australian Centre for Behavioural Research in Diabetes, Diabetes Victoria, Carlton, Victoria, Australia
[l] Melbourne School of Population and Global Health, University of Melbourne, Victoria, Australia

ARTICLE INFO

Keywords:
Type 1 diabetes
Insulin pumps
Real time-continuous glucose monitoring
Intermittently scanned continuous glucose monitoring
Lived experience

ABSTRACT

Objective: To conduct an Australian community-led survey of adults with type 1 diabetes (T1D), identifying priorities for, and barriers to, optimal use of advanced glucose management technologies.
Research design and methods: A 30-question online survey of current or past users of insulin pump therapy (IPT), real-time continuous glucose monitoring (RT-CGM), or intermittently scanned CGM (isCGM) explored perceptions regarding device design, access, education, outcomes, and support.
Results: Between November 2021 and January 2022, surveys were completed by 3,380 participants (age [mean ± SD] 45 ± 16 years; 62% female; 20 ± 14 years diabetes), with 55%, 82%, and 55% reporting experience with IPT, RT-CGM, and isCGM, respectively. Overall, most considered diabetes technology '(extremely) important' for maintaining target glucose levels (98%) and reducing hypoglycaemia severity and frequency (93%). For most, technology contributed positively to emotional well-being (IPT 89%; RT-CGM 91%; isCGM 87%), which was associated with device effectiveness in maintaining glucose in range, comfort, and convenience. Barriers included affordability (IPT 68%; RT-CGM 81%; isCGM 69%) and insufficient information for informed choices about device suitability (IPT 39%; RT-CGM 41%; isCGM 36%).
Conclusions: Technology is perceived by adults with T1D as important for managing glycaemia and emotional well-being. Modifiable barriers to use include affordability, and information regarding device suitability.

* Corresponding author at: Department of Medicine, The University of Melbourne, Level 4, Daly Wing North, St Vincent's Hospital, 35 Victoria Pde, Fitzroy, Victoria 3065, Australia.
E-mail address: dno@unimelb.edu.au (D.N. O'Neal).

https://doi.org/10.1016/j.diabres.2023.110830
Received 6 June 2023; Received in revised form 9 July 2023; Accepted 12 July 2023
Available online 13 July 2023
0168-8227/© 2023 The Authors. Published by Elsevier B.V. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

1. Introduction

Optimising glucose management to minimise both acute and long-term complications is essential for the physical and emotional well-being of people with type 1 diabetes (T1D) [1]. Increasingly, technologies enable many living with this life-long condition to realise this goal. Commercially available technologies include insulin pump therapy (IPT), glucose sensors (real-time continuous glucose monitoring [RT-CGM] or intermittently scanned CGM [isCGM]), with some devices integrating IPT, CGM capabilities and a control algorithm as an automated insulin delivery (AID) system. Clinical trials, cohort studies, and clinical audits provide compelling evidence that technology use is associated with improvements in glucose levels [2–4].

Nevertheless, despite these advances, only 20% of adults with T1D have a HbA1c level in the recommended target range [5]. Furthermore, significant proportions of people with T1D continue to experience negative emotional well-being related to managing their condition, such as diabetes distress and fear of hypoglycaemia [6,7]. Contributing factors limiting the attainment of glycaemic targets and adversely impacting the emotional well-being of people with T1D may be shortcomings in the accessibility, affordability, and design of diabetes technologies.

The financial costs may act as a significant barrier. For example, in Australia, despite subsidy of pump consumables, insulin pumps are mainly used by those with T1D who have private health insurance or the financial means to self-fund a device. Also, until July 2022, CGM subsidies in Australia applied only to a minority of adults with T1D, such as children and adolescents, women seeking pregnancy, and pregnant women [8].

In addition, shortcomings in the device design have been associated with significant user dissatisfaction, and discontinuation [9–11]. Therefore, even those who have access to diabetes technologies may have suboptimal experiences, potentially increasing the likelihood that they will not meet glucose targets. Furthermore, regardless of whether glucose targets are met or not, technology use may also be associated with substantial user burden [12].

The views and preferences of people with T1D regarding matters of device access, device related education, and device design have not been surveyed to date. To understand these pertinent matters, it is important to engage with those living with T1D who have experience with such technologies, to ensure that relevant and appropriate questions are asked. This stakeholder engagement, and co-design of research, is increasingly recognised as best practice by people with lived experience, the research community and funding bodies [13–15]. A better understanding of barriers, needs and preferences of individuals with T1D is likely to improve the design, implementation, real-world effectiveness, and sustained use of these devices.

Therefore, we aimed to conduct a national online survey, codesigned by adults with T1D, seeking the perspectives of others with T1D who use or have used technology to manage their glucose levels regarding their priorities for, and barriers to, accessing, selecting, understanding and optimal use of their diabetes technologies.

2. Research design and methods

A community-led approach was used to develop, implement, and analyse the results of a cross-sectional survey to understand the experiences and needs of adults with T1D with current or prior experience of using at least one diabetes technology: IPT, RT-CGM and/or isCGM. Ethical approval was granted by the Human Research Ethics Committee of St Vincent's Hospital Melbourne (SVHM HREC LRR 266/21).

This project was led by an Expert Consumer Consultation Group (ECCG), supported by a project coordinator with lived experience and an Expert Reference Group (ERG). The ECCG included 13 adults with T1D who use diabetes technology and were living in seven of the eight Australian states/territories. The ECCG was recruited via an 'Expression of Interest' email distributed by Diabetes Victoria via the National Diabetes Services Scheme (NDSS). The NDSS is an initiative of the Australian Government administered with assistance from Diabetes Australia. Of the 110 adults with T1D who expressed interest in joining the ECCG, 13 were selected based on diversity of age, gender, geographical location, cultural background, level of education, duration of T1D, duration and type of diabetes technology use, work experience, and general education level. The ERG was comprised of a multidisciplinary group of 10 clinicians, researchers, and industry professionals, with expertise in endocrinology, diabetes nurse education, dietetics, and psychology. The ECCG's role was to lead the project in terms of survey aims and content, seeking input as required from the ERG. The ERG's role was to draw upon their professional experience and knowledge to provide guidance on research processes, and act as a resource to the ECCG.

2.1. Survey content and design

The ECCG identified survey themes relevant to technology use based on their own lived experience, and which they perceived as important to the wider T1D community. The survey themes identified were access, device design, emotional and mental health, lived experience, support, and training. Survey-specific instructions, questions, and response options were drafted by the ECCG and revised according to an iterative review process involving feedback from the ERG. The ECCG edited the survey questions to ensure relevance, appropriate and comprehensible language, and logical presentation. The ERG reviewed the survey items for technical accuracy, analytic utility, and content validity.

Before conducting the survey, a pilot study was performed. Twelve adults with T1D provided feedback on ease of completion, survey wording and functionality, and the time taken to complete the survey.

The final survey is included as an **Appendix**. Thirty study-specific questions covered topics of current technology use, perceived benefits for physical and emotional well-being, device design, access, information and training provision, and support needs. Respondents were also asked to self-report the following sociodemographic and clinical data: age, gender identity, cultural identity, language spoken at home, state, postcode of residence, type of diabetes, age at diabetes diagnosis, and awareness of hypoglycaemia (Gold score [16]).

2.2. Participants

Participants were eligible if they were adults (aged ≥18 years) with T1D, presently living in Australia, with current or prior experience of at least one of: IPT, RT-CGM or isCGM approved for use by the Australian Therapeutic Goods Administration (TGA).

2.3. Procedure

The online survey was live for eight weeks, from November 2021 to January 2022, and hosted via Qualtrics (Provo, Utah, 2021). A short, plain language description of the study was displayed on the survey landing page, with consent sought via a yes/no response. Next, those reporting to be under 18 years old or who indicated that they did not have T1D were excluded and only those who met the criteria for inclusion could continue to the main survey.

Potential respondents invited to participate in the survey were identified on the Australian NDSS database as having a diagnosis of T1D and who had consented to being approached to take part in research. The diagnosis would have been previously established by the individual's health care professional diabetes team and is usually determined on the basis of the person's clinical presentation in combination with a C-peptide level and antibody results. Three electronic direct mails (one email plus two reminder emails) containing a link to the online survey were distributed via the NDSS to all adults (aged ≥18 years) with T1D with a valid email address recorded in the NDSS registry, who had

previously consented to being contacted regarding research opportunities (n = 32,250). The ECCG designed the image and wording used in the email invitation and a complementary social media campaign to increase survey reach (via Facebook, Instagram, LinkedIn, and Twitter). Planned and organic sharing (via informal networks of people living with T1D) of these posts was observed in the diabetes online community.

2.4. Data analysis

Once closed, survey data were exported from Qualtrics into IBM SPSS version 28. 2021 (Armonk, NY) for cleaning and analysis. Descriptive statistics (frequency, percentage, and, where relevant, means) were calculated for all survey variables. Data were imported from SPSS into R version 4.3.0 for analysis using the tidyverse, MASS, and gtsummary packages. Priorities identified for analysis included access, information provision, and well-being associated with technology use. Comparisons were made using Fisher's exact test used for chi-square analysis, and proportional odds logistic regression. To examine the effect of the survey responses for the three technologies on emotional well-being, a proportional odds logistic regression was conducted. Given the large number of potential predictor variables for each regression, stepwise regression using the Aikake Information Criterion was conducted to minimise the chances of overfitting. The base model only contained the variable "effective at keeping glucose in range". Survey responses were included in the logistic regressions only if the responder had data on all the predictor variables and emotional well-being. Statistical significance was taken at $p < 0.05$. The results of the regressions are summarised as odds ratios with confidence intervals The variables included were selected by stepwise regressions with only those coefficients which were statistically significant reported.

3. Results

There was a total of 4,933 surveys commenced of which 3,726 were completed. Of these, with duplicate responses excluded, there were 3,380 eligible adults with T1D who provided consent. (**Supplementary Figure 1**). Participant characteristics are provided in Table 1. The mean ± SD age was 44 ± 15 years, the majority (62%) identified as female, with an average of 20 ± 14 years living with T1D. Current or past use of IPT, RT-CGM, or isCGM was reported by 1,845 (54.6%), 2741(81.1%), and 1,853 (54.8%) respectively. RT-CGM were used as either standalone devices or in conjunction with IPT. All IPT use was supported by private health insurance or self-funded. A CGM subsidy by the Australian government at the time the survey was conducted supported 1,157 (34.2%) of those using CGM.

3.1. Perceived benefits of device use

Considering diabetes technologies in general, most respondents (98.3%) indicated that technology was "important" or "extremely important" in keeping their glucose levels in target range and reducing both the severity and frequency of hypoglycaemia (92.7%). Technology was also perceived as "important" or "extremely important" for maintaining happiness (88.3%), facilitating physical activity (86.7%), socialising with friends (76.3%), and for dietary freedom (73.1%) (Fig. 1).

For each class of device (IPT, RT-CGM and isCGM) over 85% of respondents indicated that their emotional well-being was "better" or "much better" since using the device with less than 5% indicating it was "worse" or "much worse" and the remainder indicating that "it made no difference". A greater proportion of people reported that their emotional well-being was "much better" with IPT (70.7%) and RT-CGM (75.7%) than with isCGM (58.0%) (Fig. 2**).**

Table 1
Respondent characteristics. Data are mean (SD) or n (%).

Characteristics	All participants N = 3380
Age*, years	44.5 (15.5)
Gender, n (%)	
Woman	2,093 (61.9)
Man	1,263 (37.4)
Non-binary	15 (0.4)
Queer/genderfluid	3 (0.1)
Prefer not to answer	6 (0.2)
State or Territory, n (%)	
Australian Capital Territory	101 (3.0)
New South Wales	911 (27.0)
Northern Territory	15 (0.4)
Queensland	767 (22.7)
South Australia	209 (6.2)
Tasmania	102 (3.0)
Victoria	928 (27.5)
Western Australia	347 (10.3)
Aboriginal and/or Torres Strait Islander, n (%)	59 (1.7)
Language other than English at home, n (%)	72 (2.1)
Duration of Type 1 Diabetes (years)	20 (14)
Current device use, n (%)	
IPT	1,700 (56.2)
RT-CGM	2,152 (67.7)
isCGM	872 (30.5)
Past device experience, n (%)	
IPT	145 (4.8)
RT-CGM	589 (18.5)
isCGM	981 (34.3)
Gold score[a], mean (SD)	2.7 (1.5)
Impaired awareness of hypoglycaemia (Gold score ≥ 4)	871 (25.8)

*Missing n = 5. [a.] Scoring range: 1–7, where 1 = always aware and 7 = never aware.
Insulin pump therapy (IPT); Real time-continuous glucose monitoring (RT-CGM); Intermittently scanned continuous glucose monitoring (isCGM).
Current or past use of IPT, RT-CGM, or isCGM was reported by 1,845 (54.3%), 2,741(81.1%), and 1,853 (54.8%) respectively.

3.2. Device design

For each class of device (IPT, RT-CGM, and isCGM), most respondents indicated that the devices were "convenient", "reliable", "easy to use", and "effective in keeping my glucose levels in target range". Most found RT-CGM (66.3%), and isCGM (69.8%) "comfortable to wear"' while the majority of IPT users did not find their device comfortable, with only 40.2% agreeing with this statement (Fig. 3).

3.3. Device affordability

For each class of device (IPT, RT-CGM, and isCGM), less than 20% of respondents indicated that their device was "affordable" with over two-thirds in each category strongly disagreeing (Fig. 3).

3.3.1. Information for device selection and training in device use

In response to "Do you feel there is enough information publicly available to make an informed choice about using the following diabetes technologies?", over 33% of respondents in each category of device answered "no" (Fig. 4 **[a]**). In response to "Were you able to access sufficient education and training when you first started using the following diabetes technologies?", more than 80% of respondents answered "yes" for IPT and RT-CGM and more than 70% for isCGM (Fig. 4 **[b]**).

Information perceived by respondents as being required to support technology use included knowledge related to device operation, understanding the data provided in real-time and retrospectively, and how to adjust insulin delivery to optimise glucose levels (**Supplementary** Fig. 2). Regarding the model for technology training provision most preferred face-to-face, self-paced online modules, or a combination

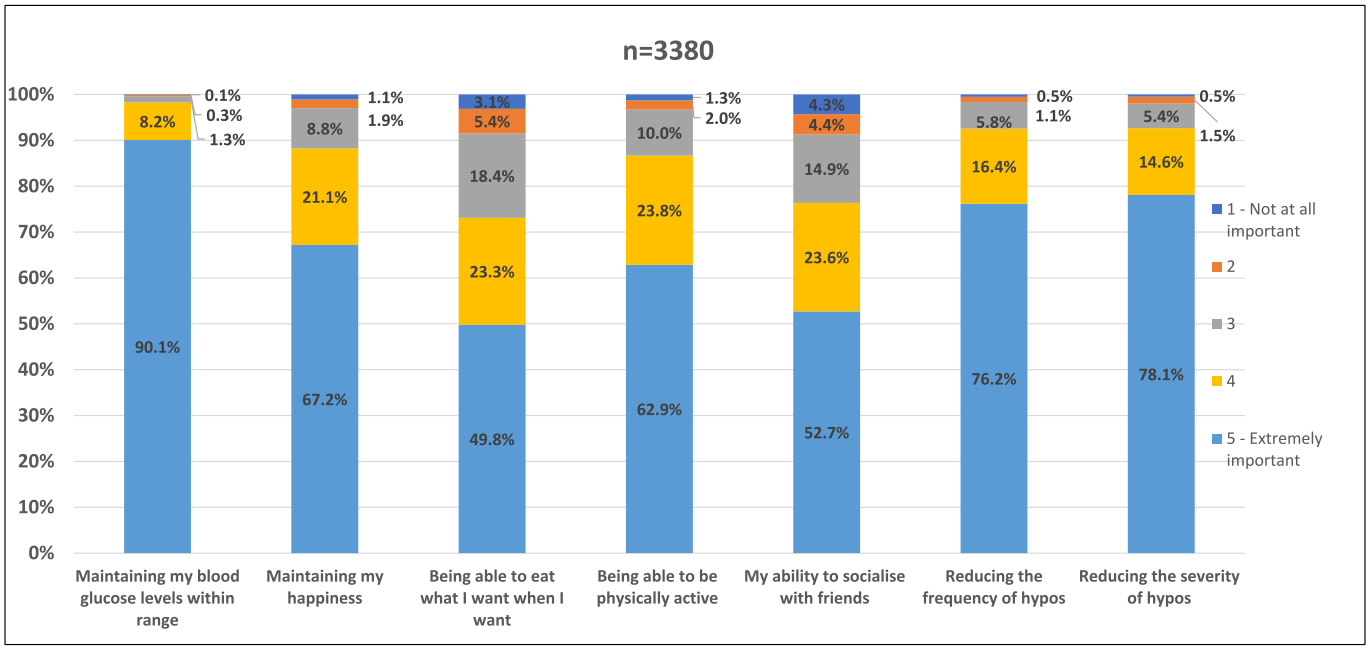


Fig. 1. Factors important in using technology for people with T1D who have experience in using these devices (any one or more of insulin pump therapy [IPT], real time continuous glucose monitoring [RT-CGM], and intermittently scanned glucose monitoring [isCGM]).

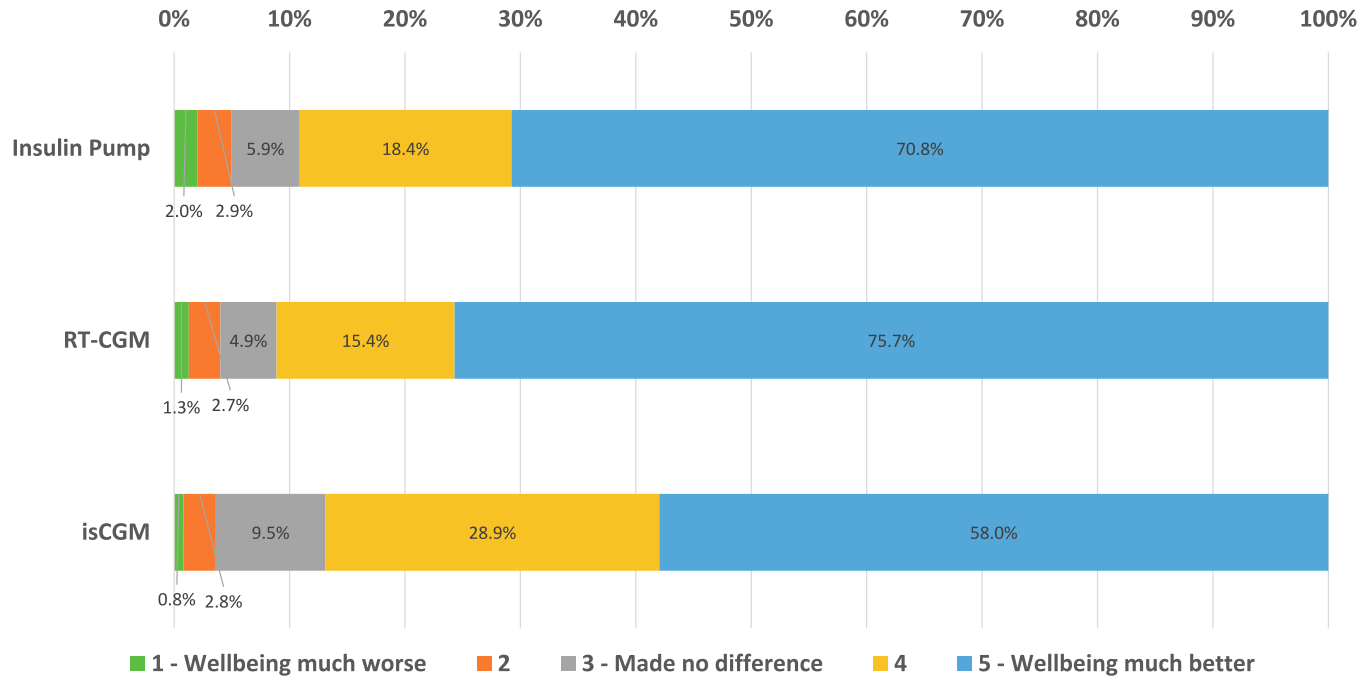


Fig. 2. Responses to the question "What differences have insulin pump therapy (IPT), real time-continuous glucose monitoring (RT-CGM), and intermittently scanned continuous glucose monitoring (isCGM) had on your well-being?" by those currently using or with previous experience in the use of these devices.

thereof (**Supplementary Table 1**). Individuals considered to be suitable for providing such training and education when starting a new technology were diabetes nurse educators (87.1%), people living with diabetes who use the technology (64.0%), and endocrinologists (52.0%). Less than half expressed a preference for industry professionals (46.1%), and far fewer endorsed training by general practitioners (13.8%), pharmacy staff (9.9%), and dietitians (6.8%).

3.4. Current vs. past device use

Comparisons were made between current and past users for each class of device.

Of current (n = 1,624) IPT users who responded to the question, 93% (n = 1,516) reported that their emotional well-being was "better" or "much better" while using IPT compared with 44% (n = 56) of past users (n = 129) while 2% (n = 22) and 40% (n = 51) respectively stated that their emotional well-being was "worse" or "much worse" ($p < 0.001$). Regarding information provision when choosing a pump, 56% (n = 906)

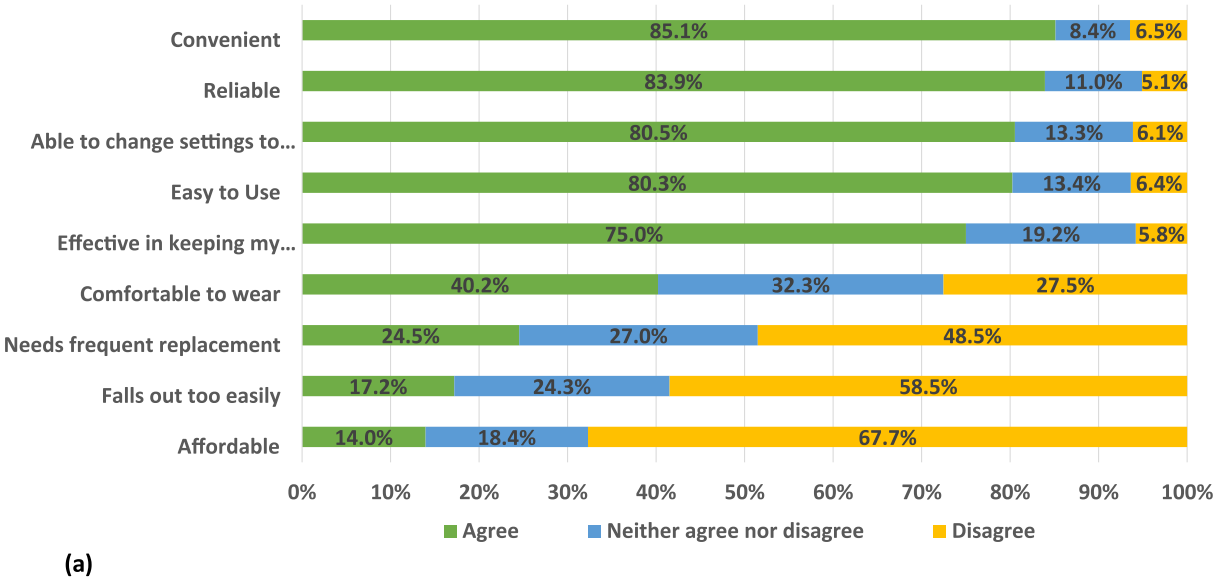


Fig. 3. Responses to questions relating to device design and affordability for **(a)** Insulin pump therapy (IPT); **(b)** Real time-CGM (RT-CGM); **(c)** intermittently scanned glucose monitoring (isCGM) by those currently using or with previous experience in the use of these devices.

of current IPT users did "agree" vs. 41% (n = 53) of past users that information provision was adequate (p = 0.004). Of current IPT users, 91% (n = 1483) vs. 80% (n = 103) of past users reported that they had received sufficient education and training when commencing IPT (p < 0.001) (**Supplementary Table 2**).

Of current (n = 2,038) RT-CGM users who responded to the question, 94% (n = 1,993) reported that their emotional well-being was "better" or "much better" while on RT-CGM, compared with 78% (n = 411) of past users (n = 526), while 2% (n = 35) and 11% (n = 56) respectively stated their emotional well-being was "worse" or "much worse" (p < 0.001). Regarding information provision when choosing an RT-CGM device, 51% (n = 1,041) of current RT-CGM users vs. 45% (n = -238) of past users agreed that information provision was adequate when choosing a device (p = 0.06; ns). Of current RT-CGM users, 86% (n = 1,749) vs. 81% of past users (n = 424) reported that they had received sufficient education and training when commencing RT-CGM (p = 0.023) (**Supplementary Table 3**).

Of current (n = 764) isCGM users who responded to the question, 93% (n = 708) reported that their emotional well-being was "better" or "much better" while using isCGM, compared with 82% (n = 663) of past users (n = 805), while 2% (n = 15) and 5% (n = 41) respectively stated their emotional well-being was "worse" or "much worse" (p < 0.001). Regarding information provision when choosing an isCGM device, 57% (n = 438) of current isCGM users vs. 50% (n = 406) of past users agreed that information provision was adequate when choosing a device (p = 0.022). Of current isCGM users, 79% (n = 602) vs. 76% (n = 612) of past users reported that they had received sufficient education and training when commencing isCGM (p = 0.4; ns) (**Supplementary Table 4**).

3.5. Device attributable emotional well-being

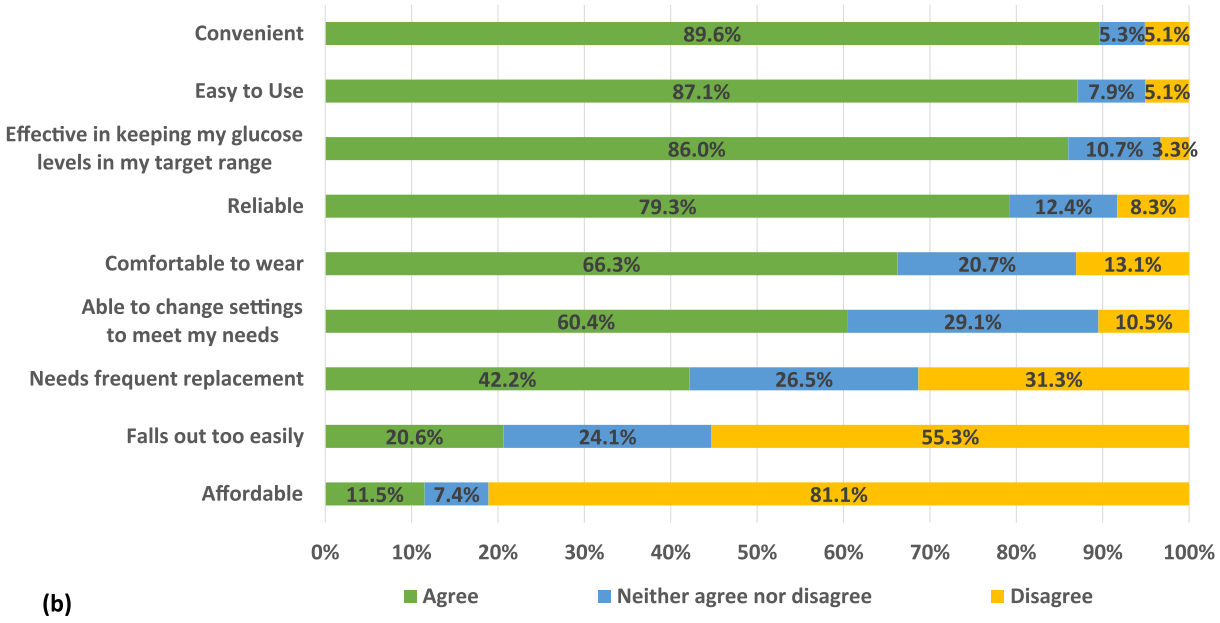
Given that current and past users of technology had differing overall distributions on the ordinal scale of emotional well-being attributable to device use from "well-being much worse (1)" to "well-being much better (5)", separate examinations for each of the three technologies regarding the relationship of emotional well-being to other survey responses were conducted. (**Supplementary Table 5**). Greater well-being attributable to the device was associated with reporting the device as "effective in keeping blood glucose in range" and "comfortable to wear", for both current and past use of all three technologies. Greater "convenience" was associated with greater device-attributable emotional well-being, with current and past use of all three technologies, except for past IPT users. Responses supporting "ease of use" were associated with greater device-attributable emotional well-being with past use of all three technologies and for current users of IPT. Responses supporting "being able to change settings to meet my needs" were associated with greater device-attributable emotional well-being for current use of RT-CGM and isCGM. Responses indicating that the devices were not affordable were associated with greater emotional well-being attributed to device use for past users of IPT and RT-CGM.

4. Discussion

We report the results of an Australian nationwide community-led survey of 3,380 adults with lived experience of T1D and current or past experience with IPT, RT-CGM, and/or isCGM. To the best of our knowledge, this is the first such large population-based survey, designed and implemented by people living with T1D. In general, technology use was perceived as important for improving glucose levels and emotional well-being for most, but not all respondents, and most reported affordability as a barrier. Additional barriers included device-related information provision, training, and support.

Importantly, regardless of device type, those who continued using their devices vs. those who had discontinued device use, were more likely to report that device use was associated with better emotional well-being. It is of note that one of the major associations of emotional well-being was perception regarding the importance of the device in enabling glucose in target range though we acknowledge that glycaemia was not formally assessed by the survey as we wished to avoid incorporating self-reported HbA1c or CGM metrics which we would be unable to verify, and which was beyond the scope of our aims.

The perception of those who have used IPT and CGM that these technologies facilitate better glycaemic management is consistent with the substantial body of evidence demonstrating improved glucose management in people living with T1D using such devices in clinical trials and cohort studies [3–4,17–18]. However, comprehensive data regarding the experiences of those using these technologies are not available from current administrative and registry databases or from data uploaded from the devices themselves. A small number of reports detailing the experiences of those using technology have been



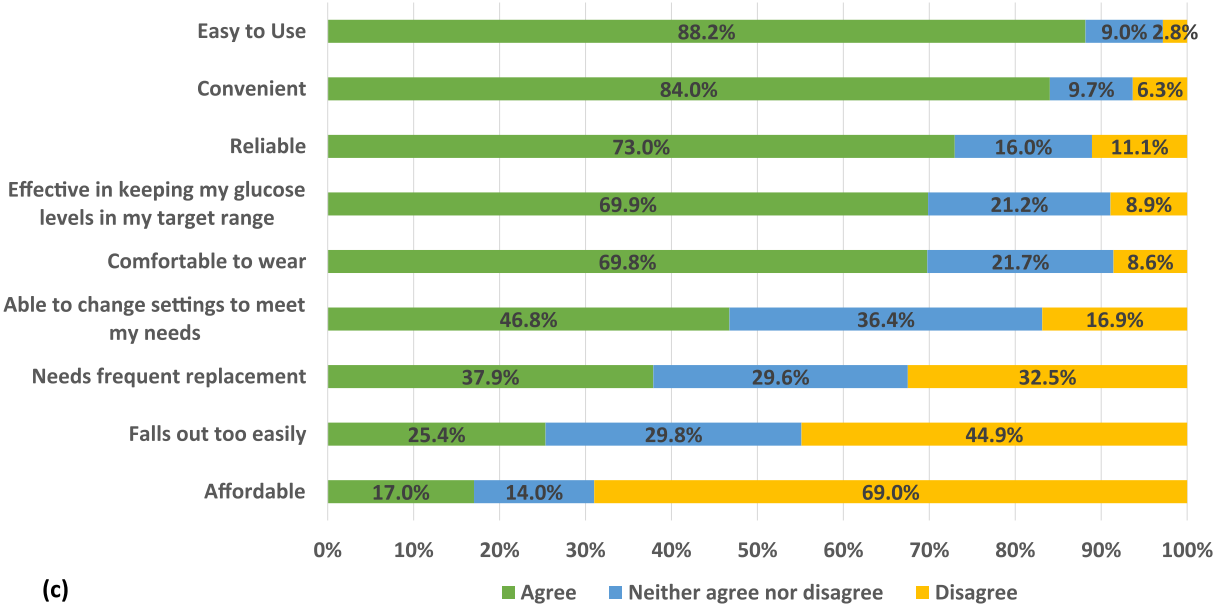


Fig. 3. (*continued*).

published, though most data have been obtained in a research environment and have focused on a single device [19–23].

Other important associations with emotional well-being related to perceptions regarding ease of use and comfort of the devices. It is reassuring that IPT and both classes of CGM were reported as being "easy to use" and "effective" by most respondents. This real-world experience reflects the priority that industry places on the engineering and the software incorporated into these technologies [24,25]. Nevertheless, we note that while RT-CGM and isCGM devices were reported to have a high degree of comfort, most respondents with experience of IPT disagreed that these devices were comfortable to wear. This is likely to affect continuity of device use and attenuate the beneficial metabolic impact associated with real-world IPT use. At the time of the survey, the only IPT devices subsidised in Australia were tubed pumps and we acknowledge that tubeless patch pumps may be less intrusive and provide a greater degree of comfort for some users [26].

The overwhelming majority of individuals reported dissatisfaction with their ability to access newer technologies. For Australian adults with T1D, IPT consumables are subsidised by the federal government, though the devices themselves, which have 4-year warranties, require self-funding or private health insurance. Our findings indicate that negative responses to device “affordability” was associated with perceptions of higher device attributable emotional well-being for past users of IPT and RT-CGM, suggesting that financial limitations may be a major factor in discontinuing use of these technologies, rather than perceived deficiencies in the device and its support. However, there were no specific questions asked of past device users on these points. As data are cross-sectional, no definitive conclusions regarding cause and effect can be drawn and further research is warranted. It should be noted that the survey was implemented prior to July 2022, when RT-CGM and isCGM were only subsidised for a minority of adults with T1D. Since July 2022 this subsidy has been extended to the entire Australian T1D population, which would be expected to have a substantial favourable impact on perceptions regarding accessibility of CGM devices.

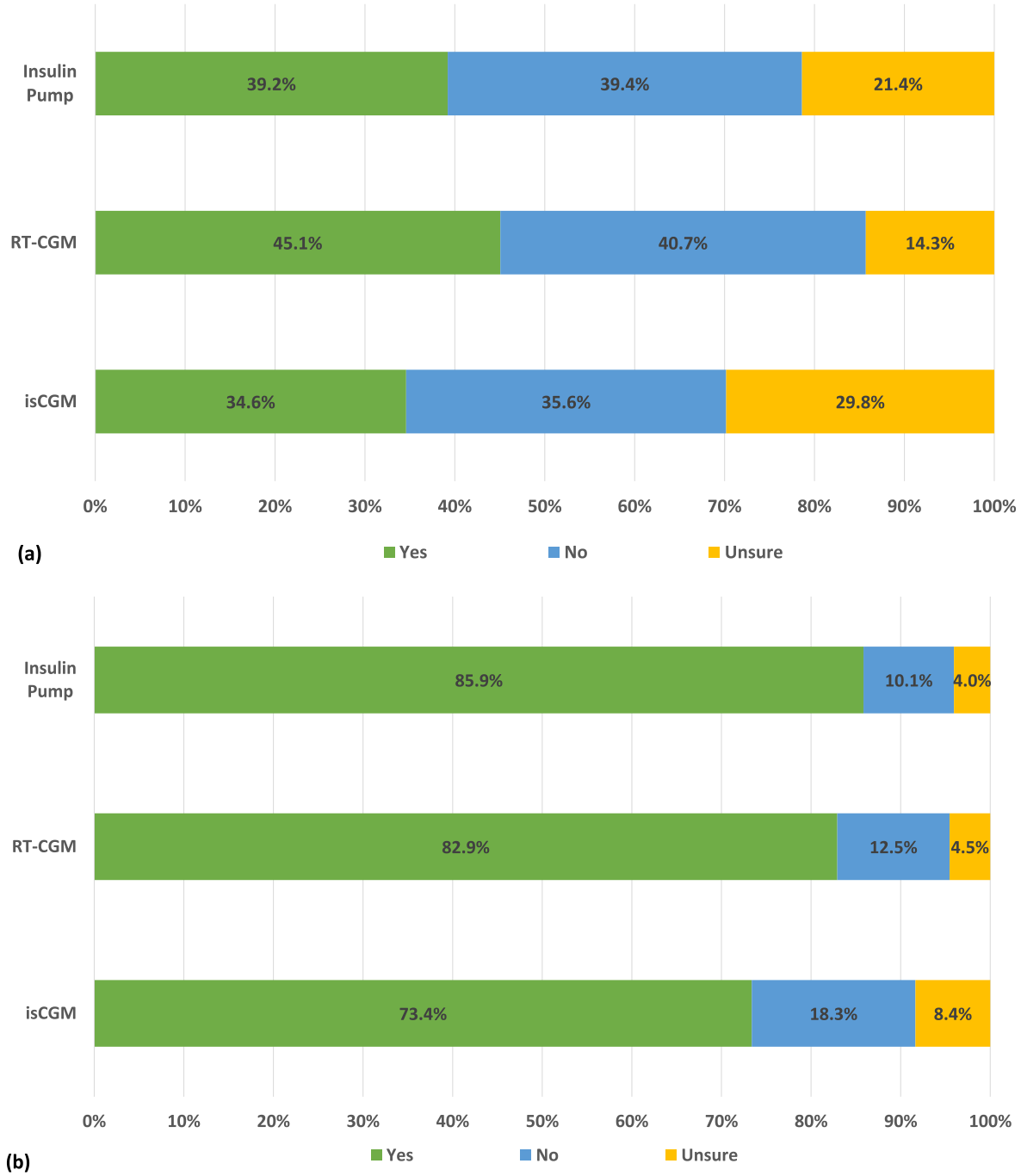


Fig. 4. Responses to the question **(a)** "Do you feel there is enough information publicly available to make an informed choice about using the following diabetes technologies?" and **(b)** "Were you able to access sufficient education and training when you first started using the following diabetes technologies?" by those currently using or with previous experience in the use of insulin pump therapy (IPT), real time-CGM (RT-CGM) and intermittently scanned glucose monitoring (isCGM).

Even if issues regarding technology access are addressed, it is notable that over one-third of all respondents expressed dissatisfaction regarding information available publicly with which to make an informed choice about use and selection of devices. Detailed information relating to device characteristics usually provided by the manufacturer, may be subject to bias, and may not always be in a suitable format for people with T1D as these resources may have been tailored for healthcare professionals. Typically, they require a relatively high level of reading skill and health literacy. This affirms the need for non-partisan, cost-free, resources detailing the pros and cons and performance of commercially available devices in a consumer-friendly format such as that provided by DiabetesWise (https://diabeteswise.org/#/) in the United States and the Diabetes Experts website in the Netherlands (https://www.diabetesexperts.nl/).

Attainment of desirable health outcomes, improved quality of life, and fewer acute and chronic diabetes complications, correlate with consistent and ongoing engagement in diabetes self-management [27]. Issues identified in the survey as important in supporting the person's engagement with the technology included not only knowledge facilitating operation of the device, and comfort with wear, but also an understanding of data (both immediate and retrospective) provided by the device, and how to use this information to adjust insulin to maintain

glucose levels in target range. The provision of training on the use of the devices and education are fundamental pre-requisites for achieving self-management.

Typically, the education of people with T1D in Australia is centred around protocolised responses to specific situations (e.g., carbohydrate counting for meals; exercise; sickness; and treatment for hypo/hyperglycaemia), but often do not address an individual's understanding of, or the assessment and review of their glucose and insulin-dosing data. While there are structured Diabetes Self-Management Education (DSME) programs for people with T1D such as Dose Adjustment For Normal Eating (DAFNE), these have been designed for those using multiple daily injections (MDI) and self-monitoring of blood glucose (SMBG) [27]. They do not specifically focus on understanding and reviewing device data. In addition, while providing education on the review of glucose patterns and mealtime insulin adjustments, DSME programs, such as DAFNE, are not routinely implemented in Australia as part of the device initiation process and need to be actively sought out by the person with diabetes. Therefore, it is not surprising that a recent survey of adults with T1D attending a tertiary service in Australia revealed that while self-review of uploaded data was associated with better glucose management (lower HbA1c levels), only a minority (32%) did so [28].

Research assessing DSME in association with device use has been limited. In a study assessing the effects on glucose of an algorithm guiding responses with IPT in conjunction with RT-CGM, the adult subgroup showed reductions in HbA1c and improved diabetes-related quality of life [29,30]. Another study showed that structured education providing skills and knowledge to make greater use of isCGM glucose information could significantly improve glucose metrics, diabetes distress, and overall satisfaction with glucose monitoring [31]. However, each of these education interventions was specific to a glucose monitoring device, and it was not clear what aspect of self-management contributed to the subsequent observed benefits.

Therefore, further research is required to develop future DSME programs for people using diabetes technologies, which are device agnostic and place an emphasis on self-review of device data by the individual with T1D and/or guardian. In addition, when implementing such an education program, our data indicate the need to involve a person with lived experience in the use of these devices.

A limitation of the present survey is that it was restricted to a single country. Given global differences in device availability, culture and healthcare provision models, caution is warranted when extrapolating these findings to other populations. Nevertheless, putting issues related to access aside, we would expect that adults with T1D using IPT and CGM devices in Australia would share many experiences with those living in other advantaged countries where technology is available to support self-management of glucose levels.

Self-reported device use was not verified as privacy requirements precluded this and there is no formal registry of those using technology to manage their glucose levels. The multiple pathways for funding IPT and glucose sensors in Australia at the time that the survey was conducted made it difficult to accurately determine the total number of people using these devices and therefore, the proportion of all potentially eligible respondents sampled by the survey. However, there were 116,570 adults with T1D in Australia of whom an estimated 25,000 were using technology to manage their glucose levels at the time the survey was conducted [32]. We restricted the survey-to those who have used the devices to ensure that responses were based upon actual experiences, and we acknowledge that the barriers and unmet needs of those who have never used these technologies have not been assessed.

While all RT-CGM devices incorporate alarms, the survey did not differentiate between isCGM with and without alarms. Libre 2, which does have an alert capability, was launched in Australia in August 2021 while Libre 1 did not. The online survey was live for eight weeks, from November 2021 to January 2022. As Libre 1 was a disposable "all-in-one" sensor with a life of 14 days, we expect that all respondents currently using a sensor at the time of the survey were using one equipped with alarms. Those respondents who had a past use of isCGM may have been wearing a sensor without alarms. However, we did not differentiate between the Libre 1 and Libre 2 experience as part of the survey.

Finally, the survey grouped all IPT together and did not separate these by manufacturer or according to level of automation of insulin delivery (low glucose suspend, predictive low glucose suspend, or hybrid closed loop functionality) to minimise the complexity and the time taken to complete the survey. At the time the survey was conducted, IPT devices in use varied significantly in their capability and sophistication in automating insulin delivery. In addition, limited access to glucose sensors for adults at that time precluded full use of these pump features for many even if these functions were available. We acknowledge that further research is needed to distinguish between IPT with and without AID functionality.

Strengths of this study are that it was designed, and implemented by people living with T1D ensuring that the survey was relevant to this cohort. It was promoted by multiple channels, including social media. The consumer design group was supported by an expert group of healthcare professionals, researchers, a peak patient representative body (Diabetes Victoria), and an expert in industry. The sample size was substantial, and respondents were proportionately represented geographically across all states of Australia as well as metropolitan vs. remote locales.

5. Conclusion

In summary, this large national survey of adults with T1D with current or prior experience of using advanced technologies to manage their glucose levels, indicated that these devices are perceived as having an important role in maintaining healthy glucose levels, reducing restrictions on the activities of daily living, and enhancing emotional well-being and quality of life. Issues relating to access were prominent and while funding and implementation structures vary globally, the issue of equity in access is an important challenge which many countries need to address. In addition, a substantial proportion of respondents indicated dissatisfaction with education, training, and support. This will be of increasing relevance beyond Australia, particularly with increased uptake of these devices as they evolve and become more attractive to the consumer in conjunction with glycaemic benefits.

6. Contributions

All authors contributed to the design and implementation of the study. KH (Kim Hider), GO, and TCB analysed the data. MR and DNO wrote the first draft of the manuscript, and all authors reviewed the final manuscript. DNO is the guarantor of this work.

Funding

The Diabetes Technology Research Group at the University of Melbourne provided an unrestricted grant support of this initiative. JS is supported by core funding to the Australian Centre for Behavioural Research in Diabetes, provided by the collaboration between Diabetes Victoria and Deakin University. D.P.Z. has received an ISPAD-JDRF Research Fellowship and research support and the Leona M. and Harry B. Helmsley Charitable Trust.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: DPZ has received speaker's honoraria from Medtronic Diabetes, Ascensia Diabetes, and Insulet Canada; and research support from the Leona M. and Harry B. Helmsley Charitable Trust and ISPAD-JDRF

Research Fellowship. She has also served on the Dexcom Advisory board. JS has served on advisory boards for Insulet, Medtronic, Roche Diabetes Care, and Sanofi Diabetes; her research group (The Australian Centre for Behavioural Research in Diabetes) has received honoraria for this advisory board participation and has also received unrestricted educational grants and/or in-kind support from Abbott Diabetes Care, AstraZeneca, Medtronic, Roche Diabetes Care, and Sanofi Diabetes; has received sponsorship to attend educational meetings from Medtronic, Roche Diabetes Care, and Sanofi Diabetes; and has received consultancy income or speaker fees from Abbott Diabetes Care, AstraZeneca, Medtronic, Novo Nordisk, Roche Diabetes Care, and Sanofi Diabetes. DNO has served on advisory boards for Abbott, Medtronic, MSD, Novo, Roche, and Sanofi; received research support from Medtronic, Novo, Roche, Lilly, and Sanofi; and travel support from Novo and MSD. The other authors have no conflicts to declare.

Acknowledgements

We acknowledge the many people living with type 1 diabetes who contributed their time and experiences by completing the survey. We also acknowledge Adjunct Professor Craig Bennett (former CEO of Diabetes Victoria) for his guidance and support. In addition, we acknowledge the Australian National Diabetes Services Scheme for disseminating the survey. We thank Dr Grant Cracknell and Dr Robyn Woodward-Kron for their assistance in formulating the survey.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.diabres.2023.110830.

References

[1] Diabetes Control and Complications Trial Research Group; Nathan DM, Genuth S, Lachin J, Cleary P, Crofford O, Davis M, Rand L, Siebert C. The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. N Engl J Med. 1993 Sep 30; 329(14):977-86. doi: 10.1056/NEJM199309303291 40PMID: 8366922.

[2] Weissberg-Benchell J, Antisdel-Lomaglio J, Seshadri R. Insulin pump therapy: a meta-analysis. Diabetes Care 2003 Apr;26(4):1079–87. https://doi.org/10.2337/diacare.26.4.1079. PMID: 12663577.

[3] Maiorino MI, Signoriello S, Maio A, Chiodini P, Bellastella G, Scappaticcio L, et al. Effects of Continuous Glucose Monitoring on Metrics of Glycemic Control in Diabetes: A Systematic Review With Meta-analysis of Randomized Controlled Trials. Diabetes Care 2020 May;43(5):1146–56. https://doi.org/10.2337/dc19-1459. PMID: 32312858.

[4] Eckstein ML, Weilguni B, Tauschmann M, Zimmer RT, Aziz F, Sourij H, et al. Time in Range for Closed-Loop Systems versus Standard of Care during Physical Exercise in People with Type 1 Diabetes: A Systematic Review and Meta-Analysis. J Clin Med 2021 May 31;10(11):2445. https://doi.org/10.3390/jcm10112445. PMID: 34072900; PMCID: PMC8198013.

[5] Foster NC, Beck RW, Miller KM, Clements MA, Rickels MR, DiMeglio LA, Maahs DM, Tamborlane WV, Bergenstal R, Smith E, Olson BA, Garg SK. State of Type 1 Diabetes Management and Outcomes from the T1D Exchange in 2016-2018. Diabetes Technol Ther. 2019 Feb;21(2):66-72. doi: 10.1089/dia.2018.0384. Epub 2019 Jan 18. Erratum in: Diabetes Technol Ther. 2019 Apr;21(4):230. PMID: 30657336; PMCID: PMC7061293.

[6] Skinner TC, Joensen L, Parkin T. Twenty-five years of diabetes distress research. Diabet Med 2020 Mar;37(3):393–400. https://doi.org/10.1111/dme.14157. Epub 2019 Oct 31 PMID: 31638279.

[7] Hendrieckx C, Gonder-Frederick L, Heller SR, Snoek FJ, Speight J. How has psychobehavioural research advanced our understanding of hypoglycaemia in type 1 diabetes? Diabet Med 2020 Mar;37(3):409–17. https://doi.org/10.1111/dme.14205. Epub 2019 Dec 27 PMID: 31814151.

[8] National Diabetes services Scheme. https://www.ndss.com.au/news/eligibility.

[9] Lal RA, Basina M, Maahs DM, Hood K, Buckingham B, Wilson DM. One Year Clinical Experience of the First Commercial Hybrid Closed-Loop System. Diabetes Care. 2019 Dec;42(12):2190-2196. doi: 10.2337/dc19-0855. Epub 2019 Sep 23. PMID: 31548247; PMCID: PMC6868462.

[10] Akturk HK, Giordano D, Champakanath A, Brackett S, Garg S, Snell-Bergeon J. Long-term real-life glycaemic outcomes with a hybrid closed-loop system compared with sensor-augmented pump therapy in patients with type 1 diabetes. Diabetes Obes Metab 2020 Apr;22(4):583–9. https://doi.org/10.1111/dom.13933. Epub 2020 Jan 3 PMID: 31789447.

[11] Berget C, Messer LH, Vigers T, Frohnert BI, Pyle L, Wadwa RP, Driscoll KA, Forlenza GP. Six months of hybrid closed loop in the real-world: An evaluation of children and young adults using the 670G system. Pediatr Diabetes. 2020 Mar;21(2):310-318. doi: 10.1111/pedi.12962. Epub 2020 Jan 7. PMID: 31837064; PMCID: PMC7204168.

[12] Tanenbaum ML, Hanes SJ, Miller KM, Naranjo D, Bensen R, Hood KK. Diabetes Device Use in Adults With Type 1 Diabetes: Barriers to Uptake and Potential Intervention Targets. Diabetes Care. 2017 Feb;40(2):181-187. doi: 10.2337/dc16-1536. Epub 2016 Nov 29. PMID: 27899489; PMCID: PMC5864141.

[13] Boote J, Wong R, Booth A. 'Talking the talk or walking the walk?' A bibliometric review of the literature on public involvement in health research published between 1995 and 2009. Health Expect. 2015 Feb;18(1):44-57. doi: 10.1111/hex.12007. Epub 2012 Oct 4. PMID: 23033933; PMCID: PMC5060762.

[14] Miller CL, Mott K, Cousins M, Miller S, Johnson A, Lawson T, et al. Integrating consumer engagement in health and medical research - an Australian framework. Health Res Policy Syst 2017 Feb 10;15(1):9. https://doi.org/10.1186/s12961-017-0171-2. PMID: 28187772; PMCID: PMC5303288.

[15] Gruber D. Consumer engagement for diabetes technology: easier said than done. J Diabetes Sci Technol 2010 May 1;4(3):754–8. https://doi.org/10.1177/193229681000400333. PMID: 20513345; PMCID: PMC2901056.

[16] Gold AE, MacLeod KM, Frier BM. Frequency of severe hypoglycemia in patients with type I diabetes with impaired awareness of hypoglycemia. Diabetes Care 1994 Jul;17(7):697–703. https://doi.org/10.2337/diacare.17.7.697. PMID: 7924780.

[17] Bekiari E, Kitsios K, Thabit H, Tauschmann M, Athanasiadou E, Karagiannis T, et al. Artificial pancreas treatment for outpatients with type 1 diabetes: systematic review and meta-analysis. BMJ 2018 Apr;18(361):k1310. https://doi.org/10.1136/bmj.k1310. PMID: 29669716; PMCID: PMC5902803.

[18] Dicembrini I, Cosentino C, Monami M, Mannucci E, Pala L. Effects of real-time continuous glucose monitoring in type 1 diabetes: a meta-analysis of randomized controlled trials. Acta Diabetol 2021 Apr;58(4):401–10. https://doi.org/10.1007/s00592-020-01589-3. Epub 2020 Aug 13 PMID: 32789691.

[19] Hendrieckx C, Poole LA, Sharifi A, Jayawardene D, Loh MM, Horsburgh JC, et al. "It Is Definitely a Game Changer": A Qualitative Study of Experiences with In-home Overnight Closed-Loop Technology Among Adults with Type 1 Diabetes. Diabetes Technol Ther 2017 Jul;19(7):410–6. https://doi.org/10.1089/dia.2017.0007. Epub 2017 May 24 PMID: 28537437.

[20] McAuley SA, Lee MH, Paldus B, Vogrin S, de Bock MI, Abraham MB, Bach LA, Burt MG, Cohen ND, Colman PG, Davis EA, Hendrieckx C, Holmes-Walker DJ, Kaye J, Keech AC, Kumareswaran K, MacIsaac RJ, McCallum RW, Sims CM, Speight J, Stranks SN, Sundararajan V, Trawley S, Ward GM, Jenkins AJ, Jones TW, O'Neal DN; Australian JDRF Closed-Loop Research Group. Six Months of Hybrid Closed-Loop Versus Manual Insulin Delivery With Fingerprick Blood Glucose Monitoring in Adults With Type 1 Diabetes: A Randomized, Controlled Trial. Diabetes Care. 2020 Dec;43(12):3024-3033. doi: 10.2337/dc20-1447. Epub 2020 Oct 14. PMID: 33055139.1.

[21] Polonsky WH, Fortmann AL. Impact of Real-Time CGM Data Sharing on Quality of Life in the Caregivers of Adults and Children With Type 1 Diabetes. J Diabetes Sci Technol. 2022 Jan;16(1):97-105. doi: 10.1177/1932296820978423. Epub 2020 Dec 16. PMID: 33322931; PMCID: PMC8875067.

[22] Polonsky WH, Hessler D, Ruedy KJ, Beck RW; DIAMOND Study Group. The Impact of Continuous Glucose Monitoring on Markers of Quality of Life in Adults With Type 1 Diabetes: Further Findings From the DIAMOND Randomized Clinical Trial. Diabetes Care. 2017 Jun;40(6):736-741. doi: 10.2337/dc17-0133. Epub 2017 Apr 7. PMID: 28389582.

[23] Wu Z, Luo S, Zheng X, Bi Y, Xu W, Yan J, Yang D, Weng J. Use of a do-it-yourself artificial pancreas system is associated with better glucose management and higher quality of life among adults with type 1 diabetes. Ther Adv Endocrinol Metab. 2020 Aug 25;11:2042018820950146. doi: 10.1177/2042018820950146. PMID: 32922721; PMCID: PMC7453453.

[24] Lee MH, Vogrin S, Paldus B, Jones HM, Obeyesekere V, Sims C, et al. Glucose Control in Adults with Type 1 Diabetes Using a Medtronic Prototype Enhanced-Hybrid Closed-Loop System: A Feasibility Study. Diabetes Technol Ther 2019 Sep; 21(9):499–506. https://doi.org/10.1089/dia.2019.0120. Epub 2019 Jul 2 PMID: 31264889.

[25] Paldus B, Lee MH, Jones HM, McAuley SA, Horsburgh JC, Roem KL, et al. Glucose Control Using a Standard Versus an Enhanced Hybrid Closed Loop System: A Randomized Crossover Study. Diabetes Technol Ther 2019 Jan;21(1):56–8. https://doi.org/10.1089/dia.2018.0279. PMID: 30620641.

[26] Filipczak J, Żelazny P, Sygacz O, Bróż S, Dankiewicz S, Swora A, et al. Omnipod® Insulin Management System - "patch-pump", As a Breakthrough in the Treatment of Type 1 Diabetes. J Educ Health Sport 2022;12:583–90. https://doi.org/10.12775/JEHS.2022.12.09.069.

[27] DAFNE Study Group. Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: dose adjustment for normal eating (DAFNE) randomised controlled trial. BMJ 2002 Oct 5;325(7367):746. https://doi.org/10.1136/bmj.325.7367.746. PMID: 12364302; PMCID: PMC128375.

[28] Kong YW, Venkatesh N, Paldus B, Lee MH, Zhu JJ, Sawyer M, et al. Upload and Review of Insulin Pump and Glucose Sensor Data by Adults with Type 1 Diabetes: A Clinic Audit. Diabetes Technol Ther 2022 Jul;24(7):531–4. https://doi.org/10.1089/dia.2021.0558. Epub 2022 Jun 6 PMID: 35167376.

[29] Jenkins AJ, Krishnamurthy B, Best JD, Cameron FJ, Colman PG, Farish S, Hamblin PS, O'Connell MA, Rodda C, Rowley K, Teede H, O'Neal DN. Evaluation of an algorithm to guide patients with type 1 diabetes treated with continuous subcutaneous insulin infusion on how to respond to real-time continuous glucose levels: a randomized controlled trial. Diabetes Care. 2010 Jun;33(6):1242-8. doi: 10.2337/dc09-1481. Epub 2010 Mar 9. Erratum in: Diabetes Care. 2010 Aug;33(8):1911. PMID: 20215457; PMCID: PMC2875432.

[30] Jenkins AJ, Krishnamurthy B, Best JD, Cameron FJ, Colman PG, Hamblin PS, et al. An algorithm guiding patient responses to real-time-continuous glucose monitoring improves quality of life. Diabetes Technol Ther 2011 Feb;13(2):105–9. https://doi.org/10.1089/dia.2010.0139. PMID: 21284476.

[31] Hermanns N, Ehrmann D, Schipfer M, Kröger J, Haak T, Kulzer B. The impact of a structured education and treatment programme (FLASH) for people with diabetes using a flash sensor-based glucose monitoring system: Results of a randomized controlled trial. Diabetes Res Clin Pract 2019 Apr;150:111–21. https://doi.org/10.1016/j.diabres.2019.03.003. Epub 2019 Mar 4 PMID: 30844467.

[32] Australian National Diabetes Audit (ANDA). https://www.health.gov.au/resources.