Title: A novel exploration of the support needs of people initiating insulin pump therapy using a social-network approach: A longitudinal mixed-methods study

Claire Reidy1, Claire Foster2, Anne Rogers1

Short-running title: A novel exploration using a social network approach

Affiliations:

1. NIHR CLAHRC Wessex, Faculty of Environmental & Life Sciences, University of Southampton, Southampton, UK

2. Macmillan Survivorship Research Group, Health Sciences, Faculty of Environmental and Life Sciences, University of Southampton, Southampton, UK

Corresponding Author

Claire Reidy

NIHR CLAHRC Wessex

Building 67 Room 3033

School of Health Sciences

Faculty of Environmental & Life Sciences

University of Southampton

Highfield, Southampton, SO17 1BJ

Email: c.m.reidy@soton.ac.uk

Tel: 023 8059 7628

Abstract word count: 246 (including headings)

Manuscript word count: 4572

Figures: 2

Tables: 6

Supplementary files: 3

Conflicts of interest: None

What’s new?

* The need for self-management support is heightened when a new technology is introduced, requiring new or renewed knowledge, confidence and resources and much fine-tuning over time.
* The intervention offered a positive disruption to self-management by prompting reconsideration of network members and how they impact on self-management as well as an avenue to connect to new activities and sources of support.
* Social support mapping demonstrated a rich range of network members ranging from partners, to family members, pets, community groups, friends and objects e.g. bicycles, glucose monitors of varying types, numbers, frequency and value.
* There was a return on investment for non-judgemental, accessible self-management support and education provided by specialist pump clinics.

Acknowledgements

We are grateful for the opportunity to undertake this doctoral research through funding from the Health Foundation, and for the support of the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Wessex. We would especially like to thank all of the people living with diabetes who participated in this study, allowing us to follow their pump journey while offering such rich and honest accounts of their experiences, perceptions and feelings. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR, the Department of Health or The Health Foundation.

## Abstract

Aims:

Few diabetes interventions approach improving health and well-being through social networks, yet social networks provide a potentially powerful means of mobilising, mediating and accessing support and resources. We aimed to establish what practical and emotional means of support are required upon initiation of insulin pump therapy and how needs change over time using GENIE, a social network intervention.

Methods:

The longitudinal design used semi-structured interviews, surveys (PAID, CLARKE) and HbA1c from pump initiation, three and six months on. Interviews used GENIE to capture participants’ expectations and experiences of pump therapy and associated support and resources. Thematic analysis was used with sequential, time-ordered matrices.

Results:

Sixteen adults undertook 47 interviews. A total of 94 activities were acquired while tally, frequency and value of network members increased over time. The novelty of pump therapy impacted on participants self-management needs. Key themes included: 1. The independent nature of managing diabetes, 2. Overcoming the challenges and illness-burden of a pump, 3. The need for responsive and tailored emotional and practical support, and 4. Useful resources when incorporating pump therapy. GENIE was thought to be novel and beneficial.

Conclusions:

A social network approach determined what resources and support people with diabetes require when incorporating a new health technology. Visualisation of support networks using concentric circles enabled people to consider and mobilise support and engage in new activities as their needs changed. The novelty of pump therapy creates new illness work but mobilisation of personally valued flexible, tailored support can improve the process of adaptation.

Key words: Insulin pumps, Social network intervention, Type 1 diabetes, Social support, self-management

# Main text

## Background

There is a drive from policy makers for prioritising self-management support in long-term-conditions [1] and increased momentum from NHS England and diabetes voluntary organisations to consider the emotional wellbeing of people with diabetes when promoting self-management support [2, 3]. The need for self-management support is heightened when new health technologies, such as insulin pump therapy in Type 1 diabetes, are introduced, requiring renewed knowledge, confidence and resources [4]. However, few diabetes support interventions explore or address improving self-management abilities or engagement with health services together with social support networks, yet for people with long-term conditions, social networks can provide an important means of mobilising, mediating and accessing support for health and well-being [5].

The World Health Organization now lists “social support networks” as a determinant of health [6]. Network members located in the personal community of a person with a long-term condition are sources of emotional, practical and illness-related ‘work’ [7] and have been associated with improving self-management [8, 9]. Personal communities of social support can range from members who are healthcare professionals, family, friends, community groups, objects [e.g. a bicycle), or even pets, which have been known to provide emotional support [10], especially when these relationships are diverse (including “weak ties”) [9]. For example, network members can be distributors of health literacy [11]. As such, interventions which seek to enhance an individual’s personal community of social support, and access to wider resources and local support are likely to compliment self-management strategies [12].

Kennedy et al. [8] implemented a web-based social support and networking tool named Generating Engagement in Networks InvolvEment (GENIE) with an isolated population of people with diabetes. The tool mapped and reflected personal network members and signposted to local sources of support. This resulted in increasing participant’s capacity and confidence for managing their diabetes. Bandura’s Social Cognitive Theory (SCT), which focuses on social influence and the dynamic and reciprocal interactions between the individual, the environment and behaviour, underpins this approach. SCT considers the unique way individuals’ acquire and maintain behaviours while also taking into account interactions with the wider social environment [13], while the need for a responsive network when managing a long-term condition has been illustrated in the recent development of a scale to measure collective-efficacy (CENS) [14]. Measurement of collective-efficacy can be a unique predictor of loneliness or an indicator of a network with the potential to provide responsive support and resource.

There is growing interest in the part network members can play in self-management of diabetes through sustaining learned self-management practices or day-to-day life [15, 16] and the impact that diabetes-related technology has on close network members [17]. In addition, The World Diabetes Day theme for 2018-2019 is ‘Family and diabetes’ to promote the role of family members in self-management [18]. Wiebe et al. [19] evaluated the social context of managing diabetes, exploring how social relationships are a central element in diabetes management. They suggest use of interventions which focus on the relational work involved in social relationships, and engagement of networks to enable access to resources as and when needed. Even when focused on healthcare professionals, social networks have been thought to improve the rate of recovery after strokes [20] where being part of a network of extended clinical expertise allows a widening of boundaries and both contribution and access to new knowledge. In terms of implementation, Kennedy et al. found that GENIE both enhanced support for people to self-manage and was acceptable and implementable in a UK setting when delivered through lay health workers in the community [8]. However, there is a lack of research exploring the range and value of network members involved in self-management of Type 1 diabetes, or of network members and resources of value when integrating a new health technology.

Here we explore the support and resource needs of people with Type 1 diabetes incorporating pump therapy over the initial 6 month period through GENIE. We considered the mechanisms though which participants valued this support and resource and how these needs shifted over time, and whether the intervention was deemed acceptable.

## Methods

### Design

Mixed-methods consisted; longitudinal interviews combined with questionnaires, HbA1c and GENIE intervention outcomes (mapping of network members onto concentric circles and activity uptake) (See Table 1). Following informed written consent, participants took part in a semi-structured interview shortly after pump initiation (Baseline), 3 months (T2) and 6 months later (T3). This involved working through GENIE (Table 1) (with an adapted database populated with Type 1 diabetes and insulin-pump-specific resources, local activities and services), followed by reflective questions about GENIE. The semi-structured interviews provided a dynamic method which enabled exploration of participants experiences, needs, values and perspectives. The interviews initially explored the individuals and groups that contribute to the participant’s personal network, how these network members contribute to self-management (at each time point), and further elaboration of the meaning and contribution of relationships within this network. The interviews also explored the nature of the context and content of the illness work that network members undertake in terms of supporting integration of pump therapy as well as their interest in social activities. The preferred activities that arose from GENIE were discussed and ways and means in which the participant may access these new activities. All interviews were digitally recorded and transcribed verbatim for analysis. The quantitative outcomes captured an overview of changes while incorporating the device, while the qualitative responses provided more depth about the nuances of these relationships and lived experiences.

Ethical approval for this study was granted by the National Research Ethics Service (Reference 17/NS/0089).

### Setting

The study took place between January 2018 and September 2018 in insulin pump clinics over three NHS Trusts in the South of England. Fourty-three interviews were conducted face-to-face and four via telephone.

### Population sample

Purposive sampling was used by each clinic to search their clinic database for potential participants who met the inclusion criteria; individuals who had been diagnosed with Type 1 diabetes for >6months aged >16 years and due to initiate insulin pump therapy. A recruitment pack including the study Participant Information Sheet (which outlined the study and the topics which would be covered in the interview) and invitation letter was sent in the post or given by a clinician during a clinic visit. Participants were purposefully sampled to ensure a range of ages, marital status, sex and employment status to reflect differing perspectives.

### Data analysis

The widely used, reliable scales [21, 22] routinely collected in the clinics selected were self-administered. The Problem Areas In Diabetes (PAID) scale was developed to measure emotional distress in people with diabetes and has 20-items which utilises a 5-point Likert scale (range 0-100), where higher scores reflect greater emotional distress. The CLARKE survey is an eight-item measure of hypoglycaemia awareness. A score of four or more suggests lack of hypoglycaemia awareness. The PAID, CLARKE and HbA1C results were collected by the clinic at Baseline and T3. The differences in HbA1c and PAID between baseline and T3 were compared using Wilcoxon signed-rank tests.

Participants completed concentric circles of network members and preference questions for activities on the GENIE database at Baseline, T2 and T3. Changes in the number of network members, frequency of contact (days per year) and value of contact (on a scale of 1-3, 3 being most valuable) of each network member were collated and compared over 6 months. Uptake in activities, and the type of activities were also recorded. Statistical data were analysed using IBM SPSS, V25.

Longitudinal qualitative interview data were subject to trajectory analysis, which focuses on changes over time utilising sequential, time-ordered matrices [23] combined with thematic analysis. Thematic analysis was guided by Braun and Clarke’s [24] well-established five-step framework. The first step required familiarization with the data through multiple readings, followed by the second step whereby an initial list of ideas about what is in the data was generated and initial codes were collated from the data. The third step is where themes begin to emerge, where we refocused and refined the analysis of the initial ideas and codes, at the broader level of themes. The themes were explored and reviewed for refinement in the fourth step, which included comparing and contrasting the similarities and difference between themes, interviews and contexts. Step five was where the themes were finally defined and named.

## Results:

We conducted 47 interviews with 16 participants. Purposeful sampling worked relatively well in this instance with opportune natural variety amongst pump starters, and with a high response and participation rate from those approached in clinic (80%). However, one participant (P8) was lost to follow-up at T3. Participants had a mean age of 38 years, mean diagnosis of 27 years and 11 (69%) were female (see Table 2 and Supplementary File 1 for individual characteristics). A Wilcoxon signed-rank test indicated that the average HbA1c of participants was lower at 6 months than at baseline (average rank of 8.5 vs. average rank of 1.5) and that the observed difference between both measurements was significant (p=0.001). The Wilcoxon signed-rank test also indicated that PAID scores were lower at 6 months than baseline (average rank of 9.1 vs average rank of 4.0) and that the observed difference was significant (p=0.001) (Table 3). There was no statistically significant improvement of hypoglycaemia awareness. However, hypoglycaemia awareness improved from 75% of participants to 81% due to one person regaining hypoglycaemia awareness.

### GENIE concentric circles

The number, frequency of contact and value of network members increased over time from baseline to T3 (Table 4). The majority of network members at each time point were family members (41%) followed by friends (15%) and Healthcare professionals (15%). Unsurprisingly, healthcare professionals had a relatively low frequency of contact compared to their (high) value (Table 4). The most commonly cited healthcare professionals were pump therapy clinicians (see Supplementary File 2) and while there was a significant decline in frequency of contact (which includes face-to-face contact, emails, texts and phone calls) over 6 months (p=0.006), the value of these clinicians did not change significantly (p=0.361) (Fig. 1).



**Figure 1: The frequency of engagement with the pump clinic over time vs value of the pump clinic**

Some participants experienced a decline in partner contact and value over time where two participants broke up from long-term relationships (Fig. 2). However, contact with family members remained relatively stable. Most described more contact with mothers than fathers, and while partners were the network member most frequently communicated with, mothers were valued nearly equally (Fig. 2). In addition, while children were often seen more frequently than a sibling(s), a particular sibling was especially valued. These relationships were discussed in more detail in the qualitative interviews.



**Figure 2: Frequency and value of contact with key family members over time**

### GENIE preference elicitation

The preference elicitation encouraged engagement and uptake of a range of activities and resources, whereby a total of 94 new activities were undertaken (and a Mean of 5.88 per participant) (see Table 5). Participants had a particular interest in online support, resources or social media (with 50 reported activities undertaken). Participants were also keen to undertake exercise and a total of 24 exercise-related activities were reported. These interests were explored in more detail in the qualitative interviews.

### Semi-structured interviews

The matrix table (Table 6) demonstrates the progression of needs over time. This process captured substantial life changes and disruption during this period. Four key themes were identified and Supplementary File 3 presents some of the quotes which elaborate on the themes identified:

1. The independent nature of managing diabetes
2. Overcoming the challenges and illness-burden of the pump
3. The need for responsive and tailored emotional and practical support
4. Useful resources when incorporating pump therapy

#### The independent nature of managing diabetes

Many participants articulated how they have to manage diabetes for and by themselves. Baseline discussions featured this topic quite heavily compared to T2 and T3, likely because it was the start of conversations about what support and resource is required or desired for self-management. Participants expressed the centrality of independence and responsibility in their self-management, such as the constant personal calculations of carbohydrates, exertion, current and future bolus’, hormones, stress levels and potential dawn phenomenon on blood glucose levels. However there were many discussions around how this effort was frequently undermined by the sheer lack of understanding of the lived experience, or passing of judgement on self-management from others (family members, friends, colleagues, strangers or clinicians). There was a narrative of unwillingness to ask others for help, as if admitting defeat, or perceived lack of capability of others to help (often from experience).

Most participants described either trying to be “positive” and “not think/talk too much about bad things”, or not thinking too much about potential complications, Considering who provides support to self-manage, and how, did seem like a novel task and evidently not something that had been considered before by most.

#### Overcoming the challenges and illness-burden of the pump

Most participants spoke of barriers they faced acquiring a pump, yet persevering and continuing to assert their wishes. Numerous participants described wanting better control over their glucose levels and that a pump may unlock opportunities for this to be realised. Some participants expressed less confidence acquiring a pump and were encouraged or inspired by partners or family members, or friends who already had the device. Where participants did not assert themselves close network members supported them to persevere.

The pump was described as relatively easy to use and logical but requiring new practices to learn and much trial and error initially. At baseline, a third of participants observed and expected that the pump would take time to accommodate and would require experimentation. There were some expressions of fear of consequences for getting it wrong. Other expectations included discomfort around having something attached 24/7, but also optimism about a new tool to help self-management. There was discussion around the associated extra consumables needed, especially from female participants. The physicality of the pump created discussions about how participants were beginning to deal with the size, noise and accessories required and the new found or increased illness-work required to place it on their body. However, some baseline discussions involved feelings of invigoration in relation to diabetes; like a positive disruption to self-management of this enduring condition.

Pump therapy initiation was described by all at T2 as a learning process of challenges and overcoming these, such as where to put the device. T2 also brought challenges to original expectations, including surprise at sleeping being “okay”. There were incidents of inconvenient alarms, batteries failing suddenly, the remote being slow, clunky or even failing, forgetting to change cannulas regularly, and the increased workload changing equipment regularly. Most participants described feelings of even more invigoration towards their diabetes self-management practices, such as dealing with diabetes all over again but with more tools and revitalised interest. Participants expressed appreciation for access to more advanced features than injections (multi-wave, extended bolus, reduced/increased basal). The device even gave way to an appealing new “robot” identity.

At T3 nearly all participants were still fine-tuning, but described how trial and error increased their knowledge and confidence and helped them come to terms with not having a perfect solution. Family members or partner suggestions were valued here. “Tightening up” or mastering long-acting insulin requirements, and “honing in” on more specific problems (exercise, particular foods, varying working patterns) were also discussed. Life events (e.g. moving home) had an impact for some being able to incorporate pump therapy as they would have liked, and grasp all the new technological options offered. Any matters encountered were resolved through speaking to their clinic, manufacturer helpline or via peer-support. All participants said they were really pleased with the pump, even though it required extra work.

#### The need for responsive and tailored emotional and practical support

Network members that influenced self-management and the ability to incorporate pump therapy included family members, pets, friends, colleagues, employers, groups and healthcare professionals. Life experiences sometimes disrupted support networks and consequent diabetes care.

Where people had long-term partners they were cited as the closest sources of support within a personal community. They were often described as being central to emotional and practical support but there were also some conflicting reports of criticism and lack of understanding about diabetes in general. Some partners attended pump initiation and clinic appointments, providing another ear to remember the complex information, and would seek out further support on behalf of their loved ones. This was especially helpful with the extra work required by the pump (more blood-glucose checking, more information to retain, more appointments). They also provided or supplemented support where the participant had to provide support to others e.g. children and older parents. As time went on partners were especially valuable when participants were sick or needed extra support. Over time some participants reflected that their partners had been on this journey of adaptation too. Single participants relied more heavily on close friends and close family members, and expressed concerns over their safety concerning hypoglycaemia, especially at night.

Mothers were often described as calming, encouraging, and supportive although sometimes anxious or judgemental. Sometimes mothers were considered more helpful than partners for emotional support and diabetes management. In some cases the roles had reversed where parents now knew much less about diabetes-related experiences or regimen, and so could provide less technical and practical support than before. Fathers were generally deemed “less helpful” than mothers, usually due to providing less communication and emotional support and less interaction with diabetes management growing up, but not by all. Sometimes fathers were described as a calming presence and sometimes offering humour.

If participants had any family members who had diabetes as well it was apparent that they provided support or understanding that only others with diabetes could offer. Other important network members included children, nieces/nephews, grandparents, and siblings. Some participants turned to their close siblings or children for emotional support. For one participant who was single and retired, her children were her main source of support. Family members often provided consistent and reliable support. Over half of participants had pets and most described their pets at baseline as highly valued network members. Some added their pet in later after reflecting on what/who is in their personal support network.

Friends were valued for taking part in activities and for offering non-judgemental or emotional support. There was no expressed expectations for friends to understand diabetes intricately but some participants did talk about valued friends treating them “like normal” rather than those who “do not understand diabetes”. Support or flexibility in the work place or whilst in education was valued, e.g. when undertaking night-shifts, or during hypoglycaemia. Colleagues being interested, and looking out for those starting pump therapy or supporting them if needed during hypoglycaemia were appreciated. Work colleagues could be in a position to be helpful “weak ties”. However, there were also reports of managers or colleagues being unhelpful, rude or obstructive.

There were extensive and in-depth discussions about support from clinicians, especially at pump clinics. At initiation pump therapy clinicians were considered important but with a need to create trust and reliable support. Group education sessions were appreciated by most participants, but with a request for one-to-one sessions to address more intimate issues. At baseline the clinic held the key to understanding discrete and important features of the pump. New pump users relied on the expertise and chosen delivery of that integral expertise. This did not appear to in conflict with independent self-management but complimentary when non-judgemental, supportive, consistent and accessible. This created positive engagements and collaborative relationships enabling participants to integrate pump therapy into their lives gradually, and in ways that were not fully captured by most former clinicians. Most participants did not consider their GP as a self-management network member, yet 100% put their pump clinic. However, a couple of participants spoke of important relationships with their GP or Practise nurse who had created highly valued sustainable and trusting relationships and responsive emotional support.

At T2 many participants discussed issues acquiring essential pump prescription items. The clinic became especially important when there were experiences of general healthcare professionals not understanding Type 1 diabetes. Participants also expressed appreciation at the clinic having honest and potentially difficult conversations with them. The current clinic was described as “more friendly”, with former clinics disparaging and “less supportive”. Most participants spoke about speaking to the clinic for practical tips since pump initiation and the value of these opportunities.

At T3 participants shared experiences of reaching out for help. If participants had not contacted the clinic they usually had a list of items to discuss and troubleshoot at follow-up appointments. Clinics were now opportunities for troubleshooting rather than “having to go” or for “being judged”. They were utilised well and the resources available in clinic were appreciated.

1. ***Useful resources when incorporating pump therapy***

Many participants wanted more information about developments in diabetes technology or self-management tips. Information and support were sought and desired from a variety of sources including; the pump manual, manufacturer helpline, social media and apps. Social media use included social networking sites (namely Facebook, Twitter, Instagram), blogs, video-blogs (YouTube), and diabetes websites. Social media was prominent in baseline discussions and continued throughout and it became apparent that social media provided convenient access to information and peer-support. Peers were deemed useful for practical and emotional support by many (both online and offline) and were integral to their support networks due to the uniqueness of knowledge (about diabetes) held by peers. Most mentioned being a lurker rather than an active participator but appreciated reading other’s comments, especially when they did not know others with Type 1 diabetes. Video blogs helped relieve anxiety by visualising complex new pump tasks. A few participants conveyed how being on pump therapy felt more like being part of a community, where peers seemed more accessible. However not all peer communication on social media was deemed useful with potential exposure to negative self-management practices or unwarranted advice.

The pump manual assisted with troubleshooting at T2 for many and access to this comprehensive information reduced the need for additional contact with the clinic. The helpline heavily featured in follow-up interviews. Participants expressed assurance knowing there was an emergency point of contact, and as time moved on where half contacted the helpline, were further reassured to know it was also reliable and useful.

At T2 and T3 new activities had commenced and participants spoke of activities they had undertaken as a result of GENIE. Participants mentioned engaging with various health, exercise or carbohydrate counting apps. Exercise in general was deemed important, with walking and yoga or Pilates particularly of interest, although undertaking personally chosen activities in general were referred to as supporting both physical and mental health and reducing insulin requirements through keeping active. An example of this is one participant who joined “Men in Shed’s” which provided the opportunity to get back into recreational work as an electrician which he was forced to stop professionally due to heart problems. He felt this not only improved his mental health but his physical health too. However, barriers to undertaking activities for participants, either old or new, included provoking anxiety about meeting new people, groups not catering to diabetes-specific needs (for weight loss or exercise) or feeling unable to do an activity previously enjoyed, although these were also a drive to take up interests again.

### Reflections on the social network intervention

GENIE prompted conversations about various elements of living with Type 1 diabetes and a pump, personal interests and what support was present, or not. All participants identified personalised activities through GENIE. GENIE also enabled participants to reflect on and express what they desire to help them manage, and why.

#### Concentric circles

All participants enjoyed engaging with the concentric circles activity due to having a novel visual image of their support, and the reflective nature of the task. Most participants reported the usefulness of visual reflection of their support network leading to re-evaluation of current network members and reconsideration of support received, and identification of further sources of support. The reflective space within GENIE enabled novel reflection and illumination of the mechanisms in which network members do or do not support or engage in self-management tasks when integrating a complex new technology. Identified mechanisms included: modelling of behaviour (e.g. peer-learning, sharing of practical tips); persuasion (e.g. network members encouraging pump therapy or self-management techniques); providing information, support, or even criticism and social pressure; and engagement with more diverse activities and connections.

#### Preference elicitation

Participants’ mostly described how GENIE offered specific and tailored preferences and an element of safety in searching for online or local groups and activities. However, some participants said that they did not want to be directed to resources and did not feel the need to be encouraged to do any activities, preferring instead to take up activities on their own. On the other hand, some of these participants did express specific reasons for not taking up activities, such as lacking a companion to attend activities or lack of confidence attending groups alone.

Modifications were also suggested including; making GENIE available as an App, more explanations about particular activity options and network interactions; adding clarity to what the preference entails rather than being over generic, and offering more language options.

#### Delivering GENIE

Some participants suggested accessing GENIE within the clinic setting, offering the opportunity to reflect on their diabetes self-management and preferred activities in a focused clinic rather than busy day-to-day life. Other suggestions included access via local diabetes groups for convenience, or having a drop-in space during clinic.

## Discussion

At the centre of a diagnosis of Type 1 diabetes is the individual living with diabetes. Participants were keen to establish their own levels of responsibility and capabilities to manage their diabetes, but there was also evidence of engaging with the network of people, objects and resources around them to support self-management during adaptation to a new health technology. This study offered the opportunity to explore the network and resources around people in the process of incorporating a pump from the point of initiation up to 6 months on. This exploration utilised a social network tool, GENIE, to offer personalised, tailored opportunities and signposting to further support and resource. Using concentric circles within GENIE, this cohort demonstrated a rich range of network members of varying types, numbers, frequency and value.

Participants expressed an initial liminality when introduced to pump therapy, which required an increased need for practical and emotional support and reassurance. As time went on participants’ confidence grew to trial new methods to integrate, relate to and wear the pump. Qualitative results highlight the complexity and nuances of social relationships. Partners and mothers were frequently highlighted as sources of integral support. This occurred even when these network members also created sources of anxiety or judgement. Pump therapy was also a source of new anxiety for network members but as time went on this anxiety decreased. Participants who had been diagnosed in childhood discovered a new imbalance of expertise and experience in the management of diabetes between parent and (now adult) child. Where parents could no longer provide technical or practical support or knowledge they provided vital and valued emotional support.

It was not expected that all healthcare professionals (e.g. GPs, pharmacists) would know a lot about Type 1 diabetes, but language did matter; participants expected to be spoken to with some respect of their capabilities. This could be the difference between clinicians being a viable option to turn to for support or any form of collaborative relationship. While frequency of contact with clinicians decreased over 6 months, other sources of support, resource and activities were gained. There appears to be a return on investment for the non-judgemental, accessible self-management support and education given by pump clinics. Specialist clinic support at the outset provided reassurance and skills, which enabled participants to self-manage more confidently. However, these clinics do not seem to represent the majority of diabetes clinics where there are concerns around the effectiveness and appropriateness of communication methods and approaches in the delivery of diabetes healthcare [3]. It has been noted that interactions with healthcare professionals can elicit distress when they do not acknowledge limitations to managing Type 1 diabetes and (unintentionally) disempower patients to self-manage through unrealistic expectations [25]. Recent research also shows that clinicians do not feel confident, or familiar in approaching or delivering psychosocial support to meet the needs of people with diabetes [26]. These clinics represent a model of good practice for the delivery of structured education and healthcare. Accessing support on their own terms was important for participants and any contact with clinicians was carefully selected, preferring to manage on their own where possible. Participants’ demonstrated determination and capability to self-manage but were keen to collaborate with engaged clinicians to address concerns.

Users expressed a desire to access GENIE conveniently and in an accessible setting (such as a drop in service in clinic or in local groups). Kennedy et al. [8] found that those in lay roles provided the best fit for facilitation of GENIE, and so implementation may benefit from utilising peers as volunteer Facilitators (or ‘peer support workers’). Peer facilitation offers a combination of informational, instrumental and emotional support, whilst bridging the gap where healthcare professionals are not equipped to approach or deal with day-to-day self-management tasks and requirements [27]. With training and support, peers can potentially, and economically, bridge this gap utilising established communication and behavioural strategies (e.g. preference elicitation, goal setting) [27]. For example, Small et al. [28] found that telephone self-management support interventions that were delivered by lay and peer support workers significantly improved HbA1c level and self-management behaviours.

This study captures this unique process of changing needs over time and an avenue to respond to these changing needs. Providing an opening to help people with diabetes navigate their social network and means to personalised support and resources as and when they needed through GENIE appears to have supported identification of new ways to support self-management and more smoothly incorporate a new health technology. In addition, facilitation to personally tailored activities was not only acceptable to participants, it also provided opportunity and social restructuring to open up new opportunities. The use of a social network intervention offered a positive disruption to self-management through novel considerations of network members and how they impact on self-management. In addition, the pump offered positive disruption through offering something new to approach self-management with. Suddenly there was a reason or a potential to try new techniques (e.g. variable night-time background insulin for dawn phenomenon). However, there are distinct technicalities to consider with the pump that created increased illness-work and burden for new pump users. People with Type 1 diabetes are “super users”; experts in their own diabetes, and so in reality it is then a case of tapping into tailored support when it is deemed necessary.

Limitations

An increase in social network size should not be viewed as an end in itself, but the means to support people to achieve other recovery goals. It is worth noting that while the tool does not intervene directly with maladaptive networks or network members it does incite change within the individual through engagement with the Facilitator and renegotiation of existing network members but also through an increase in network and variety where there is a potential for further sources of support outside of the relationships in existence before engaging in the tool. In addition, while peer-support and social media featured strongly here, it is not desired by all, and there are concerns over how and when social media is used by people to self-manage [29]. It is worth pointing out that while purposive sampling sought a diverse range of participants, women do represent the vast majority of participants in this study (69% vs 31%). However, while the male voice is not as well explored here, there is a national (UK) disparity between men and women in uptake of pumps more generally (61% vs 39%) [30]. The In addition, while reductions in HbA1c levels were achieved and some improved awareness of hypoglycaemia, we cannot know whether this is a direct result from engaging with this social network intervention, or whether this would have occurred regardless. Rather, this study provides rich descriptions of the complex and conflicting process that occurs when integrating a new health technology to manage a long-term condition and a potential means to support navigation of self-management support.

Conclusion

Utilising a social network intervention like GENIE provided the opportunity to explore the specific needs of people with Type 1 diabetes who are utilising a new health technology. However, access to such an intervention must also be a choice and not a one-size fits all model. Whether confident or actively seeking more support, there was value in offering people the unique opportunity to reflect on the current status of their support network and to consider what options they may wish to employ in future. In this instance social networks offered varying and rich opportunities for support which amalgamated over time and in response to life events and changes in circumstances. It would be valuable to widen the scope of this tool to target other people with diabetes, especially those experiencing any form of isolation, new health practises (diagnoses, new health technology) or going through any form of transition. While this tool was deemed acceptable and enlightening, more work needs to be done to consider implementation and whether the improvements experienced by participants in this study can be demonstrated on a larger scale.

## References

1. NHS England. Involving people in their own health and care: Statutory guidance for clinical commissioning groups and NHS England. 2017.

2. Diabetes UK. Position statement on emotional and psychological support for people with diabetes. 2018.

3. Lloyd CE, Wilson A, Holt RIG, Whicher C, Kar P, Group tLM. Language matters: a UK perspective. Diabetic Medicine. 2018;35(12):1635-41.

4. Reidy C, Bracher M, Foster C, Vassilev I, Rogers A. The process of incorporating insulin pumps into the everyday lives of people with Type 1 diabetes: A critical interpretive synthesis. Health Expectations. 2018;21(4):714-29.

5. Holt-Lunstad J. Why Social Relationships Are Important for Physical Health: A Systems Approach to Understanding and Modifying Risk and Protection. Annual review of psychology. 2018;69:437-58.

6. World Health Organization. Health Impact Assessment: The determinants of health: World Health Organization; [Available from: https://www.who.int/hia/evidence/doh/en/.

7. Vassilev I, Rogers A, Sanders C, Kennedy A, Blickem C, Protheroe J, et al. Social networks, social capital and chronic illness self-management: a realist review. Chronic illness. 2011;7(1):60-86.

8. Kennedy A, Vassilev I, James E, Rogers A. Implementing a social network intervention designed to enhance and diversify support for people with long-term conditions. A qualitative study. Implementation Science. 2016;11(1):27.

9. Vassilev I, Rogers A, Kennedy A, Wensing M, Koetsenruijter J, Orlando R, et al. Social Network Type and Long-Term Condition Management Support: A Cross-Sectional Study in Six European Countries. PloS one. 2016;11(8):e0161027.

10. Brooks HL, Rushton K, Lovell K, Bee P, Walker L, Grant L, et al. The power of support from companion animals for people living with mental health problems: a systematic review and narrative synthesis of the evidence. BMC Psychiatry. 2018;18(1):31.

11. Edwards M, Wood F, Davies M, Edwards A. ‘Distributed health literacy’: longitudinal qualitative analysis of the roles of health literacy mediators and social networks of people living with a long-term health condition. Health Expectations. 2015;18(5):1180-93.

12. Seeman TE. Social ties and health: the benefits of social integration. Annals of epidemiology. 1996;6(5):442-51.

13. Bandura A. Health promotion from the perspective of social cognitive theory. Psychology & Health. 1998;13(4):623-49.

14. Band R, James E, Culliford D, Dimitrov B, Kennedy A, Rogers A, et al. Development of a measure of collective efficacy within personal networks: A complement to self-efficacy in self-management support? Patient Education and Counseling. 2019.

15. Rankin D, Barnard K, Elliott J, Cooke D, Heller S, Gianfrancesco C, et al. Type 1 diabetes patients' experiences of, and need for, social support after attending a structured education programme: a qualitative longitudinal investigation. Journal of Clinical Nursing. 2014;23(19-20):2919-27.

16. Rintala T-M, Jaatinen P, Paavilainen E, Åstedt-Kurki P. Interrelation Between Adult Persons With Diabetes and Their Family: A Systematic Review of the Literature. Journal of Family Nursing. 2013;19(1):3-28.

17. Barnard K, Crabtree V, Adolfsson P, Davies M, Kerr D, Kraus A, et al. Impact of Type 1 Diabetes Technology on Family Members/Significant Others of People With Diabetes. Journal of diabetes science and technology. 2016;10(4):824-30.

18. The Lancet D, amp, Endocrinology. Family matters in diabetes care. The Lancet Diabetes & Endocrinology. 2018;6(12):911.

19. Wiebe DJ, Helgeson V, Berg CA. The social context of managing diabetes across the life span. The American psychologist. 2016;71(7):526-38.

20. Hand PJ. The power of networks. Medical Journal of Australia. 2019;210(8):352-3.

21. Polonsky WH, Anderson BJ, Lohrer PA, Welch G, Jacobson AM, Aponte JE, et al. Assessment of diabetes-related distress. Diabetes Care. 1995;18(6):754-60.

22. Geddes J, Wright RJ, Zammitt NN, Deary IJ, Frier BM. An Evaluation of Methods of Assessing Impaired Awareness of Hypoglycemia in Type 1 Diabetes. Diabetes Care. 2007;30(7):1868-70.

23. Grossoehme D, Lipstein E. Analyzing longitudinal qualitative data: the application of trajectory and recurrent cross-sectional approaches. BMC research notes. 2016;9:136.

24. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology. 2006;3(2):77-101.

25. Snow R, Humphrey C, Sandall J. What happens when patients know more than their doctors? Experiences of health interactions after diabetes patient education: a qualitative patient-led study. BMJ Open. 2013;3(11).

26. Byrne JL, Davies MJ, Willaing I, Holt RIG, Carey ME, Daly H, et al. Deficiencies in postgraduate training for healthcare professionals who provide diabetes education and support: results from the Diabetes Attitudes, Wishes and Needs (DAWN2) study. Diabetic medicine : a journal of the British Diabetic Association. 2017;34(8):1074-83.

27. Funnell MM. Peer-based behavioural strategies to improve chronic disease self-management and clinical outcomes: evidence, logistics, evaluation considerations and needs for future research. Family practice. 2010;27 Suppl 1(Suppl 1):i17-i22.

28. Small N, Blickem C, Blakeman T, Panagioti M, Chew-Graham CA, Bower P. Telephone based self-management support by ‘lay health workers’ and ‘peer support workers’ to prevent and manage vascular diseases: a systematic review and meta-analysis. BMC Health Services Research. 2013;13(1):533.

29. Reidy C, Klonoff DC, Barnard-Kelly KD. Supporting Good Intentions With Good Evidence: How to Increase the Benefits of Diabetes Social Media. Journal of diabetes science and technology. 2019:1932296819850187.

30. NHS Digital. National Diabetes Insulin Pump Audit, 2016-2017: England and Wales. 2018.

## Tables

**Table 1: GENIE elements (taken and adapted from Kennedy et al. 2016) [8]**

| **Elements** | **Details** | **Theory of how it works** |
| --- | --- | --- |
| Filter questions | The process starts with questions to provide details of the user’s context. This includes postcode; gender; age and health condition. | • Providing filter questions allows tailoring of suggestions and helps to reduce choice at the preference stage. |
| Concentric circles: Stage 1https://media.springernature.com/lw785/springer-static/image/art%3A10.1186%2Fs13012-016-0384-8/MediaObjects/13012_2016_384_Figa_HTML.gif | Social network members (family, friends, groups, professionals) are represented and mapped, depending on subjective importance, onto three concentric circles. Details of relationship and frequency of contact are recorded. | • To explore everyday relationships and how network members contribute to support• To note change over time• To provide a visual image to enable engagement• To help people become conscious and reflexive of contributions made by others to self-management support (SMS)• As starting point for a discussion about how to extend existing support, access support from new sources, or change existing practice. |
| • Support work can be: illness-related (taking medications and measurements, understanding symptoms, making appointments); everyday (housekeeping, child rearing, support for diet and exercise, shopping, personal care); or emotional (comforting when worried or anxious, well-being, companionship). |
| Typologies: Stage 1 | Feedback and a summary is provided on network types: | • To help people become conscious and reflexive of network structure and availability of SMS• Act as a prompt for healthcare professionals and others to take action where there are obviously fragile networks |
| Diverse - family, friends, and community groups with *regular frequent contact*; |
| Friend and/or family centred – mainly friends and/or family members with *regular contact and support*; |
| Friend and/or family contact - some mostly friends and/or family members with *limited or patchy support*; |
| Isolated or professional contacts only |
| Preferences: Stages 2,3,4https://media.springernature.com/lw785/springer-static/image/art%3A10.1186%2Fs13012-016-0384-8/MediaObjects/13012_2016_384_Figb_HTML.gif | The user co-produces and owns the network map. | • Non-intrusive methods are more effective than highly directive approaches which often fail because they do not deal with existing relationships to negotiate time and space for new activities (intimidating to attempt by oneself) or needing help with transport• The user is made a capable and willing to reciprocate participant• To reduce choice and complexities arising from information overload counterproductive for learning, social engagement and social support particularly where there is poor health literacy. |
| Choices are tailored using a series of questions and based on preference and enjoyment rather than on health-based need. For example, the facilitator prompts by asking: |
| “Are there things you used to do that you don’t do anymore? What stopped you from continuing to do these things?” |
| This gives clues about how to identify the most relevant type of support, the likely barriers they may encounter, and how to encourage them to restart these activities. |
| Network members are selected as potential buddies to accompany them to new activities. |
| Asked to select the three activities or resources they are most interested in and agree to try them out. The locations of the activities are displayed on a Google-based map. |
| Links to Voluntary and Community Organisations (VCOs): Stages 2,3,4 | The preference questions link to community resources in a pre-created database (populated with Type 1 diabetes and insulin-pump-specific resources, local activities and services). | • Diverse networks which include VCOs enhance health and well-being through providing access to new acquaintances for advice, support and links to resources are often missing where there is reliance on strong family ties.• Support from VCOs is non-clinical.• Specific benefits for people who are isolated. |
| Categories in the database include: activities and hobbies, health, learning, support, independent living and volunteering |

**Table 2: Baseline sociodemographic characteristics of participants**

|  |  |
| --- | --- |
| Insulin pump users | % (n=) unless otherwise stated |
| **Age** (Mean, SD, range) | 37.63 (15.62), 21-65 |
| **Sex** (Female) | 68.75 (11) |
| **Ethnicity** (White British) | 87.50 (14) |
| **Income** (average UK = £26,500)Lower than averageAverageHigher than average | 56.25 (9)25 (4)18.75 (3) |
| **Marital status**Never married or formed a civil partnershipMarried or in a civil partnershipDivorced | 43.75 (7)43.75 (7)12.50 (2) |
| **Work situation %**In paid full time work (full or part-time)Retired from paid workIn full time education or trainingLong-term sick/disabled | 56.25 (9)25 (4)12.50 (2)6.25 (1) |
| **Education level** (Degree level or above) | 43.75 (7) |
| **Time since diagnosis** (Mean, SD, range) | 27.06 years (12.81), 11-45 years |
| **Diabetes-related complications a** | 50 (8) |
| **Ever been in hospital for hypoglycaemia or DKA?**  | 56.25 (9) |

a Eye damage; Background retinopathy/Treated retinopathy/Neuropathy/Cardiovascular disease/Other complications

**Table 3: Participant clinical outcomes**

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Participant | HbA1c baseline mmol/mol (%) | HbA1c T3 mmol/mol (%) | HbA1C change | PAID baseline | PAID T3 | PAID change |
| 1 | 59 (7.5) | 46 (6.4) | -13 (-1.1) | 1 | 5 | +4 |
| 2 | 72 (8.7) | 70 (8.6) | -2 (-0.1) | 17 | 6 | -11 |
| 3 | 68 (8.4) | 60 (7.6) | -8 (-0.8) | 11 | 5 | -6 |
| 4 | 68 (8.4) | 65 (8.1) | -3 (-0.3) | 50 | 35 | -15 |
| 5 | 51 (6.8) | 53 (7.0) | +2 (+0.2) | 30 | 10 | -20 |
| 6 | 67 (8.3) | 60 (7.6) | -7 (-0.7) | 6 | 4 | -2 |
| 7 | 98 (11.1) | 75 (9.0) | -23 (-2.1) | 38 | 5 | -33 |
| 8 | 85 (9.9) | 81 (9.6) | -4 (-0.3) | 59 | 16 | -43 |
| 9 | 60 (7.6) | 53 (7.0) | -7(-0.6) | 22 | 8 | -14 |
| 10 | 80 (9.5) |  |  | 46 | 51 | +5 |
| 11 | 64 (8.0) | 60 (7.6) | -4(-0.4) | 11 | 13 | +2 |
| 12 | 62 (7.8) | 57 (7.4) | -5(0.4) | 9 | 6 | -3 |
| 13 | 86 (10.0) | 74 (8.9) | -12(-1.1) | 14 | 13 | -1 |
| 14 | 56 (7.3) | 49 (6.6) | -7(-0.7) | 69 | 33 | -36 |
| 15 | 68 (8.4) | 60 (7.6) | -8(-0.8) | 10 | 8 | -2 |
| 16 | 68 (8.4) | 63 (7.9) | -5(-0.5) | 30 | 16 | -14 |
| Average/Total | 68.74 (8.4) ±13 | 61.73 (7.8) ±10 | -7.01a(-0.6) | 26.75 ±20 | 14.30 ±14 | -12.45b |

A P= <0.001

B p= <0.005

**Table 4: Changes in numbers, frequency of contact and value of network members**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Count of network members** | **Frequency of contact (collective days per year)** | **Value of contact** |
| **Baseline** | **T2** | **T3** | **Baseline** | **T2** | **T3** | **Baseline** | **T2** | **T3** |
| **Healthcare professional** | 24 | 23 | 19 | 520 | 380 | 52 | 52 | 52 | 43 |
| **Family members** | 64 | 57 | 64 | 12021 | 12177 | 12049 | 155 | 163 | 153 |
| **Friends** | 24 | 26 | 27 | 2020 | 1763 | 2164 | 44 | 47 | 55 |
| **Pets** | 6 | 9 | 8 | 1877 | 3285 | 2607 | 12 | 20 | 18 |
| **Fitness activities** | 12 | 16 | 19 | 624 | 1025 | 1534 | 24 | 37 | 46 |
| **Groups** | 6 | 12 | 14 | 497 | 1082 | 825 | 10 | 23 | 23 |
| **Health technology** | 5 | 10 | 10 | 1150 | 2984 | 2984 | 13 | 26 | 26 |
| **Social media** | 3 | 4 | 4 | 469 | 521 | 521 | 6 | 7 | 7 |
| **Colleagues** | 6 | 6 | 8 | 1524 | 1524 | 1901 | 11 | 11 | 13 |
| **Object** | 3 | 3 | 4 | 742 | 734 | 1099 | 7 | 7 | 10 |
| **Education** | 3 | 2 | 3 | 20 | 8 | 373 | 3 | 2 | 4 |
| **Other** | 2 | 3 | 3 | 369 | 373 | 20 | 4 | 7 | 5 |
| **Total** | **158** | **171** | **183** | **21833** | **25856** | **26129** | **341** | **402** | **403** |
| **Mean (SD) per participant** | 10.20 ±3.29 |  | 12.20 ±3.75a | 1354.73 ±790.99 |  | 1747 ±933.29b | 22.13 ±1.83 |  | 26.73 ±9.92c |

a P= 0.017

b P= 0.018

c P= 0.033

**Table 5: Participant uptake of activities**

|  |  |
| --- | --- |
| **Types of engagement** | **Total** |
| Online or telephone support/social media | Diabetes information websites | 10 |
| Peer-support group (online) | 8 |
| Pump accessories website or blog | 8 |
| Video blogs/instructions | 6 |
| Blogs | 5 |
| Online health forum | 2 |
| Twitter | 3 |
| Googling carb content | 1 |
| **Total** | **50** |
| Health | Walking | 7 |
| Yoga/Pilates | 5 |
| Ice skating / Snowboarding | 2 |
| Team sports | 2 |
| Running | 2 |
| Swimming | 2 |
| Cycling | 2 |
| General exercise/gym classes | 2 |
| **Total**  | **24** |
| Activities/groups | Volunteering | 3 |
| Sewing / Baking | 2 |
| History group | 1 |
| Book club | 1 |
| Men in Shed’s | 1 |
| **Total** | **8** |
| Other | Carbs & Cals app | 4 |
| Fitbit | 2 |
| Flash Glucose Monitor | 2 |
| **Total** | **8** |
| Learning | Recipes | 3 |
| Diabetes book | 1 |
| **Total** | **4** |

|  |  |  |
| --- | --- | --- |
| **Total** |  | **94** |

## Supplementary files:

**Supplementary File 1: Participant baseline characteristics**

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Participant | Age | Sex | Diagnosis (years) | Complications? | Pump | Income | Marital status | Has children? | Work situation | Education level |
| P1 | 48 | Male | 40 | Background retinopathy | Roche Accu-Chek Insight | Higher | Married or in a civil partnership | Yes | In paid work | Doctoral degree |
| P2 | 22 | Female | 17 | Similar to Diabetic Amyotrophy | Roche Accu-Chek Insight | Lower | Never married or formed a civil partnership | No | In full time education | NVQ or equivalent |
| P3 | 21 | Female | 20 | None reported | Roche Accu-Chek Insight | Lower | Never married or formed a civil partnership | No | In full time education | A-Levels or equivalent |
| P4 | 22 | Female | 17 | Background retinopathy | Roche Accu-Chek Insight | Lower | Never married or formed a civil partnership | No | In full time education | Bachelor’s degree or equivalent |
| P5 | 55 | Female | 44 | None reported | Roche Accu-Chek Insight | Lower | Divorced | Yes | In paid work | Bachelor’s degree or equivalent |
| P6 | 22 | Female | 12 | None reported | Roche Accu-Chek Insight | Lower | Never married or formed a civil partnership | No | In paid work | Bachelor’s degree or equivalent |
| P7 | 27 | Male | 20 | None reported | Roche Accu-Chek Insight | Average | Never married or formed a civil partnership | Yes | In paid work | A-Levels or equivalent |
| P8 | 29 | Female | 26 | Retinopathy | Roche Accu-Chek Insight | Lower | Married or in a civil partnership | Yes | In paid work | NVQ or equivalent |
| P9 | 52 | Female | 45 | None reported | Roche Accu-Chek Combo | Higher | Married or in a civil partnership | No | In paid work | Bachelor’s degree or equivalent |
| P10 | 23 | Female | 12 | None reported | Roche Accu-Chek Insight | Lower | Never married or formed a civil partnership | No | In full time education | A-Levels or equivalent |
| P11 | 40 | Male | 34 | Retinopathy | Roche Accu-Chek Insight | Average | Married or in a civil partnership | Yes | In paid work | Bachelor’s degree or equivalent |
| P12 | 65 | Female | 27 | None reported | Roche Accu-Chek Insight | Average | Divorced | Yes | Retired from paid work; Voluntary work | NVQ or equivalent |
| P13 | 55 | Male | 44 | Retinopathy; Neuropathy; Nephropathy; Cardiovascular disease | Roche Accu-Chek Combo | Lower | Married or in a civil partnership | Yes | Long-term sick/disabled | GCSEs or equivalent |
| P14 | 32 | Female | 11 | Neuropathy | Medtronic MiniMed™ 640G | Lower | Married or in a civil partnership | No | In paid work | Bachelor’s degree or equivalent |
| P15 | 32 | Male | 20 | Pre-proliferative retinopathy | Medtronic MiniMed™ 640G | Average | Never married or formed a civil partnership | No | In paid work | Doctoral degree |
| P16 | 57 | Female | 44 | None reported | Roche Accu-Chek Insight | Higher | Married or in a civil partnership | Yes | Retired from paid work; Voluntary work | GCSEs or equivalent |

Supplementary File 2: Count of healthcare professionals by type



**Supplementary file 3: Quotes from semi-structured interviews**

|  |  |  |
| --- | --- | --- |
| Theme/sub-theme | Time | Quote |
| 1. The independent nature of managing diabetes
 |
|  | T1 | Interviewer: You normally wouldn't put them before the pump, put the diabetes clinic?P10: No, I don't think so because I'm quite independent with that… Yes, and it's not your first thought to be like, "I'm going to ring them again" or something like that. It's not your first thought. You think, "What can I do here right now?" |
| T1 | P13: Most of it is down to me and I've done it all myself, because nobody else knows how I feel. You can tell them and they go, ''Yes, yes, yes. Put a plaster on it. It'll be okay.'' It doesn't work like that. Life is not like that and diabetes is certainly not like that. Even healthcare professionals, if you tell them how you're feeling, they don't really understand how you're feeling…They probably heard it a thousand times before, but they don't understand it. |
| T1 | P16: I think that’s why you don’t get people involved because they just wouldn’t know. What’s the point, they just don’t get it, or they might half get it. |
| T1 | P12: Well. I tend to all on my own, to be honest. I've not really-- I just get on with it. |
| T1 | P12: I'm quite independent when it comes to most things. I have to be pretty desperate before I—yes. |
| T2 | P3: Hmm. It’s difficult because something happens and he’s like, why didn’t you tell me. I’ve dealt with it my entire life on my own and it’s difficult to say oh by the way. |
| T2 | P16: Well I’m not one that really shouts out I’m a type 1 diabetic. So, most people wouldn’t know don’t know. So, support, there isn’t much and that is fine because nobody could know it as well as I do… That’s right. So, as support goes there’s really me because I support myself a lot in what I do so I’m the most important that’s why I’m in the middle. |
| T2 | I: Healthcare professionals, what is their role in your life?P12: Nothing.I: Introducing you to the pump for example?P12: Oh, yes. Better tools for diabetes, but actual management of it nothing because I do that. |
| T3 | P13: I think diabetes can be such an individual type of condition anyway, we all know you need insulin to treat it but not everybody is the same and I think that’s half the complication with having diabetes, no two people are the same. |
| 1. Overcoming of the challenges and illness-burden of the pump
 |
| * 1. Technicalities of the pump
 |
|  | T1 | Researcher: How do you find solutions?P11: Observing the results and of course making some changes and seeing what happened after the changes. |
| T1 | P9: And I'm probably starting to use some of the functions that at the moment I don't know, what I don't know. I don't need to know what I don't know because I'm still getting used to the basics probably. |
| T2 | P5: I think there are a lot of things to learn to start off with, sort of scary things like fitting the catheter in is a completely different skill, isn’t it? The first time I did it I was a bit gung-ho and it was fine, but the next time I did it I messed up loads of times and then the third time I got my daughter who is not medically trained but I said can you stand there while I do it please. |
| T2 | P1: It’s still new enough that you are concentrating on it, still new enough that you are thinking about changing catheters and just do it slowly. That phase of making things happen rather than just using it. |
| T2 | P12: I’ve got the basics and I know how to do the basics, so at this point I feel I’m in control now. So, however, many classes we had to start with, let’s say we had three. For the first two I was really on it and got it all and I think I must have slept through the third one because I really, or whether there was just so much information I switched off. I’m not sure what it was, whether I was having a bad day, but I was really panicky about the first time I had to change the battery, the first time I had to change the cartridge. |
| T2 | P10: It just feels like the last three months have been so intense, not that it wasn’t the best time to start the pump, but I feel like from now on I can really concentrate on using the pump rather than, and using it properly, rather than being, oh I’ve got all this stuff to do and get into a proper routine now. |
| T3 | P4: Still a way to go but I’m happy. We need to tighten up my basal dose a bit, but we gave me a bit more in certain periods of the day because there was a trend of me going a bit high towards the end of the day. So, hoping that will fix that. I feel like my results have been better since our meeting as well so that’s good. |
| T3 | P5: Yes. I think as I said to [DSN], I did find the start quite difficult. I was quite a slow starter in coming to grips with it. But I think the last three months has been really good and in fact the other day I was thinking, oh no I wouldn’t be without it now. At the beginning I really didn’t think I’d think that. |
| 2.2 The physical pump |
|  | T1 | P12: We did a dry run for a week. I hated it. I was like, "I can't do this". I hate this being stuck to my body. I hate this great lump I'm carrying around on the side of me. Three days in, we had to change the cannulas. Mine dropped out within the day, "Thank goodness" so I took the whole lot off.” |
| T1 | P12: It's like "No, I've got to see this through because it's going to tighten my control. I've got to see it through". |
| T1 | P14: Sort of having a constant monitor, that's it isn't it? If they can, that's why it helps. It's supposed to, sort of, give you less ups and downs, ideally. |
| T1 | P5: The worst thing was when-- the alarm goes off at work, to say you only have 25 units left, and my colleague was saying "What is that noise? What is that odd—oh.” … And then a few days later there was this funny alarm that went off… and he went, "Is that you running out of medicine again?" |
| T1 | P5: My bag has got heavier rather than lighter. |
| T1 | P16: I think going to the toilet now is going to take a lot longer than what I used to be. |
| T2 | P1: Frustrating sluggishness, this is ten years out of date. |
| P1 | P1: So it went to 90% and I thought, OK, it is beginning to fall, that happened quite quickly. Then from 90% to stop was within hours, from almost literally nowhere. |
| T2 | P3: Yes, so you are always attached to it, so when I’m getting dressed do I hold it, do I put it on my bed, do I un-attach it completely? |
| T2 | P6: Sometimes I’ll get up in the middle of the night to go to the toilet and I completely forget I’m attached to the pump and it just drags behind me and I’m like, oh pump! |
| T2 | P5: A little bit. I’m surprised how easy I found it just to have it when I’m sleeping and stuff. |
| T2 | P1: It’s still new enough that you are concentrating on it, still new enough that you are thinking about changing catheters and just do it slowly. That phase of making things happen rather than just using it. The learning point that you realise that doesn’t work either so. |
| T2 | P16: I was talking to somebody at the group today and they’ve given me a couple of tips, so I will take that on board. But, yes, at the moment in jeans you can pop it in your pocket, dresses and skirts are more difficult, but I have bought something which was way too big, but someone has given me a few tips on how I can cope with that, so I will try that. |
| T2 | P11: The only thing really is just a matter of sorting the pump itself placing it somewhere else, I need to find a firmer holder for it. |
| T3 | P6: I don’t know just sort of I guess, even just little things like getting used to having it on me. I don’t even notice it’s there half the time. I did back in June on one occasion I’d taken it off, I think I’d had a shower, taken it off and then come back out and I forgot to put it back on…I think it’s because I’m so used to it being there that I don’t notice it’s not there. I guess that’s one not so good thing. But, yes, and just getting used to it. |
| T3 | P3: It is weird, you have this thing connected to you. Sometimes you forget it, you’re on the bed and you get yanked backwards. |
| T3 | P12: I’m just so aware of it. Maybe I’ll put a piece of tape over it. I don’t know what the answer is to that. Pop it in your bra but that would still show. |
| T3 | P9: Well I’m only using my stomach, which I think long term I probably need to use more areas otherwise it’s going to end up, it’s already looking a bit. |
| T3 | P12: Just not having to have those injections, it’s so much easier in public to get this out and pretend it’s your phone rather than have to get your needle out. |
| 2.3 The impact of the pump on daily life |
|  | T1 | P10: But it’s exciting and it adds something to you, like changes things up a bit… Just try something new. It's almost like starting a blank. |
| T1 | P2: I had a pudding. Instead of saying, "No, I'm not going to have a pudding because I'll have to have another injection." Now I'm like, "I'll have a pudding, just fiddle with the machine." |
| T1 | P16: Sometimes I would just do an injection but if it was difficult I wouldn’t. |
| T1 | P3: It is a worry actually, isn't it? Because I don't know how-- I didn't really take any notice of how exercise affects me, but now I have to. |
| T2 | P7: It’s been a lot easier to manage because sometimes, well before in the summer my blood was always sky high not giving a reading, but I’ve had a few high ones, but it seems to be a lot easier to correct it than having to just have three or four units or insulin injection every so often. It’s just a lot easier to do it at the press of the finger. |
| T2 | P10: I found that it’s making me do more research. I’m Googling how many carbs are in things instead of being like, oh I know that, because that was what it was ten years ago. |
| T2 | P10: I think it’s like when you get a new phone you just want to play with it don’t you. It’s just like the same thing, it’s just like a, oh I want to do this. |
| T2 | P4: It feels like dealing with diabetes all over again, it’s a renewed interest in how to look after it and also feeling like I can actually improve this time where I felt I was steadily, what’s the word when you are just? …Plateau. When I just plateaued, when I’m at a steady level… It felt like that for ages and then now I’m keener and more positive about it. |
| T2 | P15: Very good. For every hour of the day the insulin is matched to me as much as possibly it can. Of course every day is different, and you are going to get ups and downs but it’s far better. Even if things are going a bit higher or lower I can adjust that with the temporary basal rate which absolutely brilliant. |
| T2 | P9: Yes, I’ve got some sort of base rules now, like I drop the meal one 50% and then an hour or two before exercise I’ll drop the basal by 50%, so quite big changes. Then if I go to aqua I take it off, I’m now confident it’s not going to go, when I first went I was like oh my God no insulin for an hour I’ll be shooting up, but actually the exercise seems to keep it just about. |
| T2 | P11: So, it’s a big advantage of the pump. The other thing I would say that you can use the different options like delaying or extending your insulin according to what you eat. So I think it’s a big advantage. |
| T2 | P6: Yes, definitely. I am part robot and I’m happy with that, I’m proud of it. |
| T2 | P9: When I go on a new yacht I always say at the beginning I’ve got diabetes and now I say I’m now the new improved version because I’ve got a turbocharge, I’ve got the pump and everything… |
| T3 | P2: It’s been so much better. I had my meet up with [DSN] last week and I said I feel like a different person a bit. I’m not stabbing myself every day, it’s not hurting, I used to dread it because you always have to get it out in front people and it always hurts. But I just feel so free with it and because my control is so much better I’m not having a hypo every day. So I sometimes will react like, oh, yes, I forgot I’m diabetic. Yes, its life changing, I would say its actually life changing. |
| T3 | P4: It improves your confidence with diabetes I think and knowing you can make these small adjustments rather than, just having something that works a bit more like a pancreas I guess and making those small adjustments might actually change your results for a few weeks. |
| T3 | P6: It's a bit like routine because I like to go out every evening to feed the guinea pigs their fresh vegetables and top up all their food and their hay and stuff like that. So I guess it gives you a good routine and it was my trigger. “Okay, I'm feeding the guinea pigs. I need to do my-- before I have the pump, I need to do my long-lasting insulin." Yeah, it all just went in together. |
| T3 | P6: But I still to this day get days that I get in bed and I’m like oh I haven’t done my long lasting, oh, yes, I don’t have to do it. I can just go to bed, this is great! |
| Loving the pump | T3 | P8: It’s been brilliant. I enjoy it. |
| T3 | P3: Pretty good. I wouldn’t go back, I do like it, I’m still getting used to it and getting all the carbs right, but I do like it. |
| T3 | P6: Overall, it’s been good and as I keep saying to people I’d never go back. I’m not giving my pump back to anyone, I’m going to guard it with my life. |
| T3 | P16: I’m really pleased with it, I really, really am. It’s good, it’s really good. It’s different, you’ve got so much more control. I know we’ve been through this, but I’m really, really pleased with it. |
| 1. The requirement of responsive and tailored emotional and practical support
 |
| * 1. Sources of support from family members
 |
| Mothers | T1 | P1: She does still worry. If I'm on the phone, “are you being okay is everything all right?” This [the pump] will worry her silly. This was worrying her silly on Saturday she was already saying “you'll be okay”. Then “what will you do?”, “You're going to test enough, won't you?” |
| T1 | P4: Yes, my mum wants us to have a long, healthy life because my grandad didn't. That kind of means that sometimes she's a bit stressy but she's still my biggest support system. |
| T1 | P6: I was quite excited when I could show her a really good day I’d had and I’d talked all about it. But other than that, I just—[pause]. I guess she's just always concerned for my health because I'm her daughter. |
| T1 | P10: My mum… She leaves it to me, but she'll just be there like, "Okay, what are you going to do about that?" We talk every day and stuff like that. |
| T1 | P16: Well I would have said my mum, but she’s died, because she lived with it and understood a lot about it. |
| T1 | P3: My mum’s been a good help. She doesn’t know much about the pump but when I was younger she had full control, my dad is diabetic as well, so she’s a bowl of knowledge that woman. Really good. |
| T1 | P3: My mum and dad were always there but obviously with this new equipment they don’t know, my dad is diabetic, but he will always be on injections… mum is like, well I don’t know anything about it I can’t really offer you any advice. I think it’s probably the nurses because they’re there. [Boyfriend] tries but sometimes I get annoyed, I’m like, no, shut up, I don’t want to talk about.  |
| Closet network members | T1 | P4: I think my mum is more the emotional one and my boyfriend is more like the day to day stuff… I just always -- if I get overwhelmed I would call my mum. It's just habit. He'll comfort me with things to do with uni and stuff because we're both feeling it. With my illness, my mum dealt with it first and she's just the person that I always went to. |
| T1 | P14: He's the one I moan to first. Mainly because we live together. He's the first person I see when I go home at night, and he tends to drive me to all my appointments and stuff… |
| T1 | P13: She wants to be able to do it, she wants to be able to understand it but she just- sometimes she just doesn’t get her head around it. |
| T3 | P2: I would feel like I’m totally alone if they weren’t there. I go to them for advice. [Boyfriend] comes to every appointment with me because he’s so interested in it and he wants to help, and he likes to know what’s going on because I’m not very good at remembering. So he’s like, remember you’ve got to do that, and I’m like, oh yes cheers [Boyfriend]. If I didn’t have them I don’t know, I think I would struggle a lot more. |
| T3 | P4: [Boyfriend] has been really good recently as well. I went through a period where I was just randomly higher, and I tested it at dinner time and I was 5 or something and I was really lucky, and he said I know how stressed you’ve been, but he didn’t want to talk to me about when I was stressed so he just talked to me about it afterwards. So it shows that he’s paying attention… He knows it will freak me out more if I talk about it. |
| T3 | P9: I think maybe husband could come in a bit. Yes, I think I do mention things to him from time to time and he’s always supportive. Yes, so maybe I think he needs to come in a bit… He’s said to me he can notice that I’m more relaxed and it’s taking less effort for me to keep things going. |
| The role of Fathers | T1 | P10: My dad doesn't know I suffer mental health issues. My brother and my mum do.  |
| Family members with T1D | T1 | P6: But he [brother] was actually diagnosed with Type 1 on the 22nd of December last year-so we’re really close… Before, I probably wouldn't have put him in. He probably would have just been, “He’s one of my family members. He knows I've got it,” kind of thing and that’s that. But since he got it, we've been messaging a lot and he's obviously asking me a lot of questions and then vice versa, it's just nice to have someone to talk about things like that and I'm like, "Oh, have you heard about this?" |
| T1 | P6: I think at the moment, it's just nice to know that someone else who understands as much as me. I feel like, I can imagine that my family think they understand, but I don't really believe that they do. Because I think back to sort of like, I think, “If I didn't have it, would I really understand?” I don't think so |
| T1 | P5: He was the one who said “you really ought to try a pump, it's so good”… he loves it, it's so fantastic… So that's really been a positive thing…so that was a big encouragement for me. He keeps on phoning up saying "how's it going?", and "is it good?" |
| Other family members | T1 | P5: Okay. So if I put my youngest daughter first… She knows quite a lot about diabetes from living with me. Plus she is interested in medical things. She's fascinated with the pump… So when I had to change my infuser the first time, I was a bit anxious about it and so she said, "I'll come over and I'll help you." … So that was quite good, it was like a bit of moral support. |
| T1 | P12: Well. I tend to all on my own, to be honest. I've not really-- I just get on with it. I suppose two of my children, who live locally, they're probably the ones –they’re the ones that I've been discussing the pump with over the last week… I suppose they would be the most important in the support network for me…Over the last week, there has been some ups and downs because of the pump and that and yes they've been there and just listened to me rant on….and then we just come up with some pearls of wisdom or something, or some encouragement. |
| T1 | P11: I would say my daughter as well. She's obviously small…She's got some understanding and interest. I would put it in the way like positive that she's around and she's trying something to check my blood sugar or for example the pump, she likes to play around to understand how it works. It's the way that it's someone else who is around you and supports you. It's not actually diabetes treating but just psychological support. It's very good. |
| T1 | P12: I'd go through periods where I'm hypo in the night. Living on your own, that's- obviously, could be a concern…I'd say to them, "Do you understand I just get hypo in the night and there doesn't seem to be any rhyme or reason for it?" I don't expect them to say anything to do because they can't. Again, it's just sometimes getting it off my chest. Also, I suppose so that they know that "Okay, mum might be hypo in the night. Maybe I just give her a text in the morning, make sure that she's okay"…Yes. They'd be able to say, "Well, she's been saying that she had something".  |
| T2 | P12: Yes, they’re quite, you know, want to know what it’s all about and how it works, well not how it works but what it’s all about and how’s it going. Not so much now because we’re about three months in, aren’t we, so not so much now. |
| 3.2 Pets |
|  | T1 | P2: She's my baby. Obviously, if I'm having a high day where I'd rather might take her out for a walk and do a little bit of exercise where she keeps me because I go running with her… She's just my best friend. |
| T2 | P13: Probably a bit more active. Yes, certainly more active. It’s another responsibility you have isn’t it, but it’s all part of looking after a dog, isn’t it? All animals are like that. |
| T3 | P14: It was quite funny because she basically is my life, I love her to bits, but it wasn’t until we spoke about it that time that I was like, actually, she’s a proper – yeah, she just chills me out. And obviously my mood affects my diabetes anyway, but I wouldn’t have thought about it – yeah, I just wouldn’t have thought about it. |
| T3 | P4: That’s what I like about being home I get more of a routine. Dogs actually improve life so much, dogs are really good for things like that…They make you get out of bed. |
| T3 | P16: They calm you down as well, when you feel a bit uptight you just give them a stroke and it’s actually quite a stress-relieving thing to do, so if you have a bad day, stroke a dog and then you get a lot of hair because they’re retrievers and they’re fur making machines but - |
| 3.4 Support outside of the home |
|  | T1 | P6: Because I feel like if I needed to I could turn to her and talk to her about anything. And yes, she's good and she's been quite understanding at ice skating…it's quite funny actually because we'll be practicing something and I'll start to get maybe wobbly on my feet and she’ll say, “Just take it easy. Go check your number.” And I’ll go, “Actually, yes, you might be right. Yes, I might be running a bit low," and so it's quite nice. She's just-- she doesn't make a big deal of my diabetes but she's aware of it. |
| T1 | P9: The friend that's recently been diagnosed with multiple sclerosis. Since she's been diagnosed, I think she knows that I know what it's like for her to deal with something and have good times and bad times. I feel now, I can also empathize with her. Actually, it's quite nice to talk to her because I would very gladly listen to how it's going with her…It doesn't go away and with her multiple sclerosis, obviously, she has to deal with it every day and she sometimes, I think, she has to put on a brave, like, "Oh yes, it's not too bad, I'm going okay." |
| T1 | P12: She's one of my oldest friends, I've known her since I was 16…We've both been there for each other, seen each other through divorces, and child-rearing years, and so- shared experiences… sometimes, all we want is to just be able to offload. We don't necessarily want somebody to sort our problems, unless it's something that we just don't know the way forward. |
| T2 | P14: She treats you like a normal person and I love that… sometimes I’m iffy about telling people straight away that I’m diabetic… sometimes I want to be treated like a normal person…it’s almost like they want to be your carer…And you’re like no I just want you to be my friend. That’s what I absolutely adore about [Friend] because she knows but it’s not her first thought about you. |
| Unhelpful friends | T1 | P16: Yes there are friends, but they wouldn’t have a clue. They know that blood sugar is high or low, but I don’t think they really know… Yes, yes that’s right, all you need to do is lose a couple of pounds…They are confused between type 2 and type 1, they don’t know. If you lose some weight, you know. |
| Difficulties making new friends | T3 | P15: I suppose the trouble is down in [Area], I didn’t have many friends down there I suppose but I suppose that’s a bit of a reason why I’m back up here. It’s far easier for me to make friends when I already had friends; when I don’t have them, it’s extremely hard. When you go to university, everyone’s in exactly the same situation so it’s not a problem but when you’re an adult, it doesn’t work the same way. |
| Supportive colleagues | T3 | P6: I hadn’t really thought about how much they actually are looking out for me until recently. That lady has always been like, “are you OK?”, and I hadn’t really thought about it and it wasn’t until this other colleague then was like, “you are drinking loads”, and I thought actually they are quite aware and quite helpful, so in a way they are like a support to me. That’s quite good… Even if I’m a bit strange that day they are just like, are you OK? I’m like, yes, it’s just me, don’t worry. |
| HCPs | T1 | P4: My pump team, though, they're completely different. I love [Dietician]… Exactly, yes, that's what I had with my first ever diabetes nurse, but she was part of a pump clinic as well. She was like [Dietician], basically. She was so supportive and she'd always encourage you and be like, "The thing is, yes, you're going high, but you're correcting it really quickly," and things, or "You're testing so at least you know you're going high and that shows you're putting effort into." That's what you need to hear. You don't want to be told -- That's not going to encourage you… I don't know actually, they have been very helpful, so I'll put them. |
| T1 | Interviewer: Where would you put them, do you think? In terms of support, would you put them in the centre circle, as quite important in your own healthcare?P9: Yes, definitely, knowing that they're there and particularly the support of [Dietician] and others…she was there straight away, no panic. I'm sure, if I rang them up they would definitely be there… I'd be very confident, number one, they'd respond and number two, they give me good advice and so I'd probably put them quite close. |
| T1 | P9: They have the, obviously they have the professional expertise but I think the [Area] team also have a good way of making you feel confident and take ownership yourself. They're not too judgemental and they're very much let's find out-- give you the freedom to work out what's going to work for you. So give you the tools and then be there to support you and help you analyze how it's going with their professional-- |
| T2 | P1: I’ve never called them [the clinic], I’ve pinged them a couple of emails and I actually sent them a picture of that Libre graph and said, what the hell is going on here? I said what’s happening, is this ultra-slow release carbs kicking in at 9pm or is this that my 9pm rate is wrong? … Between us we came up with a plan, so I said this is what I think might be OK are you OK with this? Good … Share an image and it arrives on their desk, that’s quite clever. So them being able to see that is useful because then they know what the hell you are talking about.  |
| T2 | P2: I think DSN 8 and Dietician 8 with the texting as well it’s very easy. It’s good. You’ve got the manual. I think it’s fine, I think I’ve got everything. |
| T2 | P3: Yes, if you leave messages they’ll ring you back. I had to change this appointment, it was supposed to be a couple of weeks ago. I had a lecture and I couldn’t miss it and they were really good. |
| T2 | P5: Well it’s good because you know what it’s like when it’s your life you just go through every day, you don’t reflect, it’s very good. The last 14 days what do you think happened? Oh, yes. And what happened then? There’s no judgement, it’s about how would you manage this, so it gives you time for reflection and I think that’s the most valuable thing. |
| T3 | Interviewer: Would you be more confident going to the pump clinic to ask?P11: I’ve got the feeling that probably they are a bit more experienced [than other HCPs]. Maybe they meet a variety of cases with diabetes? I don’t know, it’s hard to say, I can’t really, but when you come and talk to them... I think the other thing is maybe when you meet the team there are usually the dietician and the nurse, so maybe together they can support you from different angles. Maybe that’s why you feel more confident coming to them because if there are two of them and both of them give you some advice on different points of view… Yes, because they are kind of supporting each other that’s why probably there are two of them. |
| T3 | P4: Mainly we were talking about the fact that I’m moving home so I need to get transferred to another hospital, so has been really helpful with all of that. She’s written a letter to my GP, so they’ve got all the information about my pump, so I don’t have to remember everything because a lot of the time people have just passed on without any information apparently and then it falls on them to remember everything accurately. Yes, so I’m glad she did that, so that was nice. She was positive. I had to fill out a questionnaire and she was trying to, because I was a bit disappointed that my HbA1c hadn’t come down even more and she was just like keeping me motivated. |
| T3 | P3: I don’t know actually because they aren’t diabetic, are they, but yet they’re knowledgeable, they know their stuff and I find them really helpful. The good ones they say, “I don’t know what it’s like to have diabetes, but this is known to help”. (P2) |
| 1. Useful resources when incorporating pump therapy
 |
| 4.1 Access to information, social media, peer-support and diabetes technological advancements |
| Pump manual | T3 | P12: Especially when it’s something new like the pump, you get two huge books with it and when my pump was playing up at night I tried going through these books and I was getting so frustrated and upset really because I need to have this sorted now. This can’t wait 24 hours or even until morning really. So eventually I did give in and I did ring them. |
| T1 | P6: Just to know what else there is that maybe I could incorporate in what I'm doing and am I missing something or have I forgotten things because I've had it so long? |
| T1 | P13: I'd love to know what's going on, what's coming up… When I heard about all these weird and wonderful things going that were supposedly being tested like the Google eye contact lens, which I though was a brilliant idea and the stem cells, insert them into your kidneys so they could work. I would really like to see more of that happening and all of the weird and wonderful things like that, and you think, "Yes, that'd be good". |
| T1 | P9: I'm always interested in research. Like with most people- what's coming next. |
| Need for carb counting | T1 | P4: I went to the carb counting groups and things. I like refresher courses because I forget stuff. |
| Social media and peer-support | T1 | P4: Yes, and it's just good to see people trying new things out… It's a big help but it's more just like the comfort of it more than anything, it's not like I'm turning to anyone in the group…because my sister definitely makes me feel isolated. |
| T1 | P14: It’s nice to sort of read stuff —you can tend to search something and find the answer to something off of the post of someone else. It’s quite handy. |
| T1 | P12: Talking to somebody who's diabetic is such a help. When I first became diabetic, the nurse they sent me had all the textbook knowledge. It's like "Okay, that's helpful". I don't know why a different nurse came the next time and she said, "I shouldn't tell you this, but I'm diabetic". I said, "That's great". I could ask her all the things that had been going through my mind that I felt I couldn't ask anybody else because they really wouldn't understand what I was feeling. It was so helpful just to be able to talk to this nurse who was diabetic. |
| T1 | P14: I'd quite like to do something with other diabetics that want to lose weight as well. It's so different trying to lose weight with Type 1 diabetes. I've had personal trainers in the past, and they don't get it at all. They're like, "Why are you having juice at this point?" "Well, because I have diabetes” "Yes, but that's going to make you put on weight. "Yes, but I need sugar." "No, you need to quit sugar." "Well, I can't quit sugar." |
| T2 | P7: I’m going to say probably [Pump peer-support group] because it’s 24/7, sort of thing. I’m often on there even if I’m not asking questions I just look through it and it’s already been asked, so, it’s a lot easier. |
| T2 | P4 Maybe [Diabetes peer-support group] into the middle. I’ve been reading a lot more of their stuff on Facebook and it’s quite nice that, well it’s good to see people’s positive stories because, oh well done, but then it’s also good to see that everyone struggles with it on some days. Some days you just can’t tell why something is going wrong and it’s just irritating so it’s not just me… I’m paying more attention to them recently. |
| T2 | P3: I do value them definitely because of the support. The people are on there are all diabetic, they know what it’s like, they know the issues that come about and how to solve a problem. That’s what I like. People you can talk to who are diabetic and not that are just trained in diabetes. There is a difference between that. |
| T2 | P6: I think it’s partly because you have these group, because you start your pump with a group of people so straight away you start hearing about people’s back stories and you think, yes, I’ve experienced that, and you start to think actually yes, you could benefit from speaking to similar people more and obviously because you are all learning a new thing. But I think all diabetics could gain from speaking to others, but I just think when you are on pen you just go to your clinic, get interrogated and then you leave. That was my experience anyway. So it was kind of like diabetes is just a background thing, it was the thing you had and maybe once or twice a non-diabetic person would be like, oh wow what are you doing, and be all interested, and you tell them all about it and that would be that.  |
| T2 | P6: I remember when I went to my carb counting that was quite exciting because I then again met more people and was like, oh this is exciting. But then there is no continue on from that, so you are like, oh, OK |
| T2 | P10: That’s the other thing as well, I find sometimes people go on these things looking for an answer, but every type 1 diabetic is different as well. Then you get people on it like, oh you said do this, and obviously it’s the internet so everybody hides behind their keyboard don’t they and start shouting at each other.  |
| T2 | P9: Yes, if they can say, yes, actually I did have this problem and I’ve found that this is really helpful, you might find it helpful. Rather than, oh this is happening, that’s happening, I can’t do anything, I’m doomed. |
| T3 | P5: Oh, yes, very useful because it means, well like I said about the people on the course, you get a wider, if you speak to somebody or go on a forum you’ll find somebody has done that already. If you were going to Australia and didn’t know what to do about your pump you go on there and there will be a lot of people, they will all have dealt with it probably in different ways, but you’ve got an idea of how they did it and then you decide the way you want to do it yourself. |
| T3 | P6: Like I said about the whole community thing because it’s like you are not the only one and there are loads of other people and look at all these amazing things some people are doing; people do all this cycling and stuff and just, I don’t know, I certainly haven’t felt alone since I’ve been on the pump in a weird way. |
| T3 | P7: Well you go around asking questions and learn new things about it. Like at the conference they said to write all your basal rate is down. I’d never thought of that and I’ve done it now, but it’s that simple what can really help quite a lot. |
| T3 | P4: Yes, because I use YouTube like when I had complications with the pump when I first got it I used You Tube, so I think it’s good they’ve got lots of explanatory videos about how to set certain things up if I had any other complications. You know sometimes it does those electronic errors and things? |
| 4.2 Activities and apps |
|  | T1 | P3: I do like it. It’s good for my mental health. I find if I don’t exercise, I’m so, ugh, sluggish |
| T1 | P16: I love walking, I do know it’s great, it’s good for the diabetes not having so much insulin. So, I’ve thought at the moment that it’s all beginning to fall into place. |
| T2 | P3: You do notice when you are not exercising. It helps control I think exercise as well. I don’t know how but it does…Especially mentally as well, you feel low don’t you when you haven’t got the hormones going around. |
| T3 | P13: I have been down to the Men in Sheds…I: And would you like to do that?MP: Oh, God, yes. Well it was part of my work… So, yes, getting into something like that would be good…Take my mind off everything else… Yes, get into something else… when I told them that I was an electrician they went, oh! Ah! Their eyes lit up. Welcome, come on in. So I thought, OK. |
| Pump manufacturer helpline | T1 | P12: And I think probably, at the moment, not that I’ve used it; would be [pump helpline]… Maybe they'll be in the outer one because they're just going to be now and then, aren't they? |
| T2 | P13: Yes, the [Pump manufacturer] Helpline… Because when something does go wrong they are there with an answer. |
| T2 | P12: Oh, everything. Thank goodness they are there. I don’t like calling them, I guess that’s because to me it feels as if I’m not coping with my own problem, but I’m very glad that they are there. It gives you some sort of feeling of safety in a way that they are there if you need them. But I do generally like to sort things out myself, however, maybe not with this… And they’re so lovely, they’re so helpful there. It’s not as if they’re, oh it’s you again. |
| Reflections on the GENIE intervention |
| Concentric circles |
|  | T1 | P1: Concentric circles is quite good in terms of having a visual image of what is happening to you. That's quite reflective. That was quite fun. |
| T1 | P2: Very weird, because I didn't think I had that many people around me… But then going through it I’m like, "Oh yeah I see that person and can actually tell that person stuff." I realize that I do have quite a good network around me. So yeah, it was very weird, it feels like I’ve just opened up, everything…But yeah, it's very interesting to see, actually. |
| T1 | P5: It makes you realize, that actually it's quite a lot of people, it's not like you're relying on one person, but also, as you said, it's the reciprocity of it. They all ask me for help, pretty much. It's not just, like take, take, take. |
| T1 | P9: I think it’s useful, but I’m trying to sort out who is actually supporting me. Actually what is helping me and why. It’s not something I’ve actually tried to analyze like that…I think there's a lot more support out there probably online than I'm-- I think I could be getting a lot more support. |
| T1 | P11: It was actually giving some idea like, where actually you don't make me think like reflect on where do you work, who you have around, what kind of people, or groups who supports you. It can actually visualize and make you aware of, actually there are some people or some other opportunities to use. |
| T2 | P5: I did show it to everybody I think, and they were interested to see where they were. I think that might have made [daughter] think oh I’m a bit close perhaps I ought to move out a little bit. I think [daughter 2] went, oh I won’t phone you every day then! It’s really funny. That’s not why I showed them, but I just thought they’d been genuinely interested to see it. |
| Preference elicitation  |
|  | T1 | P2: I think it's all helpful actually because it was really reassuring for me to know the way I perceive people around me and also with the stuff I like doing and guide me to where I can actually do that. To those needs/wants. |
| T1 | P5: I think it's a good idea because it gives an extra dimension, of trying to find things that might interest you, or might help you. You might google something, but you wouldn't necessarily go, you might say, specifically, where is there Pilates in [Area]. But, it's giving you the bigger picture, of what's available. |
| T1 | P10: The whole volunteering thing, I've never known where to start kind of thing. That's something I've always wanted to do. I've just never gotten round to it kind of thing. Whereas seeing it there on the screen, I'm like, yes. It's like "Oh." Physically having it standing in front of you is quite nice. |
| T2 | P6: In the past I was really wanting to join up with either a knitting group or a drama group. I was desperately searching the web trying to find somewhere, but I was kind of, I’m not sure I just want to leap into the unknown. Whereas this feels a bit more safe. It’s not just some random people putting things on the Internet. |
| T3 | P7: It is helpful when obviously I was living in [Area] you could just click on it and see what all the groups were. You could click on the group and find out about the group, what time they are, where they are, even what age range normally go and everything. |
| T3 | P12: That might be something on there, a list of things that are out there that you could contact should you need to like your local diabetes centre, your local diabetic nurse, a local support group... Like signposting. |
| Delivering GENIE |
| In clinic | T3 | P3: I think in the clinics when you come and see everyone is probably if they go through that… I think you are thinking about it then, you are thinking about how you manage it whereas outside you think about here and now. In the clinic you are like what can I do… so if you have a high blood you just correct it and get on with it, whereas here you are like why was that high? When you are in the clinic you think what were you doing that day? |
| Through local groups | T3 | P5: I think probably tapping into the group, so whatever the Diabetes UK local groups are, I think they’d be interested in that and then perhaps do a workshop and say this is the principle and then let people have the opportunity to have a go and log in themselves. |
| Drop-in to GENIE | T3 | P5: And probably somewhere like the hospital if there was something like a drop-in and not just for pump clinics but to actually, so say for the diabetic clinic in wherever say well every, if you run every Tuesday then every second Tuesday so-and-so is going to come in, if you are interested in seeing this she will be there to ask questions. That kind of thing. |

A T1 - Baseline, B T2 - 3 months on, C T3 – 6 months on