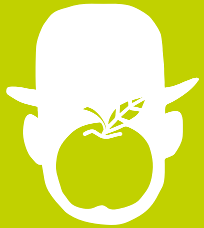

Experience Lab

Digital Diabetes

DIGITAL
HEALTH & CARE
INSTITUTE

GSofA
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scoping report

Authors

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Introduction

Following a diabetes targeted Digital Health and Care Institute (DHI) funding call in February 2015, the Digital Diabetes Programme was established to create a platform for integrated and collaborative innovation across seven projects selected for funding. The DHI Experience Lab Team were tasked with uncovering insights and themes to inform the design of digital innovation for people living with diabetes, alongside the complementary aim of exploring how these insights might also inform the development of a business case for personal digital health and care records for all citizens.

Aims of the report

This report seeks to share the preliminary findings of scoping activities as general themes to inform the design of research to explore and develop the Digital Diabetes projects with people living with diabetes and the people who support them. In addition to informing the subsequent research study design, the themes have been translated into design implications for digital health services. This report is supported by a short film, which includes footage gathered during public engagement and excerpts from interviews with people living with diabetes.

Background

'Digital diabetes' (i.e. digital products and services for people living with diabetes and their support professionals) is significantly further forward than other conditions in terms of acceptance and everyday use due to the need to monitor and record glucose levels and diet. This presents an opportunity to explore innovations in digital health technology with a group of stakeholders who are already using technology as 'experts' or early adopters with additional potential to apply the learning to other long term conditions.

Methods

Following scoping workshops with the seven applicants in late September, interviews were conducted with: people living with diabetes (n=10), carers (n=4), support organisations (n=2), health professionals (n=4) and relevant academics (n=4), alongside pop-up public engagement and desk-based research.

The interviews targeted a range of people living with diabetes, with a mix of: ages, genders, type 1 and type 2, people living in urban and rural environments, level of technology use, people also living with additional conditions and complications; and people in support roles including: parents and marital carers, nurses, GPs, diabetologists, consultants, third sector organisations; and experts

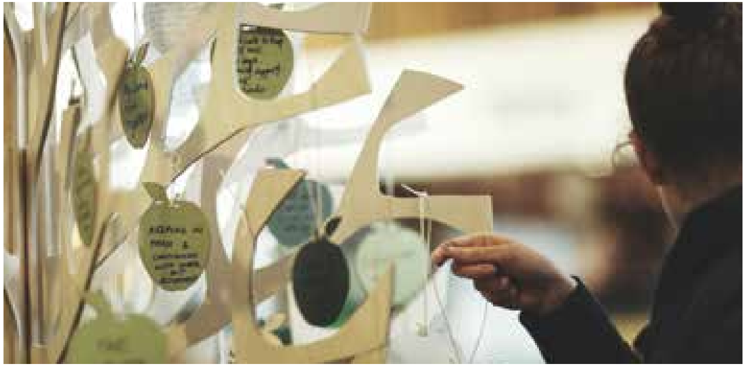
Methods (cont)

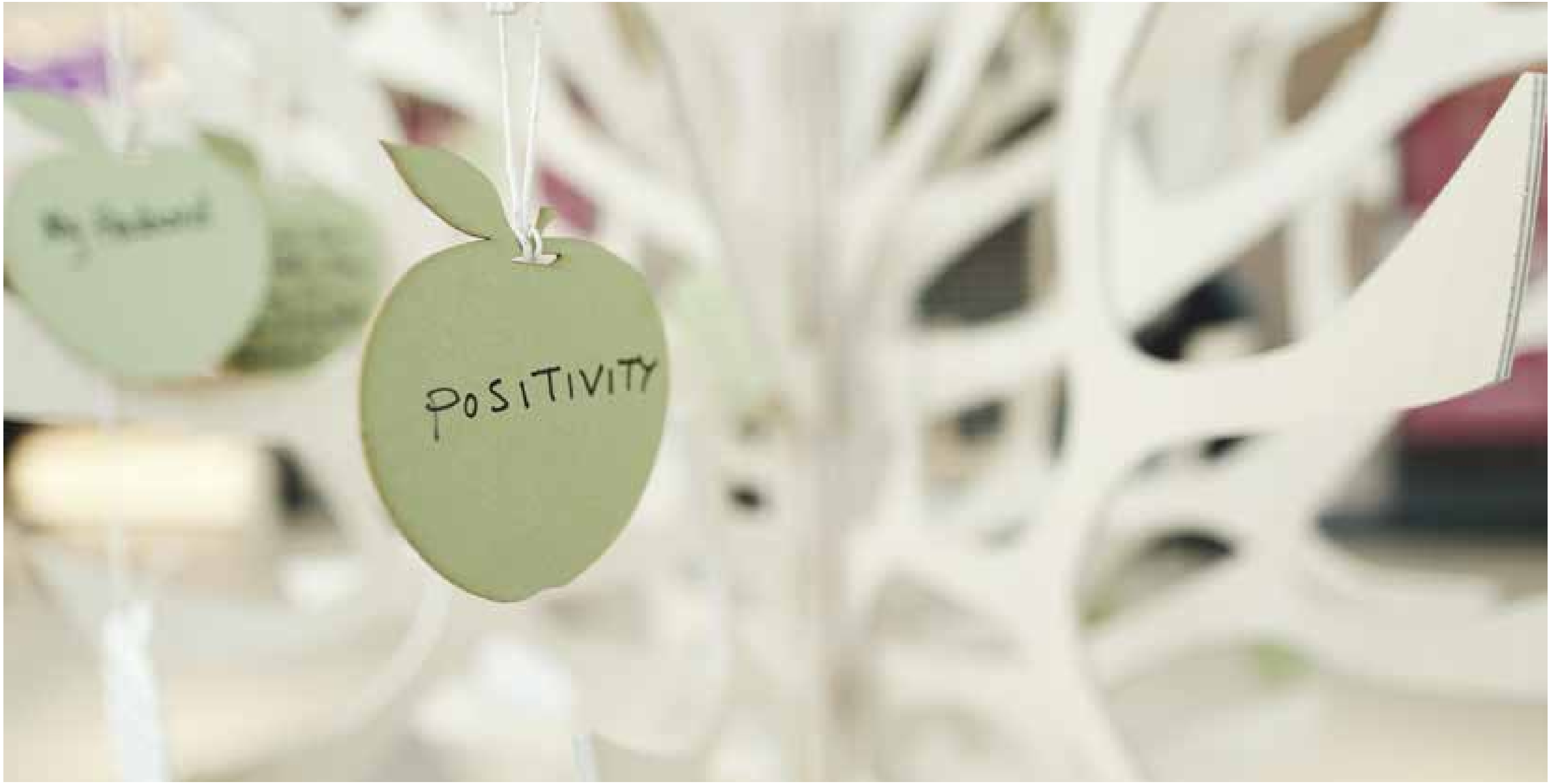
in behavior change, self management and using the internet and social media for health. These interviews explored people's experiences of living with diabetes, social support, relationships with health professionals, as well as the types of information, technology and resources available to support self management of diabetes. We were interested in understanding what works to engage people in the self management of diabetes, and the challenges of engaging or maintaining engagement. These topics were also explored through desk-based research to better understand the resources available for people living with diabetes and those who support them.

In addition to the scoping interviews and desktop research, the researchers engaged with the general public at Eastgate shopping centre in Inverness and Pollok Civic Realm in Glasgow. The team engaged with members of the public (n=150) using the opening question: 'what keeps you well?' with follow up questions to explore attitudes to health, relationships with health professionals, technology and interest in accessing health records online. Answers were written on card apples and hung on a wooden tree.

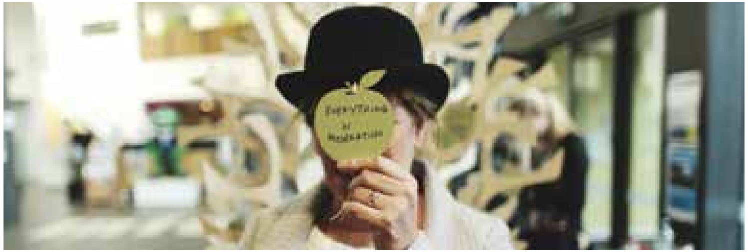
Findings

Through these activities we have heard some powerful stories about people who are living well with diabetes in challenging circumstances, and about the people who support them. We will share some of these stories as an introduction to the findings, followed by a discussion of the general themes identified through our interviews and desk-based research. Themes are supported with relevant quotes, and a discussion of possible implications for the design of digital services. Finally we draw conclusions on the relevance of our findings to digital health and care records and discuss the next steps for our research.




My Husband
POSITIVITY

Stories from engagement



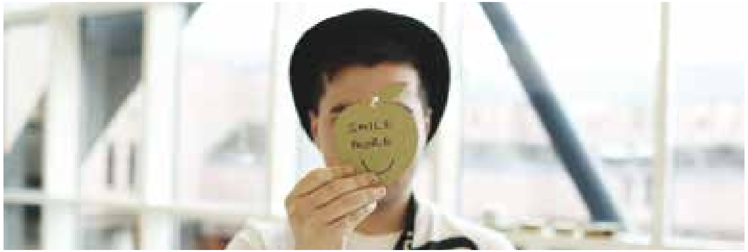
The ‘Bad Diabetic’

We spoke to a mother living with type 1 diabetes who spoke about her frustration with attempting to achieve control. Finding cause and effect has been a continuous quest, seeking out information and attempting to make sense of it all. Her hectic lifestyle does not fit with the regiments of good diabetes control and her situation is further complicated by the other health conditions she lives with, each treated in insolation by the health service. She finds that she is constantly being told off by her health professionals for not having good control despite her efforts, leaving her feeling disheartened and a “bad diabetic”. She would like her own self management information to be integrated with the doctors information to acknowledge her expertise and give her doctor a fuller picture to enable them to better support her to achieve control.

The Specialist Dietitian

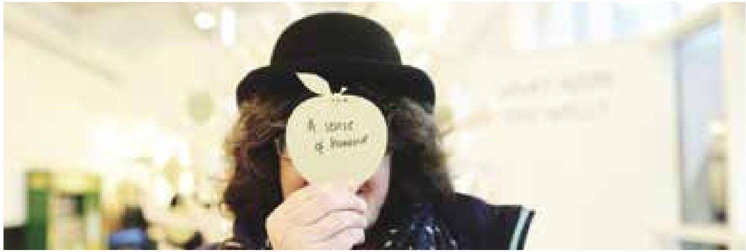
A dietitian told us about some of the challenges people experience in managing diabetes: depression, stress and competing responsibilities. Patients blame themselves because blood glucose levels can be hard to understand. It can be hard for her to provide the psychological support they need, and feels access to mental health professionals and better integration between services is required. She has undertaken a course in motivational interviewing to attempt to bridge the gap. Her unit is developing an online version of a course for carb counting and she would welcome a further opportunity to develop more resources. She has a strong desire to do more for her patients and create a more positive experience for patients.

Stories from engagement (cont)



The Father

We spoke with a father caring for his teenage daughter who was living with type 1 diabetes. Having been bullied about her condition in early life, she hates diabetes and conceals it from others, feeling it spoils everything: she just wants to be like her peers. Although well informed about managing diabetes, she has not engaged and tends to eat erratically, as a result her father has the challenging task of controlling her blood sugar levels without full awareness of her diet and activities. Using an insulin pump has made an incredible impact but they fear this will be taken away due to poor control. He often feels reprimanded rather than supported by health professionals, and receives conflicting advice from different consultants. They have tried everything to engage their daughter in self management, but feel she needs support from peers living with diabetes to get through this challenging transition into adulthood.



The Specialist Nurse

We spoke with a nurse who told us about the challenges of living with diabetes when transitioning into adult life, and her strategies for supporting young people living with diabetes. She often refers to her personal experience of type 1 diabetes, and feels sharing stories is powerful as it is important for people to know they aren't alone. She feels trust is hugely important and works towards building long term relationships with her patients, often focusing the clinic appointments on something they enjoy. She has worked towards implementing care packages and guidelines for young people with diabetes so they don't miss out on normal activities such as consuming alcohol, attending music festivals and getting a tattoo. Living with diabetes requires a regimented routine that's often impossible to maintain long term, she feels devising incentives will be key to the future of self management.

Themes

Control

The overarching theme was the need for control, which can be separated into two distinct challenges:

1) ***Objective control:*** seeking to balance blood sugar levels to within a safe range by monitoring diet, medication, activity levels and other variables.

2) ***Feeling in control:*** the confidence, knowledge and experience to take actions to regain control if diabetes behaves unpredictably. Making decisions and choices based on understanding and awareness of how diabetes affects them, and knowing where to go for support when required.

The remainder of our findings relate to effective support to achieve control in terms of: relationships with health professionals, information and social support

1) Objective Control

While striving for objective control, some people spoke about the need for balance, and the risk of becoming obsessive about blood sugar levels. Some people deliberately maintained lower or higher levels than advised e.g. due to concerns about long term complications, and wanting to avoid a hypo in front of their children. Parents spoke of the emotional highs and lows of checking their children's blood sugars throughout the day, describing their desperation with a lack of control due to the unpredictable nature of the condition or the choices their children make outside the home.

> ***"Even when you are 'on it' all the time, sometimes it just does what it wants."***

Understanding the reasons for lack of objective control was the most frequently expressed frustration of people living with diabetes. People told us that diabetes affects everyone in different ways, and that there are many variables that can impact on the way the condition behaves throughout the day and the life course. There was a clear need for support to understand unpredictable readings in order to take preventative actions to regain objective control and avoid long term complications.

Design implications for digital services

i) How can we support people living with diabetes and their health professionals to engage in dialogue to better understand the reasons for lack of objective control?

ii) How can we support people to gather data and relevant information about the variables that impact on their diabetes on a daily basis?

Themes (cont)

iii) How can we support people to see progress over time that could support reflection and understanding about objective control?

2) Feeling In Control

While striving to *feel in control* and remain engaged in self management of diabetes, people described the importance of their own attitude towards diabetes and resilience when set backs happen.

The relentlessness of diabetes was a frequent topic of discussion, with participants expressing the need for pragmatism and understanding that it is impossible to always remain engaged, even for the most conscientious of people. Diabetes needs to be consciously considered in every decision taken throughout the day, however small, and in busy lives there are many competing priorities and responsibilities.

> ***"It is like a weight. But the more you do it, it's just part of your life... You can't walk away from it. You can't have a day off from it, it's just there."***

The 'weight' of diabetes and lack of control was often overwhelming when combined with the stresses of every day life, and had led some people to experience depression. Negative past experiences such as seeing a relative live with serious complications, playground bullying or intrusive medical procedures and generally feeling a lack of support (see theme 3) also leads people to ignore or disengage from self management.

Trigger points for engaging or re-engaging with self management included changes in personal circumstances (e.g. pregnancy), hearing positive stories from people in similar situations, being offered new treatments (e.g. Insulin pumps) and training courses, and receiving a worrying test result with implications for longer term complications.

Design implications for digital services

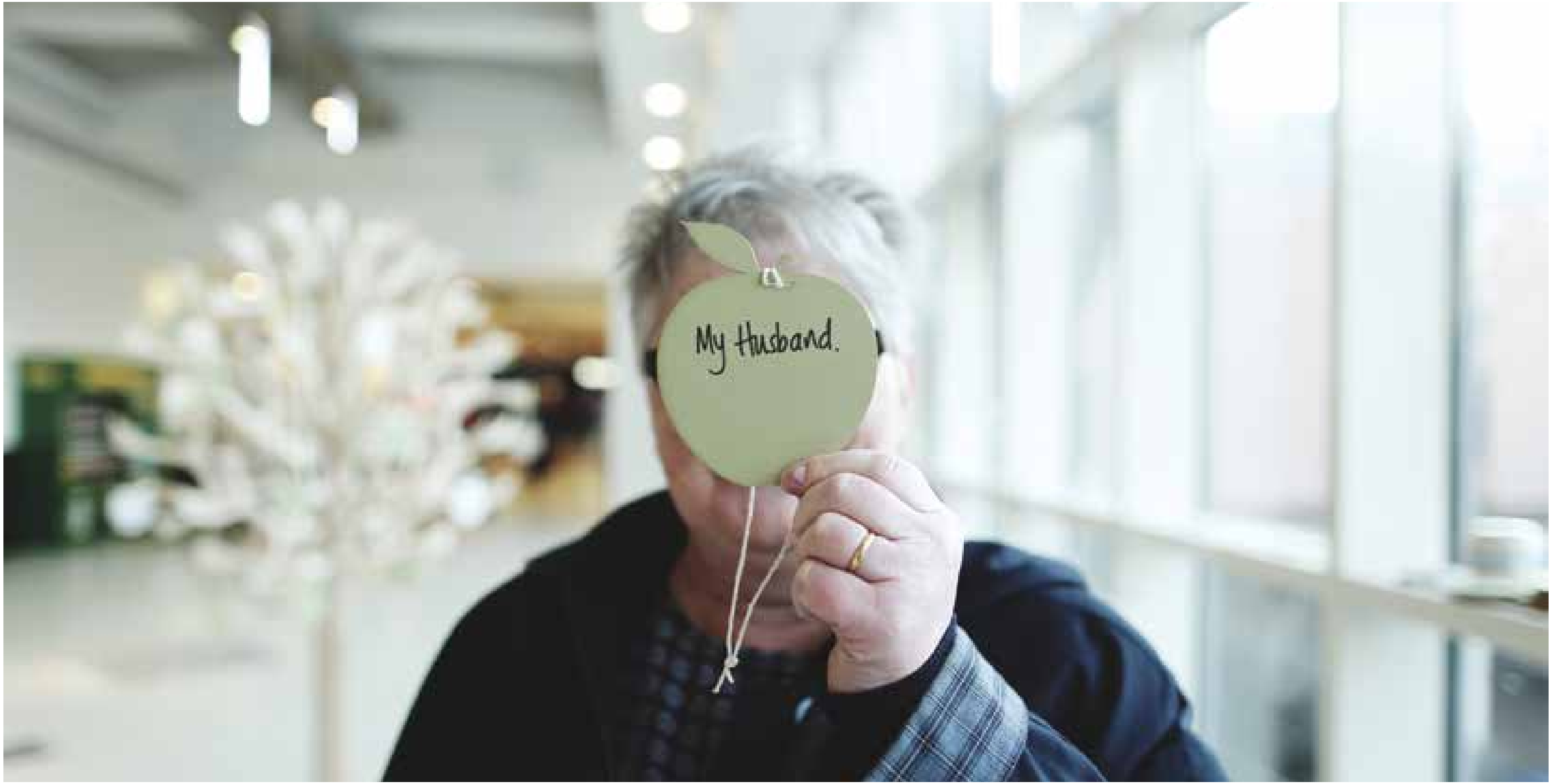
i) How can digital services make people feel more in control?

ii) How can digital services support pragmatic dialogue between people living with diabetes and the people who support them?

iii) Is there an opportunity for mobile tools support people to make better-informed decisions as and when they arise throughout the day?

iii) Is there an opportunity to include positive stories and messages?

iv) How can digital services support re-engagement at these trigger points?


My Husband.

Themes (cont)

3) Support to Achieve Control

Insights about the support and resources required to achieve control have been organised under three sub-themes: relationships with health professionals, information and social support.

a) Relationships with health professionals

Trust was seen as key to a supportive relationship with health professionals. This included trusting that the clinician was listening and understanding their concerns, trusting the quality of advice, and trusting that they were not withholding information relating to longer term complications. Conversely, people living with diabetes spoke about lying to their clinician to avoid being reprimanded for not achieving control.

People placed high value on working together with clinicians to understand the factors that affect their own diabetes, and receiving practical advice. Many expressed frustration when clinicians suggest that as the person living with the condition they know more about their diabetes than a health professional, or when they are praised: this was seen to be patronizing and wasteful of the potential value of an appointment in offering insight. In addition, receiving tests results during a consultation was seen as poor use of the appointment time offering no opportunity to reflect or formulate questions.

Some people living with diabetes highlighted the value of nurse specialists, offering a direct point of contact via phone/email for questions between appointments. Arranging appointments as required rather than scheduled around clinic availability was preferred.

> ***“I am very satisfied with my diabetic nurse... he’s a lifeline.”***

Conversations about long term complications were seen as difficult but necessary. People living with diabetes would prefer to be advised about changes in their condition as soon as they are detected so that they can consider preventative steps, rather than learning about them when they reach a pre-determined level which triggers a follow up.

Clinicians and support organisations told us about the importance of tailoring the tone, level and volume of information given to suit the person. People living diabetes and their carers found it challenging to achieve a supportive relationship with the health professionals when they saw a different consultant at each appointment, often resulting in conflicting advice.

Design implications for digital services

i) Is there an opportunity to improve trust between people living with diabetes and their clinicians by sharing data?

Themes (cont)

ii) How can small changes and trends be communicated to people to allow them to consider preventative actions?

iii) How can we share information about progress over time that could lead to changes in behaviour?

iv) How can we facilitate more direct contact and support at the time of need?

v) How can we support people to better prepare for consultations to ensure they gain valuable insight from the clinician?

b) Information

When seeking information about diabetes following diagnosis, people often relied on health professionals or family members who also lived with the condition. This was seen as an overwhelming time, and people appreciated receiving information gradually and learning through doing as challenges arose.

Many people spoke about seeking information about diabetes online. New circumstances or challenges prompted people to look online, often for highly specific or niche information and practical advice that would be unlikely to be available from their health professional. There was an appetite for up-to-date information about new technologies and breakthrough treatments, practical advice and emotional support from people in similar situations.

Filtering online information for relevance and quality by checking sources, reading discussion comments and consulting multiple sources was described. Those who didn't use online information expressed concern that they might become unnecessarily scared or worried by information about serious complications or negative stories.

When asked about accessing personal health information online, some people living with diabetes were not aware of existing resources such as My Diabetes My Way. For those who had used the service, there was positive feedback but frustration that results were only available after a consultation, with no new information between appointments. Data downloaded from Insulin Pumps was accessed using online systems, however the presentation of graphs and reports was seen to be very difficult to interpret.

During pop-up engagement, some people expressed concerns about the security of accessing personal health information online, or that they might get a unpleasant shock or become confused without their doctor to explain the information.

Design implications for digital services

i) How can statutory digital services leverage the wider eco-system of the different online information sources people consult?

Themes (cont)

ii) How can we leverage the 'wisdom of the crowd' and the lived experience of people living with long term conditions to ensure people have access to practical and emotional support?

iii) How can we support less confident technology users to engage with digital services?

iv) How can we ensure people understand what is contained within their personal health information?

v) How can we present data to facilitate pattern spotting and generate insight?

vi) How can we mitigate the risk of learning about negative test results or complications without the support of a health professional?

vii) How can we ensure people feel safe and secure when accessing personal health information online?

c) Social Support

When interviewing people living with diabetes and carers, it was clear that the support of family is vital to achieving control. In many cases, family members had spotted the changes in the person that led to their diagnosis. In every day management of diabetes, family members were experts in detecting high or low blood sugars through slight physical and behavioural changes, and experts in helping to correct these situations.

"For him it's his feet start moving… just kinda fidgety and agitated… but during the night… it would wake me up… he'll be pretty low by that point so I'll run for the Lucozade."

For people diagnosed with diabetes who had other family members living with the condition, the existing knowledge and awareness within the family made living with diabetes more manageable. For others, there was concern about a loss or change of identity within the family as people treated them differently following diagnosis. Where people didn't have a friend or relative living with diabetes, they tended to go online to seek advice and emotional support from others living with the condition.

"I guess I'm looking for affirmation that I'm not alone, just the fact that you're not the only one going through this."

Diabetes has a massive impact on the lives of carers and family members. People told us it was impossible to be spontaneous, with the need to plan ahead, remember medication and bring emergency supplies. Prompting loved ones to take a blood sugar reading or adjust their food intake tread a fine line between providing the nudge to get back in control or being the catalyst for a stressful argument.

Themes (cont)

People discussed the stigma of living with diabetes. Many people living with diabetes spoke about negative experiences of being asked not to check or treat their blood sugar levels in company. There was a perception that people living with type 2 diabetes were considered to blame for causing their condition, and many felt guilt when being reprimanded by others for not achieving control.

Design implications for digital services

i) How can we consider the needs of carers in the design of digital services?

ii) How can we include carers in conversations about health and care whilst protecting privacy?

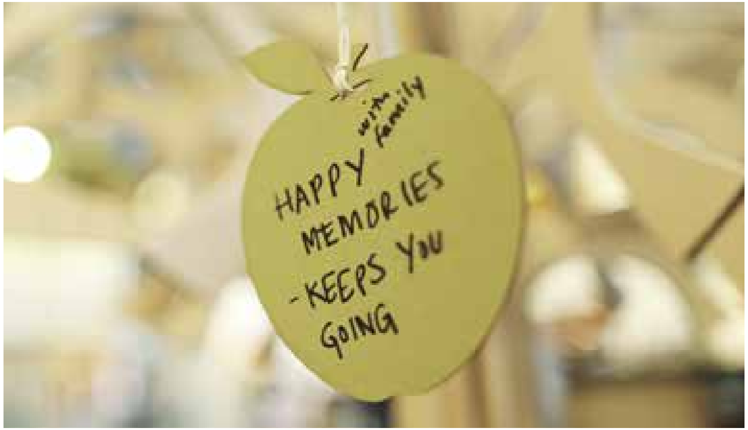
iii) How do we tackle the transition period between control passing between a parent and child as they move into adulthood?

iv) How can we support connections between people in similar situations to ensure they know they are not alone?

Conclusions

This report presents the findings of scoping activities to explore experiences of living with or supporting people living with diabetes, to inform our research to develop digital services to support engagement in self management. We have identified key themes and highlighted implications for the design of digital services. While the majority of our findings are drawn from peoples' experiences of diabetes, it is suggested that the themes and design ideas presented could have relevance to the wider population. To better understand this association, we have validated findings and gained further insights through public engagement on the subject of self management and digital health records.

Many of the insights relate to how people would hope to use their digital health information to support them to: reflect on progress and spot patterns, make changes to prevent future ill health, identify miscommunications and inconsistencies, and build trust with health professionals. Conversely, there was caution over the potential to incite obsessive tendencies, security and confidentiality, fear of uncovering unpleasant surprises or not understanding medical terminology, and concerns over a lack of technical capability. Many people told us that they felt they should be able to see and use information that is about them.



Next steps

We have identified a wide range of opportunities to improve support, alongside key challenges and ideas to enable dialogue that supports control of diabetes. We aim to develop the opportunities and ideas with end users over the course of the Digital Diabetes Programme. Our next phase of work will engage people living with diabetes, carers and health professionals in a series of three Experience Labs in January 2016, having gathered significant interest from potential participants during our scoping activities.