



**Experience Lab**  
Digital Diabetes

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## Contents

Executive Summary .....	2
Experience Labs .....	3
Digital Diabetes Programme .....	3
Key Insights from Preparatory Labs .....	4
Overview of General Labs .....	5
Experience Lab Activities .....	6
Findings .....	8
Opportunities for Design Innovation .....	16
Conclusions .....	17

## Executive Summary

This report describes General Experience Lab activity for the Digital Diabetes programme, a portfolio of seven promising innovation projects funded by the Digital Health & Care Institute (DHI) aiming to support engagement in self management of diabetes.

Experience Labs were developed by the Institute of Design Innovation at The Glasgow School of Art, aiming to offer a safe and creative environment where researchers, businesses, civic partners and service users can collaborate on innovative solutions to the health and care challenges facing our society.

The aim of the Digital Diabetes General Experience Labs was to bring together people living with diabetes, carers, clinicians and representatives from the voluntary sector to understand how people would like to be supported to engage in self management. Three Experience Labs were designed and facilitated by the Experience Lab Team, involving: people living with diabetes in rural locations (Lab 1: Inverness), people living with diabetes in urban locations and carers (Lab 2: Glasgow), and health professionals and representatives from the third sector who support people living with diabetes (Lab 3: Perth).

trusted health professionals and their community (including peers and support organisations) were seen as key to supporting engagement in self management.

The Lab findings are presented as a model of diabetes self management, describing the key factors that determine how well someone will engage in self management, and the people and

things that support them. Factors include the person's attitude towards diabetes and the relative importance it has in their life, and access to personal insight about their condition. Opportunities for new digital tools to support personal insight and positive attitudes towards diabetes were identified. Insightful and motivating conversations with trusted health professionals and their community (including peers and support organisations) were seen as key to supporting engagement in self management. Further findings relate to the differences between type 1 and type 2 diabetes, in particular the need for short term insight to improve control of type 1, in contrast with the need for insight to relate short term decisions to longer term consequences for people living with type 2.

Finally we present three key opportunities for design innovation to support diabetes self management: i) tools to generate personal insight including visual presentation of data; ii) tools to support insightful and motivational conversations; and iii) tools to give feedback on progress.

These findings will be used to shape the design of Niche Experience Labs to develop the seven innovation projects in collaboration with people living with diabetes, health professionals and project partners.

## Digital Diabetes Programme

'Digital diabetes' refers to digital products and services for people living with diabetes and their support professionals. Significant advances have already been made in this area 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 already use technology as 'experts' or early adopters with additional potential to apply the learning to other long-term conditions. The Digital Diabetes programme is a portfolio of seven promising innovation projects supported by the Digital Health & Care Institute (DHI), with the aim of fostering collaboration and integration where possible across the projects. Parallel research and development activities are being undertaken across the DHI development cycle of Exploratory, Experience Labs and Factory<sup>1</sup>. This report describes Experience Lab activity for the Digital Diabetes programme.

### Experience Labs

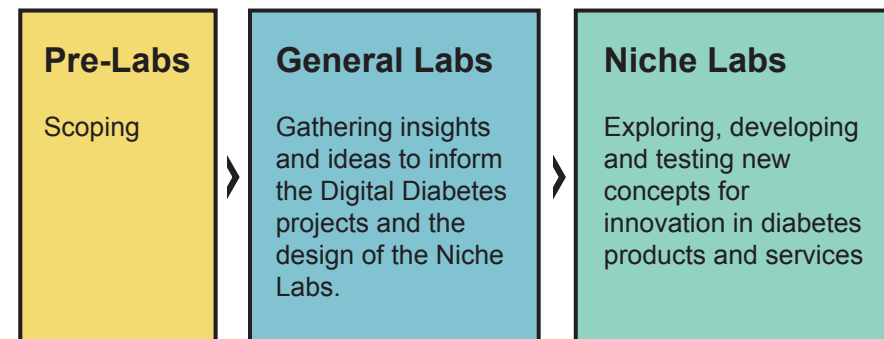
The Experience Labs were developed by the Institute of Design Innovation at The Glasgow School of Art. The Experience Labs offer a safe and creative environment where researchers, businesses, civic partners and service users can collaborate on innovative solutions to the health and care challenges facing our society.

Researchers use current and emerging design research methods to engage with our partners and participants, who are encouraged to share their own experiences. Real-life practice is often replicated to allow new technology, services, processes and behaviour to be

trialled rapidly. Researchers, partners and participants are supported to co-create potential solutions to achieve a preferable future. The resulting ideas become candidates for further research and development, allowing them to achieve their full potential.

The Experience Labs are a central element in the Digital Health & Care Institute (DHI), a Scottish Innovation Centre funded by the Scottish Funding Council, in partnership with Scottish Enterprise and Highlands and Islands Enterprise.

Following Pre-Lab scoping interviews, pop-up engagement and desk based research, General Experience Labs were designed to collaboratively explore common general themes and questions that cut across the projects. The general themes and opportunities identified through this work will inform further Niche Experience Labs research to develop the seven project ideas.



Structure of Experience Lab Activity for Digital Diabetes

<sup>1</sup> See <https://dhi-scotland.com/what-we-do#innovation>

## Key Insights from Preparatory Labs

Our Pre-Lab activities aimed to explore the subject of diabetes self management and inform the design of our General Experience Labs. We conducted interviews with: people living with both type 1 and type 2 diabetes, carers, support organisations, health professionals and relevant academics, alongside wider public engagement and desk-based research.

We identified key themes and highlighted implications for the design of digital services. The key findings were around the theme of control: both objective control, such as blood glucose readings, and the subjective feeling of being in control. We learned about the things that support self management, such as trusting relationships with health professionals, information and social support. We identified a wide range of opportunities to improve support, alongside key challenges and ideas to enable dialogue that supports control of diabetes. The detailed findings were reported in 'The Digital Diabetes Experience Lab: Scoping Report', available on request.

In translating the insights from the Pre-Lab activities into the design of the General Experience Labs, the team was struck by a metaphor used by one interview participant:

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

Participant, Pre-Lab Interview

This metaphor conveyed the burden of living with diabetes, and the relentless need to balance the many variables in order to



achieve control in their daily life. The team developed the metaphor further, likening experiences of diabetes self management to flying a hot air balloon: keeping the balloon at a safe altitude (or blood glucose level) by constantly adjusting fuel and monitoring weather conditions. The weight of diabetes became a series of sandbags (see p.14), each representing a different challenge identified through our Pre-Lab research. This inspired the design of the General Experience Lab activities, with the aim of opening up conversations to validate and develop our understanding, and identify opportunities to develop new services to support people to engage in self management.

## Overview of General Experience Labs

The General Labs aimed to bring together people living with diabetes, carers, clinicians and representatives from the third sector to understand how people would like to be supported to engage in self management. The findings of this phase of the research will be used to shape the design of Niche Experience Labs to develop the seven projects in the Digital Diabetes Programme.



### Exp Lab 1: Inverness

This Lab aimed to gather insights about the experiences of people living with diabetes in a rural location, with the aim of uncovering aspirations and unmet needs to inspire service innovation. Participants included people living with both type 1 and type 2 diabetes, recruited through a local Diabetes Scotland support group, as well as from participants of Pre-Lab scoping interviews and pop-up engagement.



### Exp Lab 2: Glasgow

This lab aimed to gather insights about the experiences of people living with diabetes and their caregivers in an urban location, with the aim of uncovering aspirations and unmet needs to inspire service innovation. Participants included people living with both type 1 and type 2 diabetes, and informal carers of people living with diabetes (e.g. parents, siblings), recruited through a local Diabetes Scotland support group and from participants of Pre-Lab scoping interviews.



### Exp Lab 3: Perth

This lab aimed to understand the experiences of health professionals and the third sector in supporting self management of people living with diabetes, with the aim of uncovering aspirations and unmet needs to inspire service innovation. Participants included acute and primary healthcare professionals who support people living with diabetes, clinical academics and a representative from a third sector organisation. They were recruited through the networks of Digital Diabetes project partners in the health service, and from participants of Pre-Lab scoping interviews.

## Experience Labs 1 and 2



As an icebreaker, participants were asked to share a personal passion, and a reflection about self management. They wrote their responses on paper flowers, which were added to a wooden tree. This activity aimed to help participants get to know each other by sharing something personal about themselves and their attitude to self management.

### Activity 1

Participants were asked to respond to a series of provocative statements gathered through Pre-Lab scoping interviews. They were invited to agree, strongly agree, disagree and strongly disagree to each statement, with an explanation why, with the aim of gauging the collective



consensus or contrasts in opinions within the group.

### Activity 2: Top Tips

Participants were asked to share their tips for living well with diabetes. Tips were written on paper flowers and added to the wooden tree, and shared with the group. This activity aimed to gather positive experiences of self management and caring, to understand what works and identify unmet needs.

Next we asked participants to reflect on and share positive feelings aligned to self management, putting these in decorative hot air balloon baskets. The top tips and positive feelings were intended to inspire the afternoon design activity.



### Activity 3: Design Challenge

Participants were asked to choose a challenge related to diabetes, inspired by our Pre-Lab insights. In small groups, they discussed the chosen challenge and developed a 'persona' or profile of a person who experiences it. Using a storyboard, they told the 'before' story for this person, informed by their collective experiences. They were then asked to imagine how this need could be met; exploring cards, describing ideas proposed in Pre-Lab interviews, and existing valued resources. The facilitator supported the groups to develop their ideas as sketches and design the 'after' storyboard, detailing how the identified challenge was overcome.

## Experience Lab 3



### Activity 1: Group Discussion

Lab 3 began in the same way as Labs 1 and 2, with a short icebreaker activity to enable the participants to get to know each other, followed by a facilitated whole group discussion. Again, participants were asked to respond to a series of provocations. The statements were framed as attitudes to diabetes self management, and reflected comments made by Pre-Lab interviewees and participants of Labs 1 and 2. Participants were then invited to agree, strongly agree, disagree and strongly disagree with each statement, with explanation as to why, with the aim of gauging consensus or contrasts in opinions within the group.



### Activity 2: Sandbags

This activity built on the metaphor of the hot air balloon, with decorative balloons suspended above the table, loaded with sandbags representing the five challenges identified in the Pre-Labs (see p.5). Participants were invited to remove the sandbags and discuss how they support people living with diabetes with this challenge (written on the tag). The discussion was recorded on tablecloths by the facilitators. A sixth sandbag asked them to reflect and discuss their personal challenge when supporting people who live with diabetes.



### Activity 3: Design Challenge

This activity largely followed the same format as in Labs 1 and 2, but was adapted to also include a persona developed to represent the health professional in the story.



## Key Findings from General Labs

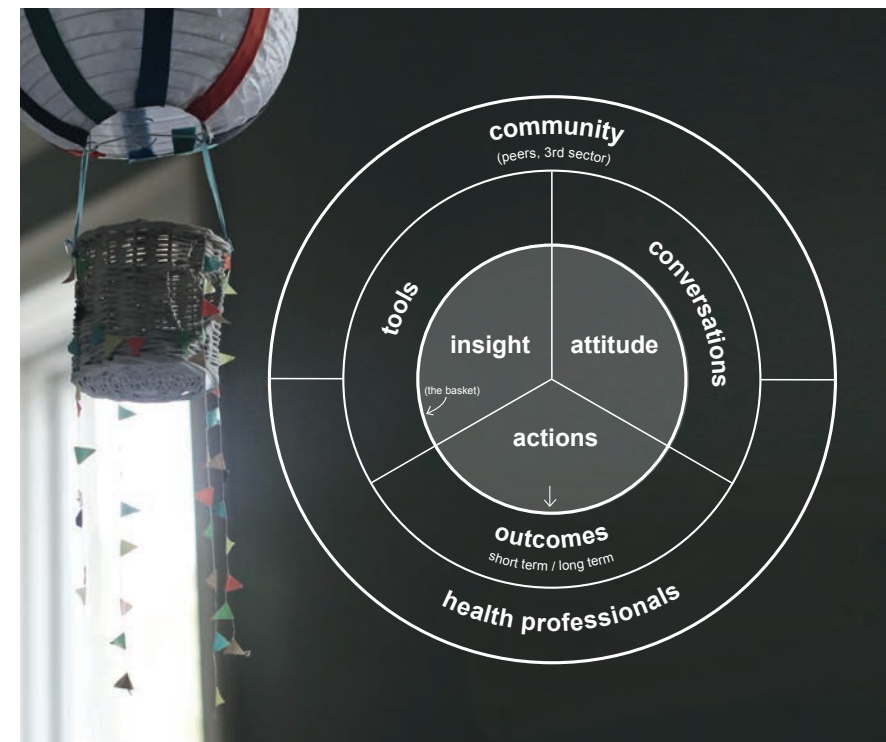
The activities were recorded using workshop materials and by note-takers. The transcribed materials and notes were thematically analysed and synthesised using a simple model that illustrates the key factors relating to experiences of living with diabetes, and supporting people who live with diabetes. This model builds on the hot air balloon metaphor developed to communicate insights from our Pre-Lab activities (see p.4), and explored during the General Labs.

We found that the metaphor was a useful tool to aid discussion during the Labs, with participants embracing and building upon the metaphor to illustrate a particular aspect of their experience or perspective. It was meaningful to people living with diabetes, carers and health professionals and became a shared point of reference during collaborative activities. As a result we have developed this metaphor into a model to synthesise and communicate our learning about diabetes self management.

The model is presented visually and discussed. Further findings relating to the discussion of the challenges uncovered in the Pre-Labs (p.5) are presented. Finally we consider the key opportunities for design innovation, identified through the outputs of the design activities across the three Labs.

## The Diabetes Hot Air Balloon

We would like you to imagine that the diagram below represents a hot air balloon in-flight, viewed from the ground. From this perspective, the basket is the inner circle, with the outer circles representing the balloon. Here the basket represents life for the person living with diabetes (the pilot) and contains the factors



Model of Diabetes Self Management

- insights, attitude and actions - that contribute to their engagement with self management. The balloon itself represents the things (middle circle) and people (outer circle) that support the basket to keep afloat.

We will explore each of the different parts of the model in detail, and explore the insights it represents about people's experiences of diabetes.

### **Life in the Basket...**

The person living with diabetes is the pilot, using trial and error to adjust the temperature of the air in their balloon to keep them at a safe altitude. As the pilot becomes more experienced, so they can better manage their control and cope with the challenges and surprises as they arise.

Many people with living with type 2 diabetes told us that they were largely left to pilot their balloon without training following diagnosis. Specialist support was often not available, and it was up to them to discover how to manage their condition through proactive research. In contrast, some people living with type 1 diabetes felt that in the early stages of receiving diagnosis their health professionals gradually taught them the techniques needed to operate the equipment and resources they needed to use.

### **The Snake in the Basket...**

It is impossible to see what is happening in the basket from the ground, as it is to know what it is like to live with diabetes if you are not experiencing it. There are many competing demands on the attention of the pilot: there may be passengers or dependents they are taking care of, or in the words of one of our participants:

*“If there is a snake in the basket, piloting the balloon will be the least of their worries.”*

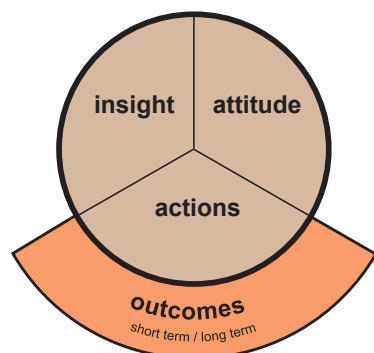
Participant, Lab 3

Until they have been able to deal with the problem of the snake, the dangers of losing control will be a much lower priority. As with diabetes, health professionals need to be aware that at points in the journey of living with diabetes, other competing challenges and stresses can make it difficult to engage in self management.

Each hot air balloon pilot glides a different path largely dictated by the wind direction, but pilots can use other balloons as a guide to know which way the wind is blowing and adjust their path to reach their preferred destination. In the same way, people living with diabetes find it helpful to talk to others living with the condition, learning from their strategies for self management and finding emotional support from the awareness that they aren't alone.

## Ingredients for Self Management

Participants told us about two factors that play an important role in determining how well someone will engage in self management, and their resulting **actions**, which may positively or negatively impact on their health **outcomes**.



### Insight

Understanding the reasons for poor control was the most frequently expressed frustration of people living with diabetes. People told us that diabetes affects everyone in different ways. There are many variables that can impact on the way the condition behaves and many actions that can help. Despite the wealth of personal data and generic advice and guidelines available, this information in itself is not insight, and it can be difficult to relate to personal experiences of diabetes. People highly valued personal **insight** that could help to make sense of their condition, from health professionals, technology, organisations and peers.

For people living with type 1 diabetes, reviewing short-term data (e.g. insulin pump data) with their health professionals was often insightful, as they could share what was happening in their lives at the time to help interpret the reasons for any unexpected results. Although this personal data is available, the output formats are difficult to interpret and do not support pattern spotting.

For people living with type 2 diabetes, there was a need for personal insights that could help them to understand, accept and action the lifestyle changes that were required to reduce risks of long-term complications. People told us that general and non-specific advice can be difficult to relate to their own daily life, and for many people the lack of any symptoms or consequences of not following advice was a challenge to self management.

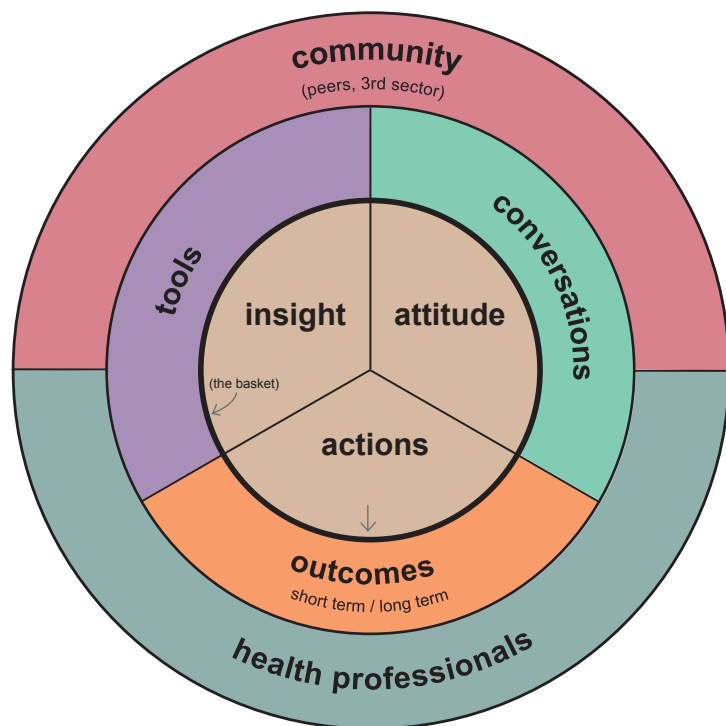
### Attitude

The other key ingredient to successful self management is a positive attitude. Through our Pre-Labs we learned that feeling in control of diabetes and was key to coping with daily challenges and making healthy choices.

Health professionals told us that understanding their patient's attitude towards diabetes and the relative importance it had in their life was key to supporting them. Reprimanding or scaring people into engaging in healthy behaviours can often have the opposite effect because it is demotivating and takes away feelings of control. Positively framing conversations around the things that matter to the person can support them to re-engage and remain motivated.

## Support to keep afloat

The hot air balloon creates the lift needed to keep the basket afloat. In our model we have used this as a metaphor for the different kinds of people and resources that support diabetes self management.



On the outer edges of the balloon we see the **health professionals** and people in the **community** who support self management.

## People that Lift the Load

### Community

‘Community’ includes the wider family, support organisations and the general public. People told us about great community organisations and local support groups that they value. Some of our health professionals felt they had little awareness of good quality community resources that they could recommend to their patients. They felt that, for many patients, support to help remove the snake from the basket would be better found in the community. We learned about an innovative new programme of Links Workers<sup>2</sup> based in GP practices to help people to access non-clinical support.

### Health professionals

Health professionals include a wide spectrum of people from specialist consultants through to community pharmacists. For people living with type 1 diabetes, this tended to be consultants and specialist nurses. For people living with type 2 diabetes, this was often their GP. Through our Pre-Labs we learned that trust was seen as key to a supportive relationship with health professionals, including: 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 and feeling that their time, as well as that of health professionals, was wasted on meaningless consultations.

<sup>2</sup> See: <http://links.alliance-scotland.org.uk>

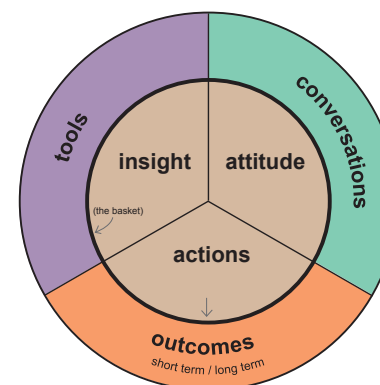
People living diabetes and their carers found it challenging to achieve a supportive relationship with the health professionals when they saw a different consultant at each appointment, often resulting in conflicting advice. One person living with diabetes told us that they found it useful to refer to national clinical pathways documentation to understand what support they were entitled to, but suggested that most people were not aware of this useful resource.



## Things that Lift the Load

### Outcomes

Seeing feedback on the results of their actions was seen as a way to influence attitudes and generate insight. For people who had accessed their My Diabetes My Way record this was seen as a useful way of reflecting on long-term progress, but lacked short-term feedback on their actions.



### Tools

We learned about a wide range of high and low-tech tools that help to generate personal insight. These include insulin pumps and continuous glucose monitors that reduce the need to manually monitor blood glucose and dosages, as well as diaries and training courses. Many of the Digital Diabetes programme projects aim to operate in this space, whether through gathering and presenting personal data in new ways or through automatically analysing personal data to provide timely advice. These projects offer the potential to meet the identified need for

personal insight to support self management. While it would be challenging for people to manually track lifestyle information (e.g. diet, physical activity) in addition to all their other health data, there was a willingness to do this for a few days per month in order to gain insight, and/or to complement this information using automatic trackers if built into existing devices.

### Conversations

Person-centred conversations with health professionals, peers and support organisations were seen as key to achieving insight and supporting positive attitudes towards self management. Conversations about long-term complications were seen as difficult but necessary. Clinicians and support organisations told us about the importance of tailoring the tone, level and volume of information given to suit the person.

A number of our Digital Diabetes programme projects aim to create tools to support health professionals to create supportive and insightful consultations. Strategies might include encouraging the person living with diabetes to reflect on their goals and questions in advance, in order to help the health professionals tailor the conversation to their needs. Positively framing conversations around the future and the things that matter to the person can support them to re-engage and remain motivated. Embedding these techniques within consultations can be challenging, and tools need to ensure they help structure and maximise the time available, rather than adding to an already long list of things to be achieved in a short consultation.



## The weight in the basket

The sandbags offer a further opportunity to unpick some of the specific challenges facing people living with diabetes, their carers and health professionals and suggest strategies for engaging people in self management.

### An Impossible Goal?



Keeping the hot air balloon at a steady and safe level seemed for some to be an impossible goal. Diabetes affects everyone in different ways, with many variables that can impact on the way the condition manifests through the day and over time.

Understanding the reasons for unexplained fluctuations in blood glucose readings was a frequently expressed need. Participants were reassured to know that others struggle to achieve the levels advised by their doctors, despite their best efforts. Accepting that control would not be achievable 100% of the time made some participants more likely to keep motivated to self manage, because they felt more positive about their ability to cope rather than feeling that they had failed. Although health professionals need to encourage their patients to strive for steady control, they are most effective when they do not reprimand if goals are not met, instead listening and providing practical advice.

### Building Trust



Trust was seen as key to a supportive relationship between people living with diabetes and their 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. Conversations that build trust should focus on the priorities of the person, although this can be challenging to balance with the demands of clinical targets for care. 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, the feeling of being shuffled through the system, and a lack of person-centred advice. One notable exception to this were the people who had access to a diabetic specialist nurse.

### Consequences



Taking a break then 'dealing with the consequences' was seen as a reality of living with type 1 diabetes. Many felt it difficult to be spontaneous, needing to plan ahead and have emergency supplies for every situation. Many people living with type 2 diabetes feel no immediate consequences or symptoms following unhealthy lifestyle choices, and as a result they struggle to accept the need to change habits. For some people who had made positive lifestyle changes, they felt that explicit information about longer term consequences was key and should be communicated at diagnosis. This was echoed by a health professional in general practice, who emphasised the positive benefits of making lifestyle changes in reversing and curing type 2 diabetes.



### Information is not Insight

People appreciated receiving information at their own pace and learning through doing as challenges arose. Filtering information for personal relevance and quality was described as a continuous process. While there is potential to gather or access many different types of personal health and lifestyle data, the information is not practically useful without support to analyse, understand and action the insights they contain.



### One Condition?

In addition to these specific challenges, the Labs also highlighted a broader point about the differences between type 1 and type 2 diabetes, and the challenges of supporting both groups using the same service and resources. Consultants told us that the increase in type 2 diabetes placed increasing demand on their service, and that some people living with type 1 diabetes found it uncomfortable to be considered as having the same condition due to the perceived stigma of type 2 being a lifestyle condition. While there were many similarities in the challenges of self management, there were key differences in the unmet needs of each group, in particular the need for short term insight to improve control of type 1 diabetes, in contrast with the need for insight to relate short term decisions to longer term consequences for people living with type 2 diabetes. This is important to consider when designing subsequent Niche Experience Labs to ensure we

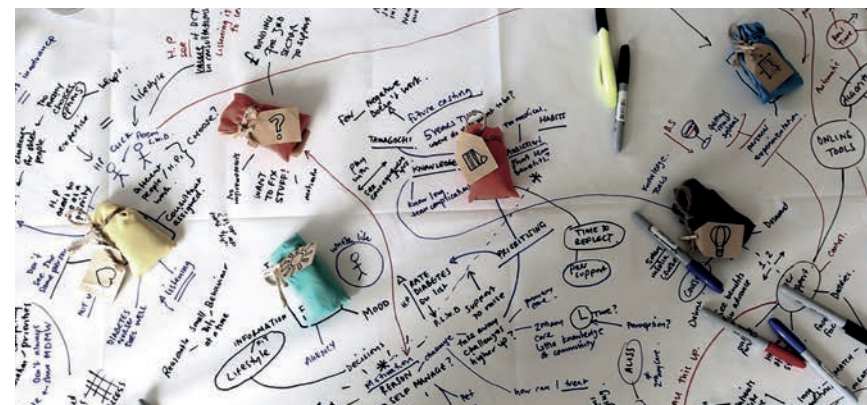
balance the needs of people living with both type 1 and type 2 diabetes.



### Challenges of Living in a Rural Area

People living with diabetes in rural areas (Lab 1) spoke about the challenges of accessing specialist health services, such as the need to travel long distances for clinic appointments and the lack of information about local information events and training. The reduced likelihood of knowing someone else with diabetes made it difficult to benefit from information and support from peers: something that was highly valued by participants in Lab 2 (Glasgow).

Health professionals with a specialist interest in diabetes working in rural communities also lacked peers to share information and support. A lack of awareness or provision of community/third sector services limited their ability to refer patients to more appropriate services within the community.





## Opportunities for Design Innovation

The general Experience Labs have highlighted a number of key opportunities for design innovation to support diabetes self management.

The hot air balloon illustrates three strategic areas to facilitate relationships between people living with diabetes, their health professionals and third sector and community resources to support self management:

### 1) Tools to generate personal insight

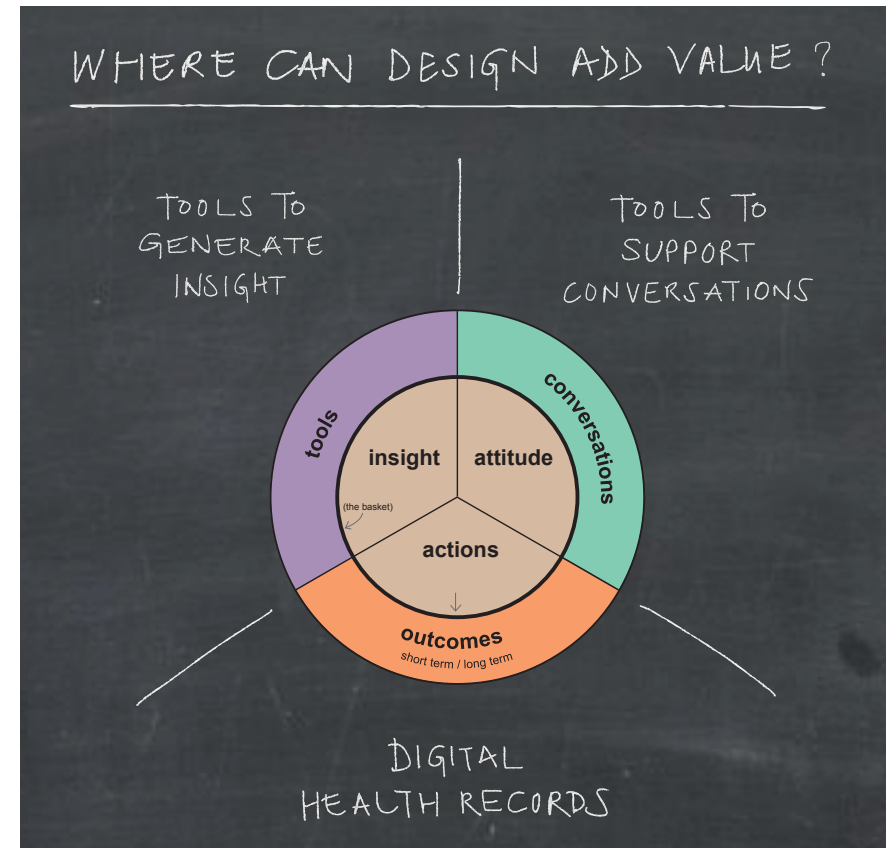
- Exploring how the visual presentation of data can facilitate pattern spotting.
- Exploring the use of algorithms to review data and give personalised feedback.

### 2) Tools to support insightful and motivational conversations between people living with diabetes, their health professionals, organisations and peers

- Exploring how behaviour change techniques can be embedded before, during and after consultations.
- Exploring how tools to generate insight can be used within consultations.

### 3) Tools to give feedback on progress, in particular access to meaningful personal health information

- The development of digital health records and services such as My Diabetes My Way to ensure they present meaningful and useful information about short and long term health outcomes.



As illustrated in the balloon model, we see these resources as the connection between the person living with diabetes - the pilot of the balloon - and the people that support them to keep afloat – the health professionals and their community.

Reflecting on our design challenge activity (p.6), it was interesting to note that in all three workshops, people living with diabetes, carers and health professionals developed ideas and solutions based around connecting with existing community resources for peer support to tackle their chosen challenges. This highlighted that in many cases, the support needed to self manage may not be clinical, and suggests opportunities to explore how design innovation could:

- Support and build on schemes like Links Worker programmes and ALISS<sup>3</sup> to support health professionals to refer their patients to community and third sector resources,
- Support people living with diabetes and their family members to connect with peers in their community.

## Conclusions

This report has presented the findings of our General Experience Labs, using the metaphor of a hot air balloon to illustrate the insights gained and relate them to opportunities to innovate support for diabetes self management. The hot air balloon visual model puts the person living with diabetes in charge of managing their condition, piloting the balloon according to their attitudes, insights and actions. Helping them keep afloat through conversations and tools are health professionals and a person's family, friends and wider community.

The next stage of the Digital Diabetes Programme will build on these insights to develop the seven innovation projects through a series of Niche Experience Labs. We are currently working with each of the projects partners to design the Labs, with the aim of collaboratively validating and developing the concepts with end users.

<sup>3</sup>See: <https://www.aliss.org>