Experience Lab
Digital Empathy

Project Report ➡

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Digital appendix

University of the Highlands and Islands + GSA

Digital Empathy

Exploring the role of 'digital empathy' within emergent and future models of digital healthcare services such as Video Conferencing (VC) consultations, with a focus on providing care for people living with diabetes.

2016

Participants: 13

Methods:
Non-participant observation
Storyboarding
Experience mapping
Low fidelity prototyping
Affinity diagramming

Three Labs
+ 3 Pre-Lab Observation sessions

Lab Team:
≫⟶ Sneha Raman
≫⟶ Jeroen Blom
≫⟶ Jay Bradley

Empathy

Lab Locations:
Forres + Skye

10 Pre-Lab observation hours

14 Lab hours

Tools:
- Scenario postcards
- Storyboards
- Modular props: Blank cubes and canvases
- Experience map
- Empathy rating discs

Academic Output:
▶ x1   x1
- Report
- Video
- Case study (under review)
- Paper (in planning)

Executive Summary

Digital Empathy is an Experience Labs project which employed participatory design methods to investigate the role of empathy within the emergent and future models of digital healthcare services, such as Video Conferencing (VC) consultations. The project had a pa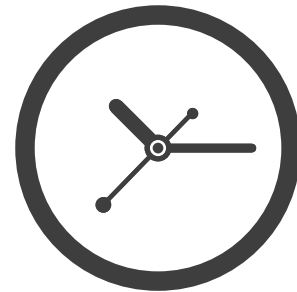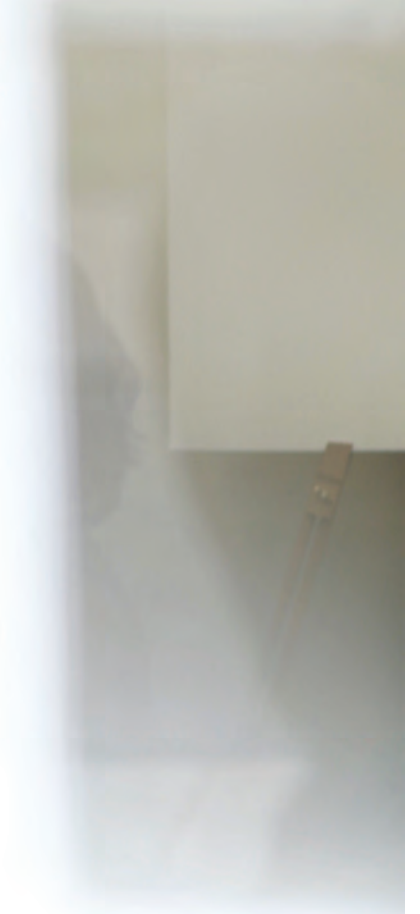rticular focus on delivering care for people living with long-term conditions, e.g. diabetes. A number of factors have an impact on empathy, such as patient pre-conceptions and other individual characteristics, the corresponding behaviours and beliefs of the clinician, and the setting of the consultation. The aim of the Experience Labs was to explore whether people's perception of empathy changes in a digital context, and to identify factors that are deemed important to empathic VC consultation. The project was proposed by the University of the Highlands and Islands, and was accepted by the Digital Health & Care Institute as Experience Labs. Two Experience Labs were held across three locations in the North of Scotland between February and June 2016. This report presents the findings from Lab activities.

Pre-Lab observations were carried out in three sites with VC clinics in the Highlands at the start of the project, in order to gain experience of the VC clinic settings and factors that contribute to an empathic experience. Experience Lab

1 was organised in two locations, with the aim to explore what empathy means for different individuals. The sessions were designed to gather stories of personal experiences of using healthcare services, in order to create a shared understanding of empathy and what 'digital empathy' might mean in the context of VC consultations. Design tools such as stories boards and a process map were used to capture insights from the session. In Experience Lab 2, the focus was on ways of delivering digital services in future scenarios in order to create a more empathic experience in VC consultations for diabetes care. Design props and an iterated version of the process map were used to explore future scenarios. The findings from the Labs highlight key factors such as access to shared and meaningful data; clear verbal communication; providing choice of preferred pathways for continued care; presence of the diabetic nurse; preparation and access to information before consultation; and summary to take away afterwards as some of the key factors that have an impact on empathic VC consultation.

Experience Labs

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

In the Experience Labs, researchers use current and emerging design research methods to engage with 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. The resulting ideas become candidates for further research and development, allowing them to achieve their full potential.

Digital Health & Care Institute

The Glasgow School of Art is a founding partner in the Digital Health & Care Institute (DHI), which is a partnership between NHS 24, Scottish Enterprise and Highlands and Islands Enterprise.

The DHI Innovation Centre creates an open community where industry can collaborate effectively with academia, health, care and social partners on innovation opportunities that will create societal and economic benefits in Scotland. The DHI will co-create sustainable economic growth through new products, services and systems. These solutions will generate high value health and social care solutions to the benefit of the people of Scotland and further afield.

Experience Lab Project Team

Sneha Raman	Research Associate
Jeroen Blom	Research Fellow
Dr. Jay Bradley	Research Fellow

Partners

Prof. Sandra MacRury	University of Highlands and Islands
Dr. Wendy Maltinsky	University of Highlands and Islands

Project background

Diabetes Care

Diabetes is a chronic and progressive disease, which if inadequately controlled can lead to a range of serious health complications. Individuals living with diabetes will have routine visits with the diabetologist if attending secondary care or GPs if managed in primary care along with others in the diabetes care service – podiatrists, dieticians, and the diabetes specialist nurse, retinal screeners and possibly a pharmacist. The objective of each visit is to review how well the individual is managing the condition, in particular blood glucose levels, as well as to check the health of feet, eyes and kidneys, all of which can be unduly affected by fluctuating blood glucose levels. Not only is a reasonably high level of health literacy required of people with diabetes in order that they can manage their condition effectively and reduce risk of future complications (Persell, Keating, Landrum, Landon, Ayanian, Borbas & Guadagnoli, 2004), but collaboration between the individual with

diabetes and the clinicians (and often family) is also paramount. The collaboration between clinician and patient increases trust and patient empowerment, which has positive outcomes in terms of self-care (Funnell & Anderson, 2004; Street et al., 2009). Interpersonal warmth and perception are often conceived as being inextricably linked to levels of empathy. Within diabetes, earlier studies demonstrated that non-verbal cues, length of time of appointment and verbal communication have correlated with satisfaction and compliance (Del Canale et al, 2012). Self-care behaviours of the person with diabetes are positively associated with a perception by the individual of being understood.

Digital Interaction in Healthcare

Different models of healthcare have been trialled to widen access and improve healthcare service (Gomez et al, 2002) that allow people to choose ways of interacting with healthcare providers that are beyond a physical clinic (text, email, phone, video consultation etc.);

and enabling service users and healthcare professionals to interact at distance. In Scotland, where remote and rural geographical regions may prohibit or compromise access and increase healthcare service costs, telemedicine is seen as a great advantage that can circumvent issues of accessibility and maximise available clinic time. Patient satisfaction in telemedicine services has sometimes been recorded as equitable to those of face-to-face provision though other factors such as timing of appointment, length of time in waiting room and, length of time travelling to appointment may also be influential factors in measurements of satisfaction (Gustke et al, 2000). The advantages of telemedicine include being able to send images, share information speedily, remove barriers of access and reduce impact on lifestyle, as well as maximising service provision (Riva, Mazzocco, & Pravettoni, 2015). However, the way we currently communicate online is predominantly text-based, which does not allow for expression of the richness or the subtlety of human interaction

– of particular importance in a healthcare context. Similarly, video consultation allows visual interaction but can lack the emotional depth of face-to-face contact.

Empathy in Digital Interaction

Empathic communication has been successful in various telehealth uses, not least of which has been in the area of palliative care and psychosocial interventions where the empathic relationship is a fundamental part of the consultation (van Gurp, van Selm, Vissers, van Leeuwen & Hasselaar, 2015). The empathic clinician-patient relationship relies on two entities: the behaviours, verbal/non-verbal, intonations etc. of the clinician, and the perceptions of the patient. Some research has demonstrated that there may be no real differences in clinician behaviour on the part of the clinician between digital and face-to-face interviews (Edison, Fleming, Nieman, Stine, Chance & Demiris, 2013); however, the patient may perceive the level of empathy as different. Miller (2011) argues that without the detailed analysis

of how and in what way the subtlety of communication changes in clinical video conferencing communications the impact on health service and health outcomes, the uptake by patients and interested clinicians will be necessarily slow due to lack of confidence. For the individual living with diabetes, quite complex information is often exchanged in consultations. Because of this, other factors may be important to consider in how the consultation is assessed as empathic. For example, the presence of the Diabetes Specialist nurse in the room with the individual may have value as a conveyer of information, technical expert and empathic conduit (Doolittle & Allen, 1997). Situational anxiety that some patients may experience prior to consultation may also be heightened by the digital technology medium and this too may possibly be alleviated by the presence of a health care professional in the room. Whatever the circumstances and factors that emerge as necessary for video-conferencing (VC) consultations to be judged as empathic, this may require

additional training. As such there is a need to investigate and develop ways of expressing our digital personhood and to isolate the factors that are deemed important to empathic VC communication. This may include patient pre-conceptions, or other individual characteristics, and the corresponding behaviours and beliefs of the clinician as well as the setting, including the presence of a diabetes specialist nurse. It is also important to consider how we can develop training in this area.
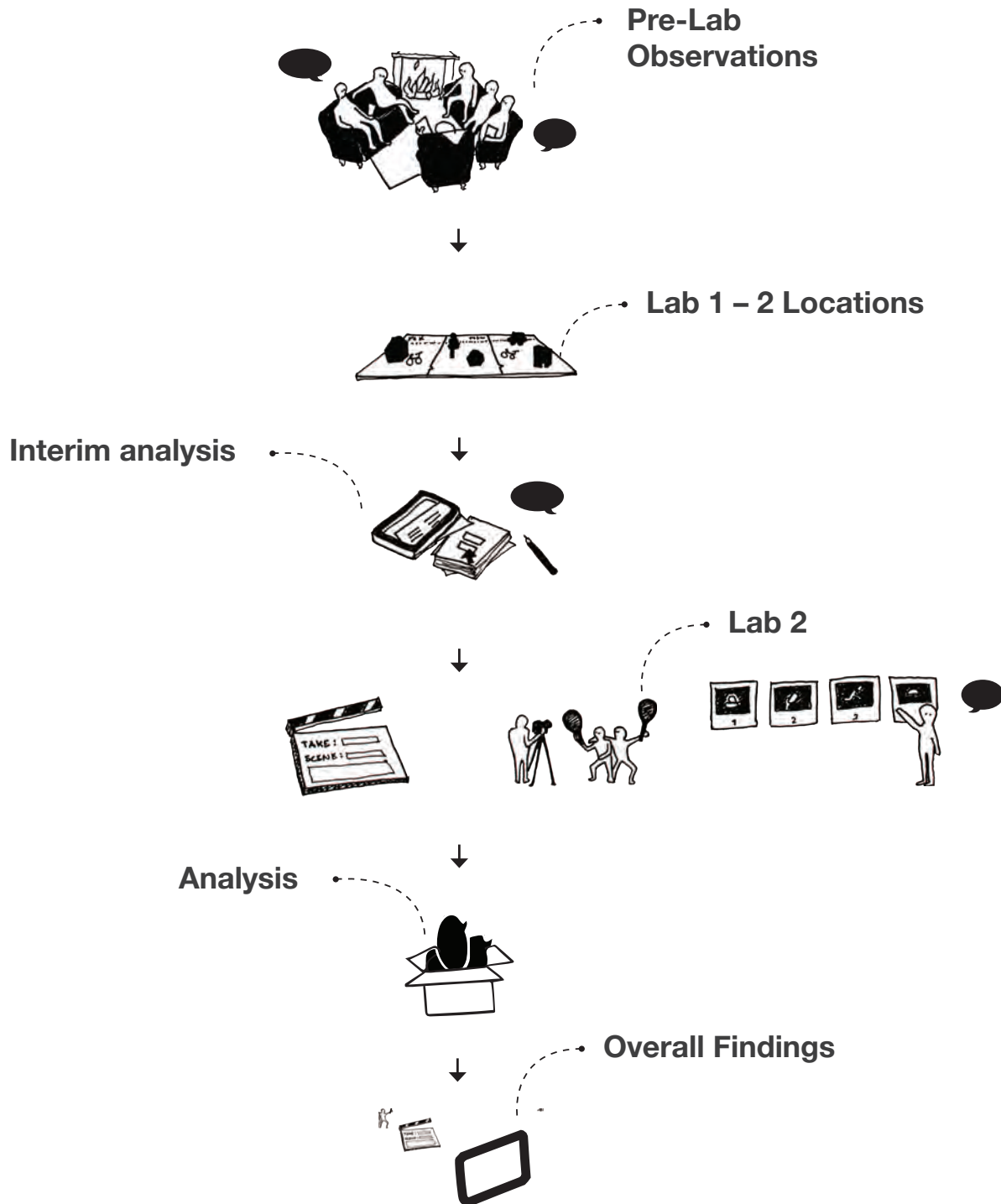
Project aims

The project investigates the role of 'digital empathy' within the emergent and future models of digital healthcare services, such as Video Conferencing (VC) consultations. Experience Labs for Digital Empathy were designed with the following aims:

→ Defining empathy and 'digital empathy' in the context of health and social care services;

→ Exploring ways to enhance the empathic experience within a more specific context, in the treatment of Long-Term Conditions – e.g. UHI Diabetes clinic pilot: VC setting for consultations; and

→ Mapping the potential for new technology/products or the use of existing technology/products in new ways to create/enhance digital empathy in the broader context of health and social care.
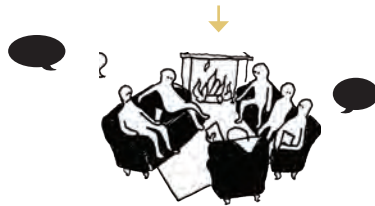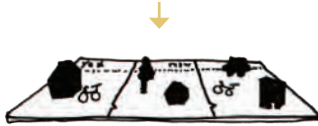
Methodology

Pre-Lab Observations

Lab 1 – 2 Locations

Interim analysis

Lab 2

Analysis

Overall Findings

Pre-Lab Observations

The main objective of this stage was to gain a first-hand experience of the VC clinic settings and to observe and gain insights into circumstances and factors that may impact empathic experience in the context of VC clinics.

The researchers visited three sites with VC clinics in the Highlands. The sites were chosen based on the variation in the VC clinic setting: in the first site, VC was set up between the consultant at the clinic in the hospital and the person with diabetes accompanied by a diabetes specialist nurse at the local outreach centre; in the second site, VC was set up between the consultant at the hospital clinic and the person with diabetes at home; and in the third site, VC was set up between the consultant at the clinic in the hospital and the person with diabetes accompanied by a student nurse at the local outreach centre. Some individuals attending the VC at the local outreach centres were accompanied by their carers. The observation sessions provided the opportunity to understand the impact of different settings on the VC experience, and identifying some of the major

factors that contribute to the overall consultation experience beyond the digital platform. The findings from the session were used to shape the plan for the subsequent Experience Labs.

Key findings

Material and digital artefacts

Information such as meter readings are captured and stored in both material and digital artefacts; e.g. diaries and digital meters. On one hand, if the meter readings were recorded purely in material artefacts, it would be difficult for consultants to access that information, especially during a VC consultation. On the other hand, individuals sometimes find it easier to correlate meter readings with lifestyle aspects such as food and exercise when they are recorded in a diary. There is an opportunity to consider how an intuitive and seamless experience of creating and sharing both material and digital information may be created.

Limiting technology interventions

There is a potential challenge of the consultant missing subtle non-verbal signs from the individual during a VC consultation. However, additional layers of new or unfamiliar technology during VC were not considered desirable, both from the perspective of the consultant and the person attending the appointment.

There is potential to explore the role of the nurse further in this setting to provide added support.

Time after sign-off

During one of the observations, it emerged that the additional time that the individual spent with the nurse after the consultant signed off from VC provided the opportunity for them to ask questions, clarify doubts and share their concerns, adding to the emotional value of the experience. In addition to this, the nurse provided a written summary of the consultation outcomes, which could be a useful reference for the individual.

Social conventions

The social conventions of VC could sometimes pose a challenge for the consultant; e.g. sustaining eye contact with the individual while referring to meter readings on a separate screen and additional documents or consultation notes on the table. During one of the observations, the consultant expressed that switching to only audio communication during the VC consultation, often due to technical challenges, provides time to focus on the information better and to make clinical decisions.
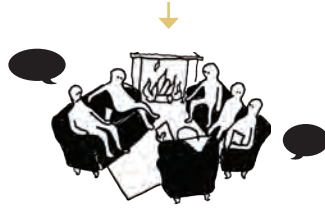
Preparing for an appointment

During the observations, many individuals appeared to be surprised while entering the VC room for the consultation. Appointment letters are not specific whether the consultation will be face-to-face
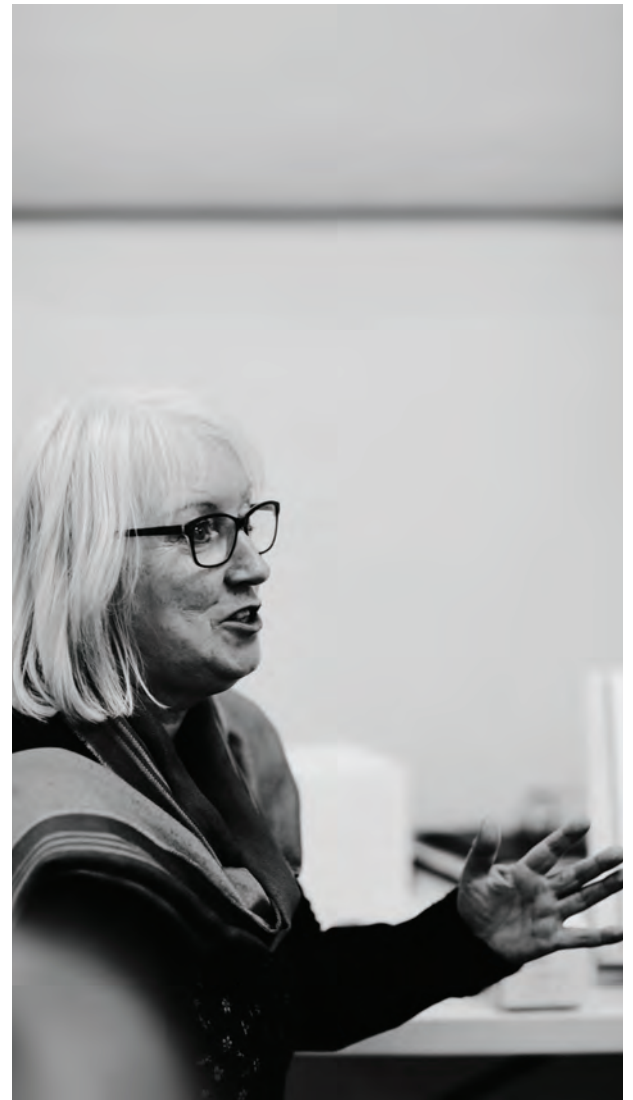
or VC. It is important to address this in order to set the right expectations for individuals who attend these sessions.

EXP LAB 1

The main objective for Lab 1 was to explore what empathy means for different individuals, and to gather stories of personal experiences of using healthcare services in order to understand what empathy and 'digital empathy' might mean in this context. Participants in the Labs included individuals who have experience of using healthcare services of which some of them are living with long-term conditions including diabetes (Type 1 and Type 2), and a diabetes consultant. Two separate but similar sessions were organised, one in Forres and the other in the Isle of Skye, to understand if distance from specialist healthcare services (in this case situated in Inverness) may influence people's preferences and expectations related to traditional face-to-face sessions versus alternate consultation models such as VC.
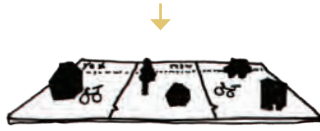
Methods

In order to define what empathy means, the activities and tools were designed with a focus to capture different ways in which empathy may be expressed and experienced during interactions; map the role of factors such as people, environment, artefacts and technology in the expression and experience of empathy; and to identify opportunities for making the experience empathic at different points along the consultation process.

Participants were asked to bring a personal artefact that represented what empathy means for them, and share their experience and articulate the meaning of empathy in relation to this artefact in a focus group. In order to set the scene, participants were introduced to some of the key insights from the Pre-Lab observations using postcards that described the main stages of a VC consultation (Appendix A). Storyboards were then used to share and discuss scenarios of each individual's recent interaction with a healthcare professional, along with mapping the overall satisfaction with the experience, perceived level of empathy, and perceived role of technology within each scenario. Participants worked in two groups and discussed key points that make an experience positive or negative based on the scenarios shared. Using this as a basis, participants continued to work in two groups to discuss and create preferable scenarios for future using design props created

with different sizes of cubes and canvases to depict the different environments, objects, technology and people involved. Finally, participants were introduced to a blank process map, which was marked with key stages involved in consultation such as receiving the appointment letter, confirming appointment, travelling to clinic, waiting for consultation, going in for face-to-face or VC consultation, etc. Participants were then asked to annotate the map to show key challenges and opportunities for digital platforms playing a role at various stages of the process and identify opportunities for enhancing empathy (Appendix B).

Key findings

Insights from the Lab were analysed using the affinity diagram method, where key quotes from the transcripts, Lab tools and observations were clustered to allow the main themes to emerge.

What does empathy mean to you?

Participants articulated many ways of describing empathy and shared personal experiences around how empathy is expressed. Some of the main interpretations are listed below:

"Empathy is understanding other people's feelings, having sympathy for the feelings and appreciating them."

"The ability to walk in someone else's shoes… If you've walked their path, it's much easier for you to empathise with them."

"An appreciation or understanding of what people want."

"It's being able to pick up on what somebody is feeling."

Other interpretations of empathy that were more personal included:

"A wee friendly face, comfort, support, companionship and fun."

"Togetherness and a shared understanding."

"It's being able to relate… you think there is a connection there and that's very meaningful."

"From a kind of closeness to fully engage in the problem and help move on from that problem."

Key findings related to experience of using healthcare services and empathy, and people's preferences and expectations related to traditional and alternative models of consultation (e.g. VC) were analysed and five themes emerged.
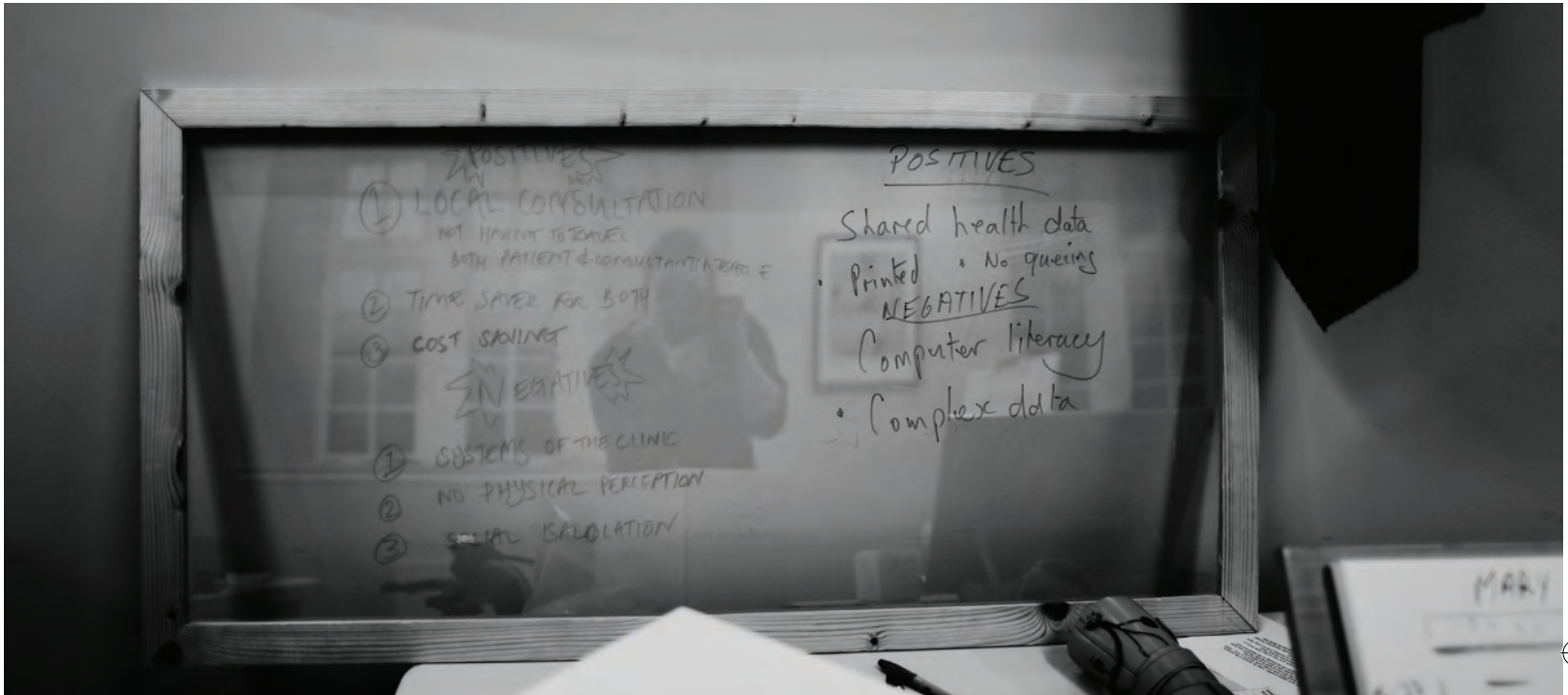
Communicating Empathy Consciously

The limited time available during consultation is currently perceived as a barrier to empathic communication. Participants noted that the lack of time puts additional pressure on the individual attending the consultation. Paying attention to small details such as the consultants introducing themselves using their full name instead of the surname, and addressing the individual using their first name was considered positive. It was also suggested that taking into account the individual's needs; e.g. offering translation support for non-speakers of English would mean additional time for translation. This would need to be taken into account while booking appointments and longer consultation offered as needed. The consultant focussing on the medical records when the individual is talking was perceived by some participants to have a negative effect on their experience. One of the participants described that an empathic consultant would show any signs of being in a hurry; demonstrate interest in the interaction; have good listening skills; and show care, respect and flexibility towards the individual. Some participants noted that open questions during the interaction as well as inviting questions from the individuals is key to building an empathic relationship, adding that the individual feels supported when they are asked the right questions.

Sharing information

Participants proposed that having shared access to their health information is important, as transparency is critical for building trust and empathy. However, it is difficult for the

individual to understand the data currently available such as meter readings and graphs, which could lead to consultants spending more time explaining data rather than focusing on the outcomes. Participants also pointed out that a summary of the average readings is not useful or meaningful for individuals. Information would be meaningful when clinical data correlates with the individual's lifestyle and show implications for their lifestyle in a simple and straightforward manner. Printouts or emails of data screenshots including comments from the consultant and exercise notes were suggested as takeaway materials for the individual, for reference and reassurance. Emails were considered a good way of sharing information both in a remote and trusted manner.

From the preferable future scenarios created by participants, it emerged that establishing empathy needs to be two-way process. In addition to appropriate sharing of information, establishing a continued and good relationship with the consultant was considered important. It was highlighted that awareness and respect for each other's time, transparency in communication and access to the same information on either side of the consultation are important not only for creating a meaningful conversation, but could also help with collaborative and informed decision-making.

Expectations from VC Consultation

Three important factors for creating an empathic experience for an individual

receiving care were identified: a trusted and familiar environment; resources, and people. It was noted that awareness of VC etiquette plays a key role in consultation. Currently training workshops on VC etiquette and equipment are provided only to clinical staff, but it was suggested that it should be extended to individuals attending VC appointments. A list of top tips on VC etiquette displayed during the consultation was suggested as another possible idea for creating awareness.

Consultations currently last about twenty minutes and the individuals do not see the consultant again for a lengthy period of time, often six to nine months. Preparing for an appointment could be stressful in such scenarios and was noted as another area with scope for improvement. Receiving information that is personal and tailored could have a positive impact in this situation. Clarity of information and setting correct expectations regarding the appointment were considered crucial. Participants felt that the appointment letters currently do not provide adequate information on what to expect during an appointment or how long it will last. They suggested that the appointment letters could be accompanied by an introductory letter or leaflet setting the right expectations and providing information regarding preparation for a VC consultation, especially if it is the individual's first time. In addition, options to

ask for support should be made available in advance; e.g. help with setting up the equipment or share concerns. As well as setting the right expectations, managing the expectations correctly was considered important. One of the participants felt that if the staff supporting the running of VC clinics (e.g. nursing, administration and auxiliary staff) lack the required technical skills, it could lead to more frustration and less empathy. Ensuring that all staff are well trained and equipment is in good condition were seen as critical points in delivering a good VC experience and managing expectations. It was emphasised that technology can be an enabler only if people are aware of using it correctly or is provided the right support.

Time spent in the waiting area prior to an appointment was seen as another opportunity for supporting individuals to prepare for the consultation. One of the participants felt that many people do not find time in their busy schedules to think about their health conditions, and the time spent in the waiting area could be used to focus and reflect better on personal health. Another participant described the information screens in the waiting area as 'the screen of horror' projecting scary facts about diseases and making the experience stressful. It was felt that they should instead project positive messages and local care information (e.g. local patient support group). The time before the appointment

is crucial for creating the right frame of mind for the consultation, and has an impact on the overall perception of empathy.

The Ecosystem of Care

While sharing scenarios of healthcare experiences, some participants highlighted a breakdown in communication between their GPs and the consultant, which had an impact on their experience and made it less empathic. The gap in communication between different points of care (e.g. primary care and secondary care) and not having access to the right information can affect the person's overall experience of care. Participants saw benefits in VC consultation if the primary care set-up and practice nurses supported them locally. The different models of primary care and secondary care and challenges such as staff shortages were perceived to be potential barriers.

The perception of different levels of empathy in different levels of the healthcare system (e.g. nurse, GP, consultant, etc.) was shared by most participants; i.e. empathy is perceived to be more in interactions at the lower levels and diminishing in interactions with health professionals higher up in the system. Some participants felt that they received more personalised care from their GP than the consultant, and as the care was provided locally it also resulted in quicker feedback on test results. Some participants also felt that they shared a more empathic relationship with the nurse, while the relationship with their doctor was more formal and less empathic. Participants noted that the health professional's familiarity with the individual also played a role in empathic handling of situations. For example, one of the participants discussed receiving a phone call from the receptionist at the practice regarding their blood sugar

levels, which caused panic because there was no further information provided. On the other hand, another participant shared that the diabetes nurse is aware of the person's fear of receiving calls from the practice and phones them personally and is able to convey things in a calm way.

Choice of Preferred Pathways

Participants broadly agreed that the choice of alternative pathways for care, including VC consultations, should be offered to people based on personal circumstances and preferences. For example, they noted that socio-economic conditions or different abilities might limit digital access for some people. They also pointed out that VC consultation might suit children in school, by not taking them out of school for long hours and could provide parents the option to join them in school instead of travelling to a clinic. Although there is a general perception that older
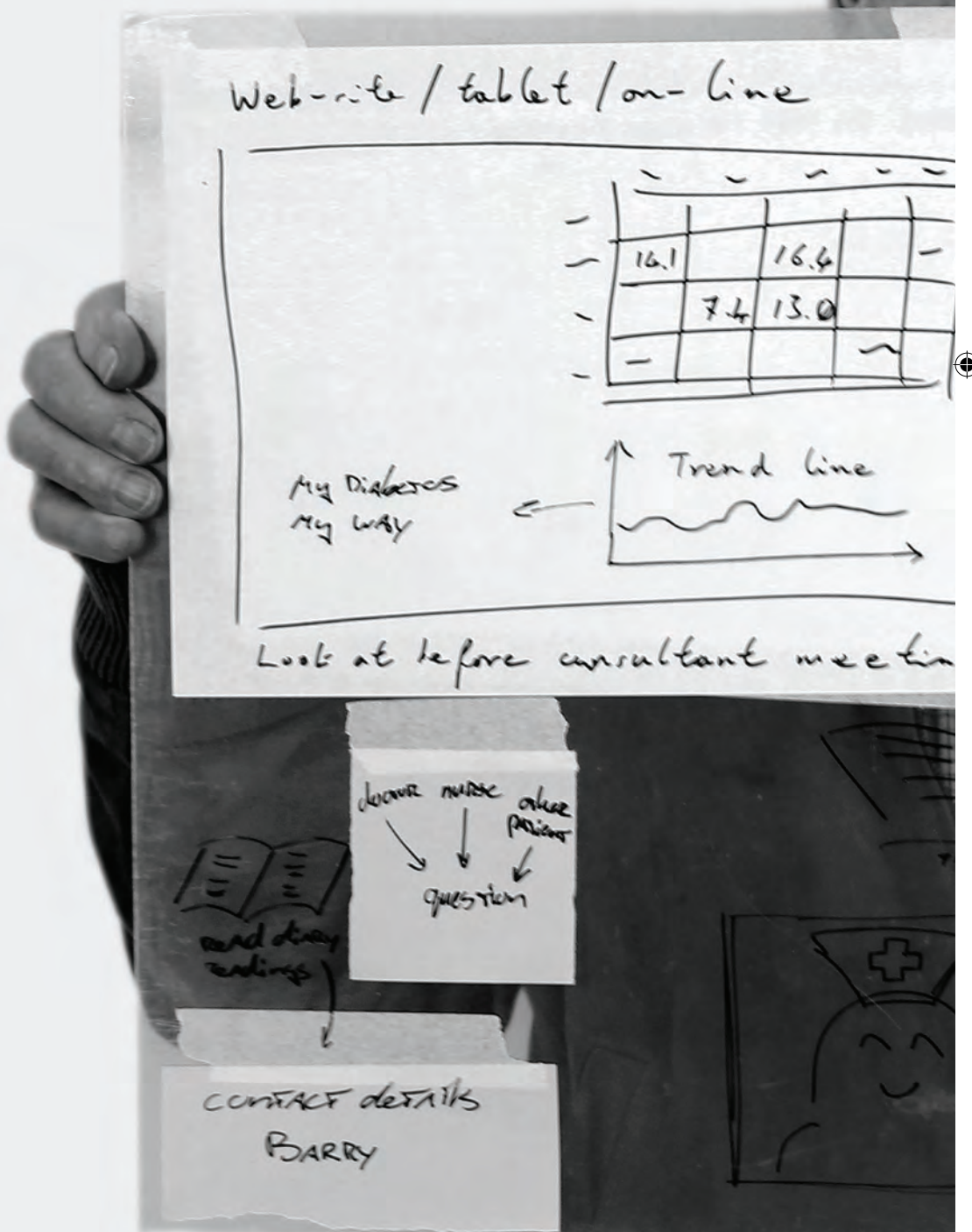
adults would be slow to use digital technology, one of the older participants in the Lab shared that they would like a tablet being provided for patient-to-patient and professional-to-patient contact. Participants shared that VC consultation has potential to set the direction of change and to take care back into the community as well as provide individuals flexibility and choice in their own care. This also changes the perception of digital as 'replacement' instead to 'new possibilities'. Participants felt that it can provide the choice to individuals based on their preferences not only around how to contact a health professional, but also who and when. Some of the alternate VC consultation venues in the community that were suggested included school, pharmacy, library and a mobile bus. Participants described these as a 'technical but trusted' environment, explaining that staff in these venues can offer technical support, and they are familiar to people in the community. However they said that it is important to note how busy these venues are likely to be and potential time commitment expected from people providing support.

The discussion also focussed on the opportunities for home VC consultations. While building scenarios, one of the groups focused on a future scenario of using home VC, where the patient is older and needed to be accompanied by a personal carer at home, while the diabetes consultant was located at the clinic. Based on the discussion, the group indicated that they perceived the overall empathy in this scenario as average. They listed the pros as reducing the travel time not only for the patient but also the carer, saving cost and providing a comfortable

environment. The cons included the concerns around the amount of time available with the consultant; e.g. if they were running late, and potential social isolation that it might cause for some groups of people for whom this might be the only activity that takes them out of their homes. During the discussion, participants also talked about how the environment could have an impact on the person's behaviour. For example,

are people less prepared for bad news in a home environment, and are they likely to share more or less personal information with the consultant?
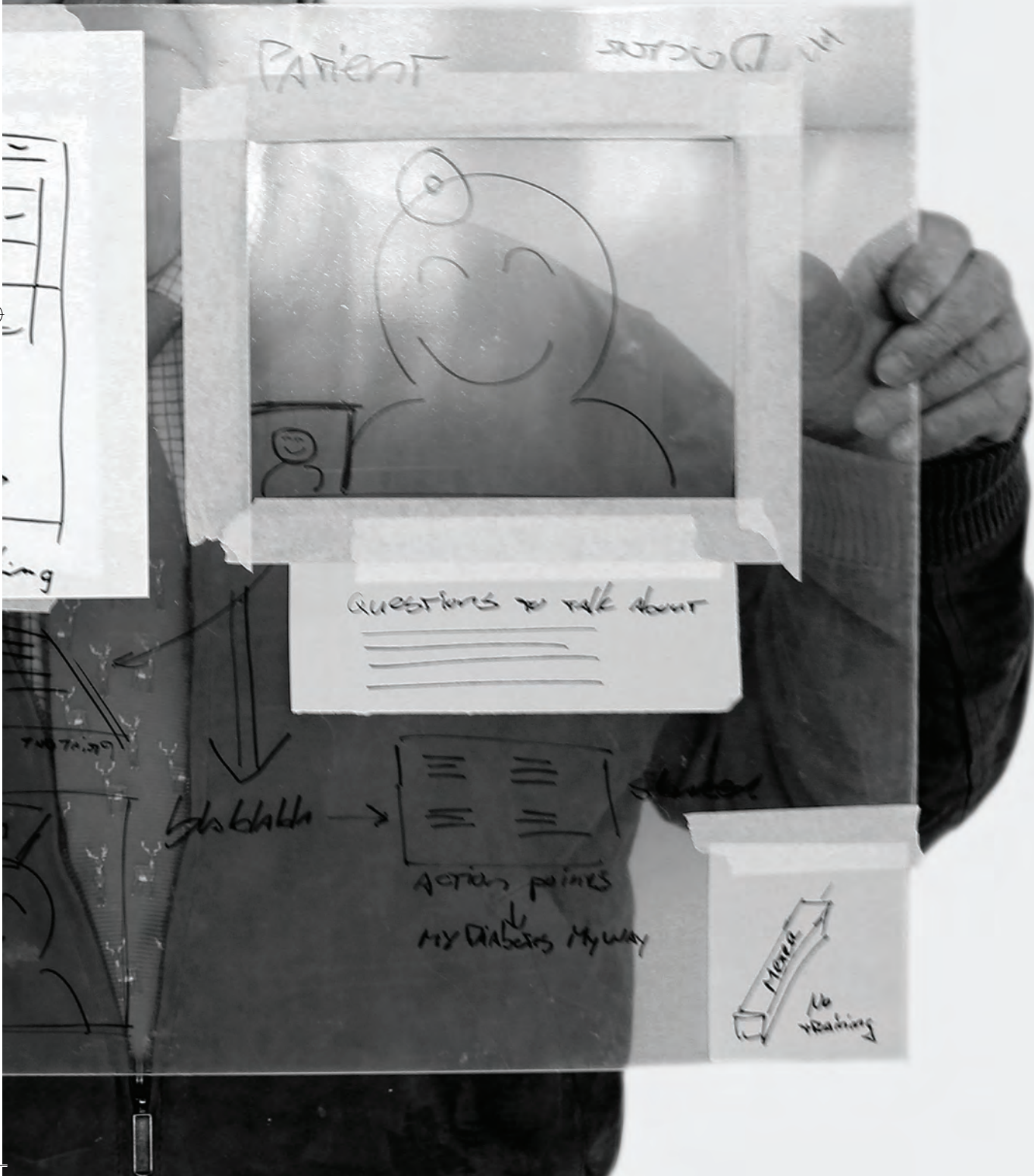
The role of the nurse also emerged as an area of focus during the discussions, and indicates that the nurse plays a crucial role in providing care and support during and beyond VC consultation. During the observation session, it was observed
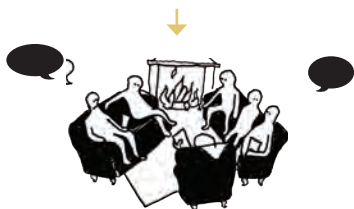
that the diabetic specialist nurse helped the person to prepare for the consultation, answered questions after the consultation and provided a written summary of the consultation to take away. This was especially true for participants in a rural context: they said the diabetic specialist nurse was their primary contact of care. One of the participants noted that they share a less formal relationship with the nurse than the doctor and felt this made the experience more empathic. Based on their personal experience, they felt that the diabetic nurse has more time for conversation about the person's overall wellbeing, while the doctor focuses on the test results and the outcomes from it during a consultation.

EXP LAB 2

The main objective for Lab 2 was to identify ways of delivering digital services, especially focusing on VC consultations for diabetes care, in order to create a more empathic experience in future. Participants in the Lab included people living with diabetes (Type 1 and Type 2) from two different locations in the Highlands and Islands, and a consultant. Two of the participants and the diabetes consultant also attended the first Lab, which provided continuity, and the other participants brought new insights to further develop the ideas that were starting to emerge from Lab 1.

Methods

As a warm-up activity, participants were shown key quotes on empathy from Lab 1. They were asked to review, annotate and add their own definitions to the board, and use stars to mark the quotes that best described empathy in the context of diabetes care (Appendix C). After this activity, the six consultation scenarios from Lab 1 were presented to the participants for discussion, and they were introduced to the key points and focus areas for Lab 2 that emerged from the scenarios, namely environment, process and digital interface (Appendix D). Based on the initial discussion, participants were asked to consider areas that they would like to focus on while making concepts.

Key Findings

Insights from the Lab were also analysed using the method of an affinity diagram, where quotes from the transcripts, Lab tools and observations were clustered to allow the main themes to emerge in the process. Key findings related to opportunities for VC consultation in diabetes care and ways of improving empathy were analysed and four themes emerged.

Effective and Clear Verbal Communication

During Lab 1, one of the perceived challenges for VC consultation was the consultant's difficulty in picking up subtle signs and non-verbal cues from their patient. In Lab 2, participants felt that making

verbal communication clearer and empathic was most important. One of the participants shared that they believed that 'to have empathy we must have good communication', and that it came down to the questions that are asked. Participants felt that asking people about their emotional health and how they are feeling at the start of a consultation is fundamental for empathy, regardless of whether the consultation is digital or face-to-face. They highlighted that lack of emotional support and mental health support for people with diabetes is a key area that needs to be addressed. One of the participants shared a past experience when they were asked whether they were depressed, but after providing an answer it was not addressed further during the

conversation. Participants agreed that it is important to follow through with the information that is asked from them. They suggested that if people are asked to think about what they want to discuss before they come into the consultation, the consultant could then ask them at the beginning 'what do you want to talk about today?' The time spent in the waiting rooms during face-to-face consultations was seen as opportunity to preparing for the consultation. The diabetes consultant shared that a HADS questionnaire has been previously used with people in the waiting room in one of the clinics. Participants identified the scope for an electronic form that can be filled in in the waiting area by the person and linked to consultant's computer. This would help the

consultant to then ask individuals the right questions around their immediate concerns. They felt that the questions in the electronic form could be related to the person's condition, feelings, and include questions they would like to ask the consultant.

Meaningful Data

During discussions, participants' insights corresponded to findings from Lab 1 that while sharing information, it is not useful for them to see only the readings, but the data should help them to understand what it means in relation to their lifestyle. A trend line or similar format of visual information was thought to be useful. It was also highlighted that in addition to sharing information

with the patient, the digital interface should support a two-way interaction; for example, allowing patients to add notes regarding concerns or questions, freeing up time to talk during the consultation. Participants also noted that there is usually a lot of new information provided during the consultation and it is difficult to understand and remember everything. Automatic speech recognition during consultation was suggested, that would allow the consultant or patient to highlight and capture the key points. It was proposed that the information that is shared should be made available to view outside the consultation environment, e.g. at home. It also emerged that although platforms such as SCI-diabetes exist currently, many participants had never heard about them. The diabetes consultant pointed out that almost 99% of people diagnosed with diabetes are entered into this system, highlighting a gap in sharing information and awareness around existing systems. The need for sharing of data between primary and secondary care systems was again felt to be important for making data meaningful for holistic care. For example, currently the diabetes consultant cannot access data from GP records unless the data is directly related to the person's diabetes, but this information might be important for understanding the person's emotional state.

Team Approach to Diabetes Care

People living with diabetes meet different health professionals and support care staff at different points when receiving care, and it emerged that people often do not perceive their care as being provided by any one professional, but by a team. Participants

felt that it was important for them to be aware of which of these professionals to contact at different points, e.g. what, where and how to reach them, to ensure continued support for all instances of care. It was proposed that there could be a database linking the different people, places (e.g. hospital, home) and platforms (e.g. VC, email, text) available to them. VC consultation could thus be one of the choices offered to people along with other face-to-face and digital services. Participants also felt that it is important to make sure that people are aware of the local services being offered.

Participants suggested that GP practices could direct people to relevant information and make information leaflets available. One of the participants proposed a dedicated call centre specifically for diabetes care, staffed with people who have specialised knowledge in the area. Another participant suggested having a specialist app, however it was observed that this would be most useful for generic information on the condition rather than particular questions or concerns people might have.

Participants again highlighted the role of the nurse in providing information, being trusted with everyday care and sharing an empathic relationship. One of the participants described the nurse as a strategic link between the patient and the consultant, as they receive new information regarding care from the consultant and are aware of feelings or concerns that the patient might have.

Non-clinical peer support was another area that was highlighted as important. One of the participants shared that they found the forum on 'My Diabetes My Way' very helpful. Many participants were not aware of 'My Diabetes My Way' but felt they would benefit from using a similar platform. One of the participants suggested an NHS tablet for people

with long-term conditions to browse information and to talk to peers and professionals. It was also suggested that existing community groups such as 'Silver surfers' could offer support and train people to use digital platforms if they are not already using them.

Appointment process

As discussed earlier, participants felt that VC consultations as a complementary option along with periodic face-to-face consultations would be preferable. Participants felt that the patient-focussed booking system is not efficient in this context. Although patients are notified four weeks in advance of when their appointment is due, the health system is currently six to twelve months behind in offering appointments, resulting in a long waiting period. Having VC consultation options can help to reduce this waiting period for patients. They also felt that home VC consultation could benefit people who might need to see a health professional when something unforeseen happens before a formal appointment. Participants suggested an open access system for making VC consultation appointments to allow individuals to see if there were any slots available. They also emphasised that additional digital technology should aim to enhance the time the person has with the consultant. Most participants also expressed that they would not like any technology such as digital meters attached to their bodies, and do not want to become 'a professional diabetic'.

"Empathy is understanding other people's feelings, having sympathy for the feelings and appreciating them."

Overall findings

The findings from VC observations, Experience Lab 1 and Experience Lab 2 provide a view on how participants experience empathy in relation to diabetes care and consultations through face-to-face as well as digital communication. In the course of the project it emerged that the experience of 'digital empathy' in VC consultations and diabetes related to two areas: the process that participants went through, and the interface that was available for communicating with professionals. Additionally, the type of empathic experience described by participants varied in different scenarios, and could be interpreted as cognitive or emotional empathy. The four categories are briefly described below.

Interface

In VC consultation settings the doctor and patient are physically separated, with a camera, screen, microphone and speakers to provide the main visual and auditory interaction. The 'interface' also constitutes other forms of interaction as enabled or affected by a digital medium such as sharing of the meter readings. In the Labs, this theme was further explored with participants to understand how digital interfaces affect a consultation session and how elements of a digital interface could be leveraged to improve communication.

Process

The process that patients go through before, during and after the consultation affects an emphatic experience. The environment of the consultation, whether it is in the hospital, an outpatient clinic or at home, was seen as a part of this process. During the Labs, the participants were asked to consider their experience throughout the process, and not just limited to the consultation scenario.

Emotional Empathy

Emotional empathy involves the capacity to enter into or join the experiences and feelings of another person [Hojat et al.] and in the context of this project we interpret it as actively enabling or supporting patients to share their emotions related to their condition.

Cognitive Empathy

Cognitive empathy involves the ability to understand another person's inner experiences and feelings and a capability to view the outside world from the other person's perspective [Hojat et al.] and in the context of this project we interpret is as a form of expression or expectation of empathy based on information rather than emotion.

The four categories described here can be positioned in a quadrant

Cognitive Empathy

- Expectations from VC consultation
- Effective and clear verbal communication
- Appointment process
- Material and digital artefacts
- Limiting technology interventions
- Sharing information
- Meaningful data
- Preparing for an appointment
- Ecosystem of care
- Team approach to diabetes care
- Choice of preferred pathways

Interface — Process

- Communicating empathy consciously
- Social conventions
- Time after sign-off

Emotional Empathy

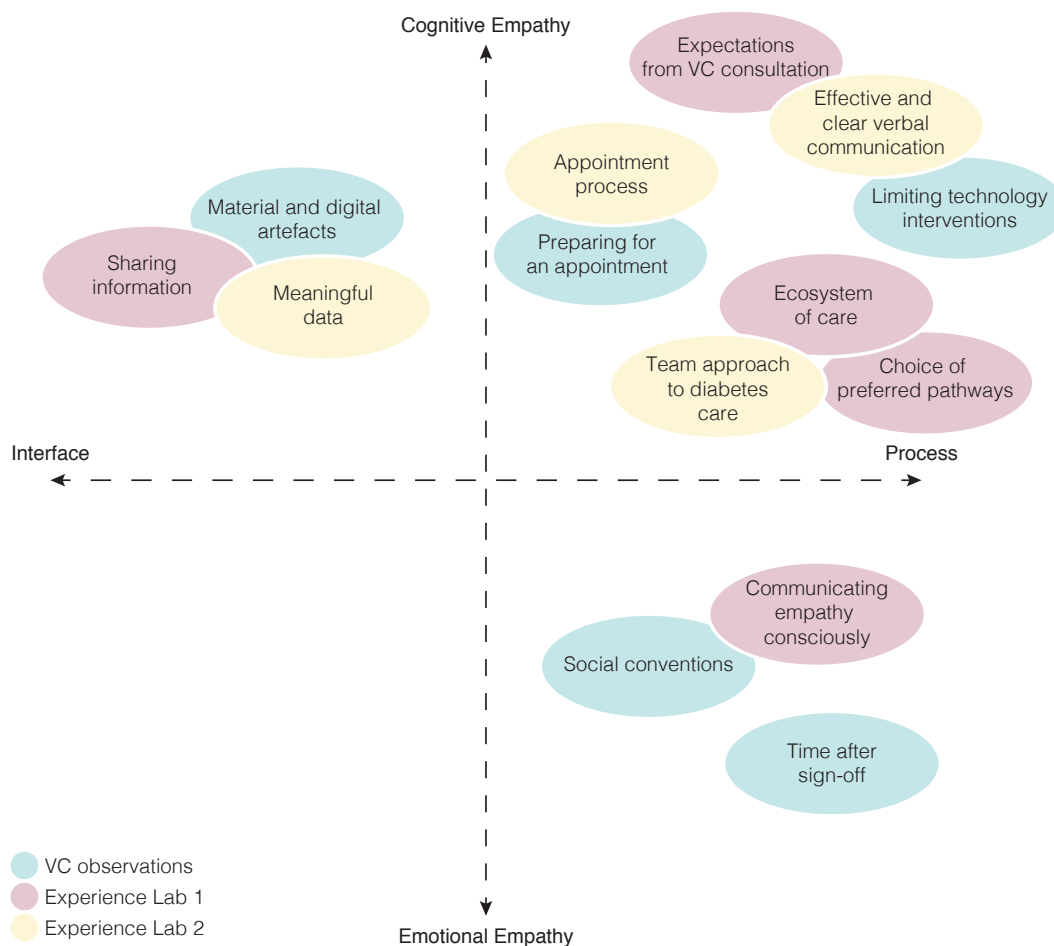- VC observations
- Experience Lab 1
- Experience Lab 2

diagram to suggest how the empathic experience in diabetes care and consultations relate to each other. The diagram does not aim to position findings from previous sections in a scaled position, but rather to suggest relations and provide insight in a larger picture of the empathic experience.

Providing human support around using technology

Throughout the Experience Lab sessions, the use of digital technologies in consultations was not seen to have a particularly positive or negative impact on the empathic experience. Good communication with the consultant, GP or nurse was key, but whether this happened face-to-face or over digital channels did not affect the perception of empathy. The key to using digital technology was the human support provided to set the patient's expectations, and help with sharing or interpreting information where needed. When communicating over VC, emotional empathy requires more conscious effort, during the consultation as well as afterwards.

Digital tools to create shared understanding

The diagram shows that the digital interface is primarily showing the potential to support cognitive empathy by sharing and interpreting data and information. Technology can also be used to support emotional empathy by picking up body signals that might be missed in digital communication as compared to face-to-face, but this did not emerge in the lab sessions as a primary value. Digitally enabled communication channels provide an opportunity to share data relevant to the patient. The interface to this data was found to be a crucial link between different environments (e.g. GP, diabetes specialist, home). Furthermore, the ability of the interface to support equality of understanding on both sides was seen as important to empathic communication.

Process of delivering care

One of key findings on improving delivery of care that emerged was to change the perception of the process of delivering care, which is currently limited to the consultation process (i.e. patient making appointment, attending appointment, leaving with clinical outcomes, etc.). Patients with long-term conditions, who might need different forms of support at different times could benefit from a process of continued care (i.e. the role of different people, places and platforms in providing continued support during and in between appointments). It also emerged that in this context, the environments delivering care may vary between clinics, homes and other local sites, and therefore the concept of an 'ideal environment' may not be relevant.

Recommendations

Shared understanding of data Glucose meter data that is being viewed by the consultant should be made easier to understand for the patient. Participants suggested a graph or some method to visualising trends over time. Creating a shared understanding of the data between consultant and patient was important to the perception of cognitive empathy. This should allow patients to better understand their own condition, understand what the consultant is seeing in the data and why decisions regarding medication are made.

Importance of the role of the nurse and the team approach

As the consultant is physically distanced from the patient in VC consultations, the role of the local nurse in providing support became more important. Patients in the VC consultations valued the presence of the nurse, and participants in the Experience Labs valued the accessibility of the nurse for asking questions. The nurse is a valuable part of the care team in providing

support to use the VC setup, and to physically be around either to provide a summary or answer final questions once the consultant has signed off from VC.

Creating more awareness around VC

The opportunity to access VC clinics was seen to be a valuable addition to pathways available for diabetes support and consultation. Most participants were not aware of this opportunity, and some patients coming into the VC clinic were unaware of the fact that it was a VC. It was suggested to create more awareness of the opportunity for VC clinics and how the clinics are run; e.g. by using leaflets or the screen in waiting areas.
After consultation – the take away

Being able to take away a summary or screenshot could potentially free up more time for emotional empathy. Providing the patient with information to take away from the virtual consultation could help to ensure the key messages are being delivered. This should contribute to the cognitive empathy perceived while freeing valuable time for building emotional empathy. Different forms of this information were suggested as: annotated screenshots of the glucose meter readings or, a summary of the conversation. This summary could be made by the nurse taking notes of the key messages or potentially by using some form of automatic speech recognition.

Conclusion

The findings from the Labs highlight key factors such as access to shared and meaningful data; clear verbal communication; providing choice of preferred pathways for continued care; presence of the diabetic nurse; preparation and access to information before consultation; and summary to take away afterwards as some of the key factors that have an impact on empathic VC consultation. The recommendations focus on some of the ways in which the existing VC consultations may be enhanced, including visual representation of data and sharing of information. People's perception of overall empathy in the care they receive, however, is shaped based on multiple interactions with the different people and environments that they interact with on a routine basis beyond their formal consultations with the diabetic consultant. Emerging themes attempt to describe the ecosystem of diabetes care, such as a team approach between different healthcare professionals, and a choice of preferred pathways for people living with diabetes to receive continued care. These themes are important when considering systemic changes towards creating empathic digital health services in future.