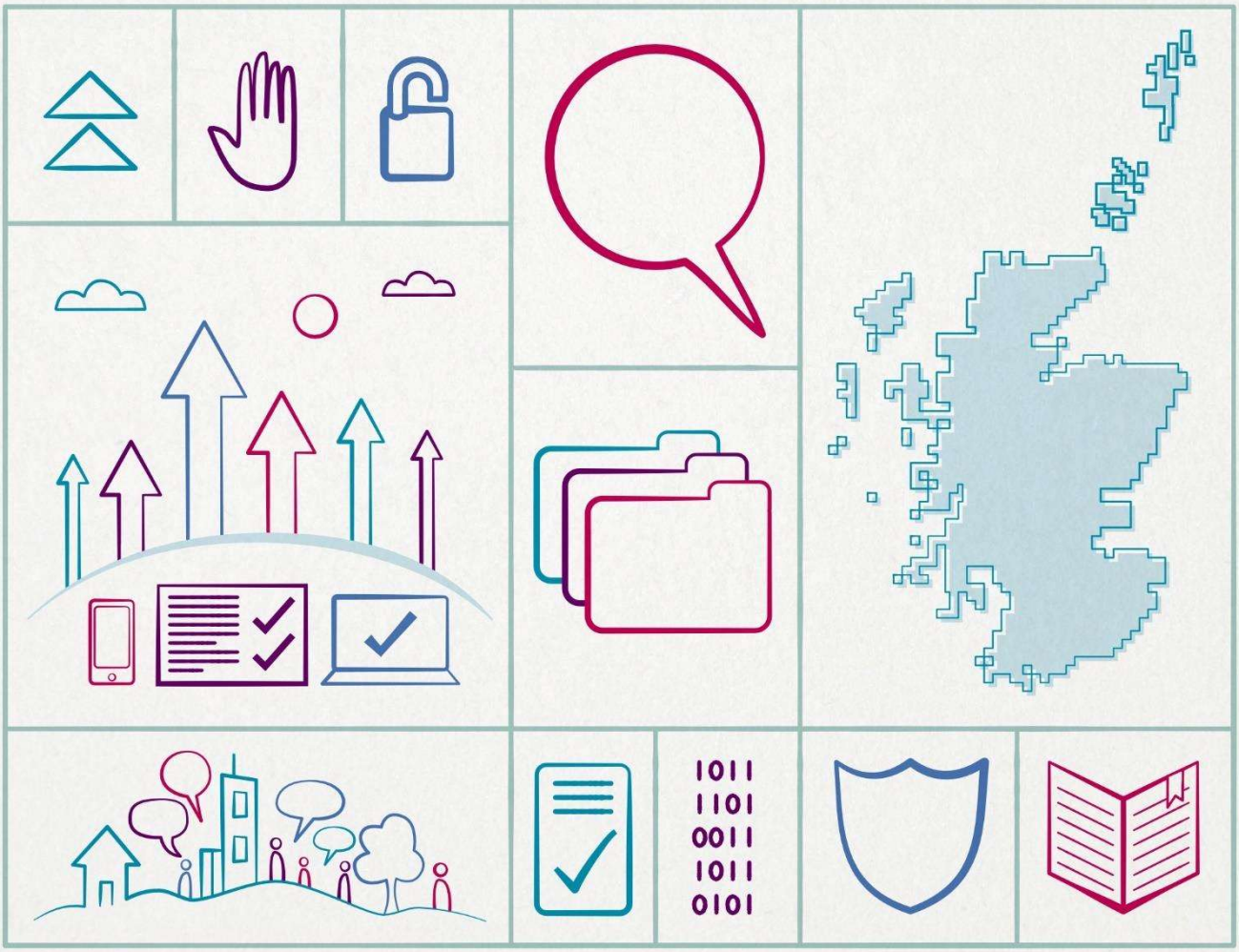
MY WORLD MY HEALTH

Insights from a dialogue on data with the Scottish public



Report by the Health and Social Care Alliance Scotland (the ALLIANCE)
and Digital Health & Care Innovation Centre (DHI)

Digital Health & Care Innovation Centre

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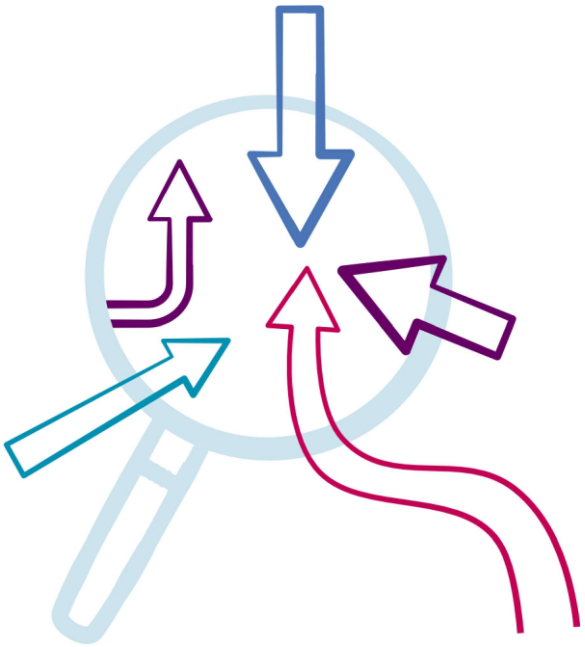
Summary

The **My World, My Health** project aimed to explore how people living in Scotland felt about data on wider determinants of health being used within public and health services. The project was commissioned by Nesta on behalf of the Scottish Government as part of the Data Dialogues programme. It was managed by the Health and Social Care Alliance Scotland (the ALLIANCE) and delivered in partnership with the Digital Health & Care Innovation Centre (the DHI).



The aim of the project was not to move the conversation away from clinical data completely. Instead, we wanted to broaden the general thinking on this topic by considering the wider factors that influence people's wellbeing and what data is linked to these factors. Furthermore, we wanted to consider how this data might be used by different services to provide better outcomes for individuals and society and understand what public attitudes would be about these matters.

The ALLIANCE carried out engagement between November 2020 – March 2021. Altogether, we engaged with 125 members of the public, as well as stakeholders, through workshops, interviews, a survey, and an online event. This provided us with extensive qualitative and quantitative data regarding people's views, preferences, and concerns regarding data collection, use and sharing more widely.

The findings showed that most of the individuals we engaged with had a good understanding of how wider factors can influence their health and wellbeing. While some participants did collect data on how environmental and lifestyle factors affected their wellbeing, they were more likely to do so if they were disabled, living with a long term condition or sensory loss. When data was collected and shared, it was most often used for self management, sharing with healthcare professionals, or for peer support and advocacy.

With regards to attitudes to data, most individuals wanted to see better data flows within health and social care. Some participants and respondents also felt that automated data collection and analysis systems could support joined up services and guarantee continuity of care for at-risk individuals, as well as support tailored interventions. However, many felt the risks outweighed the positives.

Participants identified several types of data which they considered to be particularly sensitive; with financial data, mental health and sexual health data topping the list. However, some were more likely to consider sharing data, including sensitive data sets, if there was a clear benefit to themself, others, or wider society. They were also more

comfortable with sharing this type of data if it was anonymised, or if the data was collected and shared with explicit informed agreement from the data subject.[1]

An overwhelming majority of our participants stated that the individual whose data is collected, processed, and shared should be in control of how this is done. It was also argued that there needs to be rigour in the use of data, in line with the individual's consent. Furthermore, the purpose of the data processing should be for the benefit of the individual or wider society. There should be no adverse effects to individuals whether they opted-in or -out of sharing data.

The insights gathered from the Scottish public were summarised into nine core principles for data collection, use and sharing. They include: GDPR adherence, empowering informed consent, providing clear purpose, embedding lived experience, allowing free choice, granting individual ownership of data, confirming the trustworthiness of data, providing opportunities for education and safeguarding individuals.

These principles were interpreted alongside qualitative insights from the engagement in the form of five at-a-glance 'future scenarios'. These scenarios, centring around fictional personas, can help us visualise how a data-enabled future that embeds these principles and takes account of people's hopes and fears might look. These were presented at the project 'Show and tell' event and we hope they will spark future conversations on the topic.

To help us anchor the scenarios and the principles back into current context, the DHI have developed an 'Art of the possible' interpretations of how the scenarios might be achieved using existing or emerging technology. This helps explain how some of the features presented within the scenarios could work in practice. We would welcome any feedback and comments on these, as well as further examples of possible applications of the principles we identified.

We recommend that engagement on this subject continues with Scotland's people, as we believe the level of engagement achieved demonstrates that there is an appetite for involvement in shaping data-enabled futures. Data can bring exciting new opportunities for our health and wellbeing, but it also carries inherent risks. To ensure that we build a future where people's rights are respected and where data is used to benefit individuals, communities, and our society as a whole, the conversation needs to be inclusive, accessible and transparent.

[1] By 'data subject' we mean the individual whose data is collected, processed or shared; the subject of the data.

1. Context

In 2019, Nesta and the Scottish Government embarked on a year-long dialogue with Scottish citizens to better understand their opinions and ideas for the use and sharing of health and care data, and to explore alternative or possible futures together that benefit all.[2] 'Data Dialogues' was led by Nesta, the UK's innovation agency for social good, in partnership with the Scottish Government.

My World, My Health was one of five projects funded under the umbrella of the Data Dialogues programme. It was managed by the Health and Social Care Alliance Scotland (the ALLIANCE) and delivered in partnership with the Digital Health & Care Innovation Centre (DHI), between February 2020 – March 2021, with a short hiatus between March – August 2020 due to the COVID-19 pandemic.

The aim of the project was to focus on questions which had not been explored in depth in Scotland which could offer new insights and significant added value to the Data Dialogues programme. Our hope was that these insights might stimulate ideas for how data could be used to innovate approaches to health, care, and wellbeing.

The My World, My Health project acknowledged that clinical care is only one of the determinants of health, with wider socio-economic factors and individual behaviours being larger contributors to an individual's wellbeing (Figure 1[3]). Wider social determinants of health can include (but are not limited to) housing, education, employment, social support, family income, communities, childhood experience, and access to health services.[4]

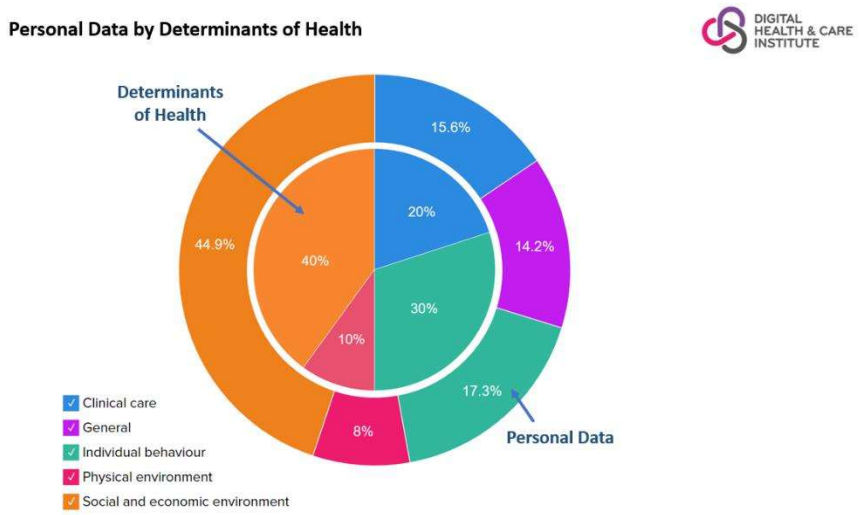


Figure 1

[2] www.nesta.org.uk/project/data-dialogues
[3] DHI. The inner circle is the degree to which different types of activity effect health outcomes, taken from: The Relative Contribution of Multiple Determinants to Health, " Health Affairs Health Policy Brief, August 21, 2014. https://www.healthaffairs.org/do/10.1377/hpb20140821.404487/full/healthpolicybrief_123.pdf
[4] www.healthscotland.scot/health-inequalities/the-right-to-health/overview-of-the-right-to-health

The project aimed to broaden the discussion and ascertain public attitudes regarding the collection, processing and sharing of data around these wider determinants of health. We felt this approach might help emphasise public health and preventative approaches and uncover the related trade-offs that people might consider in such contexts.

Moreover, this approach provided an opportunity to explore public trust and the perceived value of using data that sits outside of clinical care records. This includes citizen-held data (such as that collected by various apps and devices) and data held by the statutory sector (including housing, employment, life events etc).

With the aim of generating insights, we set out to explore the following questions over the course of the project:

1. What factors contribute to individuals' wellbeing - "what keeps you well?"
2. Reflecting on the above, what types of data are people more willing to share, with whom and in what contexts?
3. How can data on determinants of health be used in practical ways for public health and preventative approaches?
4. What trade-offs are people willing to make around data and health/wellbeing?
5. What safeguards do people want around this type of data collection and sharing?

To get a more representative view of public attitudes with regards to these questions, we aimed to engage with a diverse group of individuals. We envisaged that this would also help us tease out differences in views between population groups. Our target audiences included:

- People with long term conditions, sensory loss, or disabilities
- People over 60 years of age
- People in urban areas of multiple deprivation (referred to here as SIMD areas, focusing specifically on the 20% most deprived)[5]
- People living in remote and rural areas
- People belonging to ethnic minority communities
- People belonging to the LGBTQI+ community

We planned to use a range of innovative methods to make the project discussions engaging, participatory and to expand the project's reach across Scotland. Although we were due to deliver six workshops in physical locations across the country, our plans were disrupted by COVID-19. Therefore, all engagement has been done remotely between November 2020 – March 2021. A description of our engagement methods and practices is included in the following chapter.

[5] https://simd.scot

2. Engagement methods

The **My World, My Health** engagement spanned five months and reached over 125 members of the public and stakeholders. We employed a range of participatory tools and methods, including showcasing multimedia content, online workshops, telephone interviews, an online survey and a final 'Show and tell' event (Figure 2).

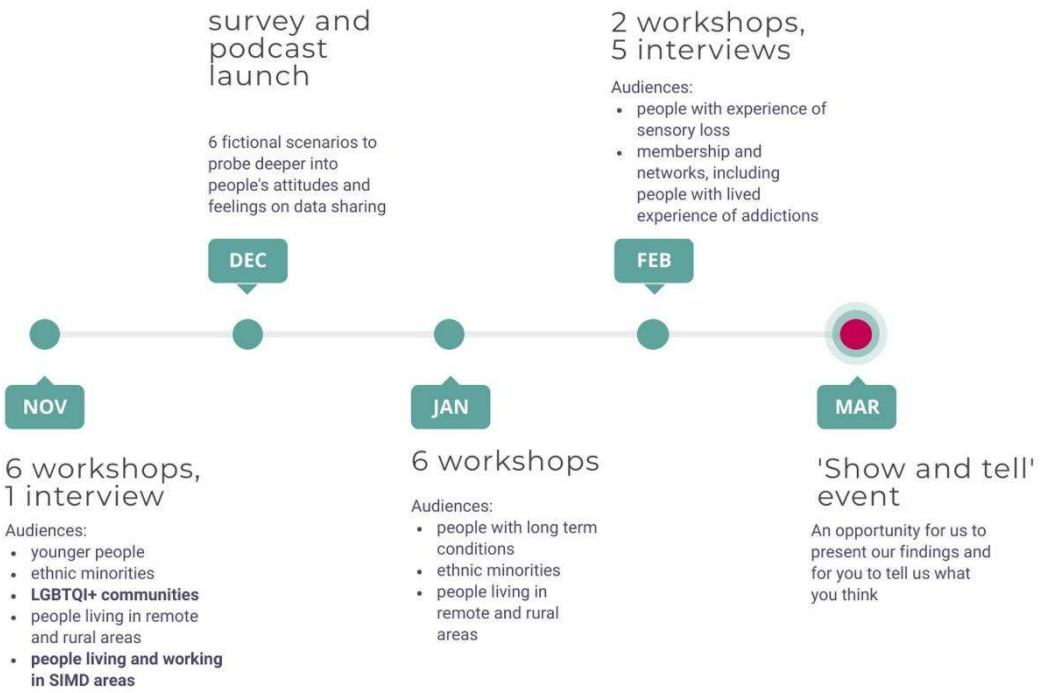
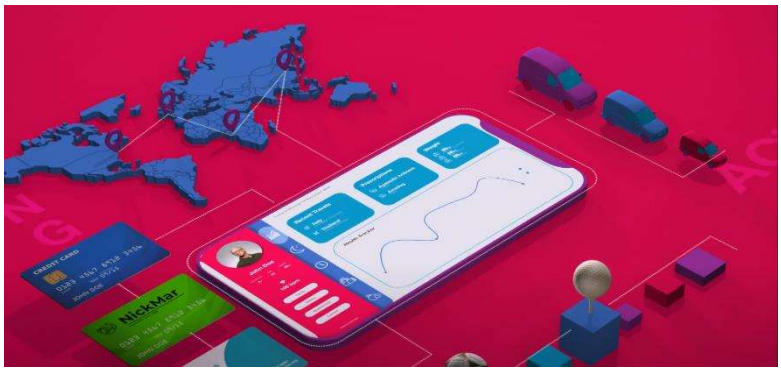


Figure 2

Video and podcast

To help publicise various stages of the project, we created an explainer video and a podcast.

The explainer video provides a short introduction to the wider determinants of health and what the **My World, My Health** workshops aimed to explore. The video was used to promote the project and to frame the workshop discussion in the introduction.



Video: www.youtube.com/watch?v=qQeQ8LdvMmg

The project podcast consisted of an interview with Chal Chute and Dr Kate Mark from the DHI, covering the topic of sharing data for public health purposes in more detail. It was used to frame the survey and further promote the project.

Podcast: anchor.fm/alliancelive/episodes/My-World--My-Health-using-data-to-help-keep-you-well-enq05c

Workshops

Between 13th November 2020 and 19th February 2021, we held 14 workshops in total. This was achieved in three phases, each targeting different demographics:

- Phase 1: general public, people belonging to the LGBTQI+ community and people living in SIMD areas (November 2020)
- Phase 2: people with long term conditions, people belonging to ethnic minority communities, older people and people living in rural areas (January 2021)
- Phase 3: people living with sensory loss, including deafblind individuals and BSL users (February 2021)

We used a targeted approach, identifying organisations for each of these demographics through www.aliss.org and the extensive ALLIANCE membership. Due to time constraints, COVID-19 restrictions and capacity, most of the workshop promotion and outreach was done by targeted emails and social media.

However, we also reached out to organisations who engaged with people who were not online and tried to ensure that our approach was accessible. For example, places on the sensory loss workshops were advertised through our colleagues at deafscotland and a British Sign Language translation video of the project information was also created: https://www.youtube.com/watch?v=FlZVQBzRzXw

Registration of interest for the workshops was done by email, offering prospective participants a single point of contact who then shared further information on the sessions, forwarded the consent form, sent the workshop reminders and joining instructions. Where participants were unable to fill in the consent form digitally, consent was gathered by phone. An explainer video on how to use Zoom and Miro was also included in the joining email: https://youtu.be/UxQRVnM099g.

The workshops were delivered online using Zoom and Miro, except for the sensory loss workshops, where we used Zoom only due to accessibility considerations. Workshops averaged 4-5 participants per session, to ensure that qualitative insights could be shared and gathered. The workshop design was developed in collaboration with the Digital Health & Care Innovation Centre (DHI), with input from design and public health professionals. The facilitated discussion was made up of six steps, described in Appendix 1.

Survey

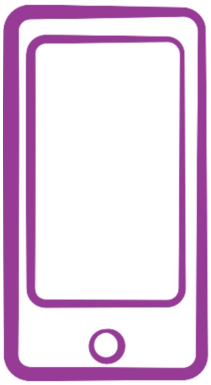
The My World, My health survey aimed to get broader views on data sharing from the Scottish public. The survey ran between 14 December 2020 – 15 February 2021 and it was built on foundations provided by the initial findings uncovered in the November 2021 workshops.

The survey presented participants with:

- Context around this work (linking to the project podcast and video)
- An expanded version of the workshop statements
- Six data sharing scenarios
- Additional questions around sensitive data sets, controls and assurances, and personal attitudes to data sharing

The survey received 64 responses, nine of which were submitted by people who also took part in a workshop or interview. Due to the survey's length and complexity, we believe that the findings are valuable despite the limited number of responses. It provided a large dataset of in-depth qualitative responses that complemented and amplified our in-person engagement.

The full survey can be viewed in Appendix 2.



Interviews

To address concerns around exclusion of those unable to access online engagement, we offered telephone interviews in addition to the workshops and survey. These were promoted through targeted outreach to specific third sector organisations and online. We held six qualitative interviews in total, one in November 2020 and five in February 2021. The interviews loosely followed the structure of the workshops and were analysed separately.

Demographics

The engagement phase reached 125 participants in total. Figure 3 shows the distribution of participants across the various engagement methods and workshops. However, it is worth noting that there was a level of intersectionality in the workshops and this is a simplistic representation of the targeted groups. For example, some of the participants belonging the LGBTQI+ community were also part of ethnic minority communities and we had participants over 60 years of age or living in rural areas who were also living with long term conditions.

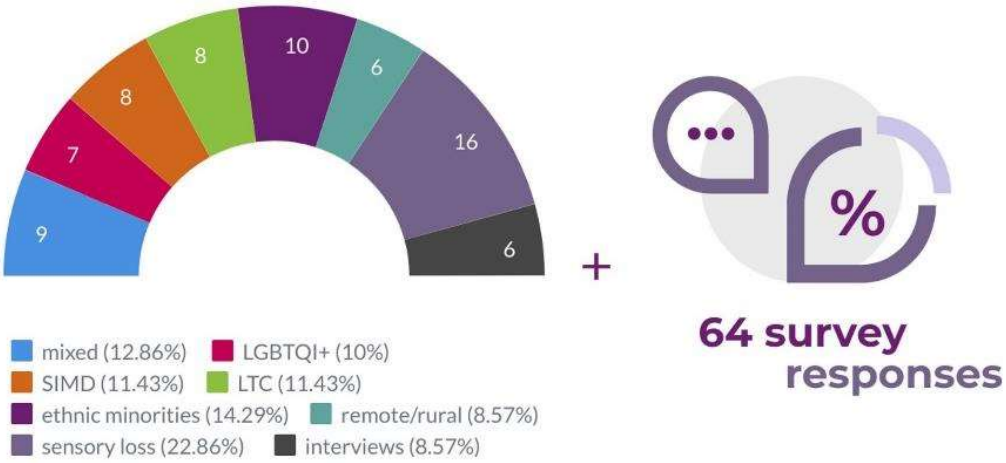


Figure 3

Figure 4

In terms of reach across Scotland, workshop and interview participants were mostly from urban locations (75%). The spread was mostly along the SW-NE axis (Figure 4). This correlates with population density levels in Scotland.

‘Show and Tell’ event

On 11 March 2021, we held a ‘Show and tell’ event to publicise some of the project findings and gather further feedback. Around 30 participants and stakeholders joined us online for this event. The event presented participants with key findings, as well as an early interpretation of the insight in the form of nine key principles and five ‘future scenarios’ embedding the principles. The discussion from this session was captured and is included in the analysis presented below under ‘Findings’ and ‘Alternative futures.’

Engagement insights

While carrying out this in-depth engagement on a rather complex topic, we had several opportunities to learn from our experiences and tailor our approaches as we went along. This flexibility ensured that we were able to engage with a diverse range of participants.

We continuously simplified the workshops, focusing on the quality of the interaction. We decided against asking participants to edit the Miro boards themselves early on. Instead, the facilitator shared the Miro screen and participants could input through Zoom, either verbally or in writing. We then limited the number of pictures to choose from in the persona-creation phase and offered less, but more targeted, scenarios during the card game.

We also became aware that certain topics of conversation (i.e., around eating disorders and mental health) were sensitive for some participants. We therefore made a point of mentioning at the beginning of the sessions that the facilitator was Mental Health First Aid trained and that if they found any of the topics distressing, they could take a break at any time, and chat with the facilitator.

Accessibility was an important consideration too. On one occasion, a participant was sent print outs of the workshop activities by post, as they were attending the workshop alongside a relative from a mobile device. The final two workshops were adapted to suit the needs of people with sensory loss. We had BSL and Electronic Note Taker support available and the workshop format was entirely discussion based, following a question-and-answer format. This allowed participants to contribute by drawing on their own experiences rather than considering a persona.

In terms of workshops numbers, we found the ideal was between four and six. One workshop had only one participant due to last-minute dropouts. In this instance, the facilitator and note-taker joined in with the conversation, but only the participant's comments were included in the analysis. On the other hand, one of the sensory loss workshops had 11 participants, which limited the scope of the conversation that could be covered in the 2.5-hour session.

Project limitations

In terms of project limitations, the online delivery method accounts for most challenges we encountered:

- Most of our participants were confident in using online engagement tools such as Zoom and email. Whereas we offered interviews to try and counter this limitation, we did not reach any people who were completely excluded from using digital tools.
- In terms of geography, our engagement did not cover all health boards, with no participants joining from the North-West of Scotland (including the Western Isles).
- Although we had high uptake for the workshops aimed at ethnic minorities, we did not manage to engage with any Gypsy/Traveller communities, who we appreciate might have different concerns with regards to data sharing.
- While our workshops were aimed at certain target groups, we did not put-up eligibility criteria or block the participation of any individuals interested in taking part. Our audience was therefore entirely a self-selecting audience, which included people with a professional interest in the topic.

It was also highlighted in several workshops that this project was very much informed by the current COVID-19 pandemic. Participants noted that their responses would had been different 12 months ago, with the key changes being in an awareness of the importance of data (due to the constant news coverage of COVID-19 statistics and population level data), increased understanding of how lifestyle changes affect one's wellbeing (as people had to change habits to adapt to lockdowns and restrictions) and greater need for peer-to-peer sharing (participants noted having more honest conversations and sharing more about how they were in social and professional settings).

3. Findings

This chapter provides an overview of the insights we gathered throughout the project, including during workshops, interviews and through the survey responses. The insights cover two main dimensions:

- ***State of play: context and practice*** - a discussion on current understanding and behaviours linked to data in a health and wellbeing context;
- ***Future visioning: aspirations and concerns*** - an analysis of participants' attitudes and preferences with regards to data sharing more generally;
- ***Attitudes to data sharing*** – an interpretation of the types of responses received throughout the engagement.

3.1 State of play: context and practice

Throughout our engagement, we sought to determine participants' understanding of the wider determinants of health, as well as their behaviours linked to data collection, usage and sharing.

3.1.1 Do people understand the wider factors that influence their health?

Most of our workshop participants could see a link between health and lifestyle choices. Food, exercise, sleep, work, and social connections were all mentioned. As it is perhaps to be expected in a self-selecting audience, most were proactive about their wellbeing, involved in civic activities and committed to lifelong learning. Very few participants said that they did not consider lifestyle and habits in relation to their health.

People with long term health conditions or sensory loss were more likely to understand how different lifestyle and environmental variables can affect their health. This was noted by the participants themselves to be down to the nature of living with their conditions. These participants also valued being able to access peer support networks and gain knowledge from them, both in-person and online. They seemed to agree that the more information they had access to, the more likely they were to understand how different factors affected their physical and mental wellbeing.

Some participants shared examples of scenarios in which their wider circumstances were not considered by medical professionals. This was noted to have caused them problems linked to receiving the wrong prescriptions, delayed diagnosis, or a lack of signposting to relevant services.

In terms of barriers to understanding, **having access to the right data can be challenging.** Too much data was also considered to be potentially overwhelming, for both individuals and professionals. An example brought up in the workshops was that individuals

recovering from addictions might find certain information triggering and therefore harmful instead of beneficial. For people living with sensory loss, the importance of having access to data in suitable formats was a recurrent theme. One workshop participant noted that, for example, dietary information on products can be very hard to access as a blind person.

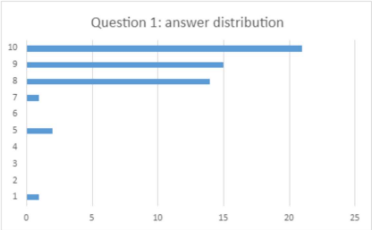
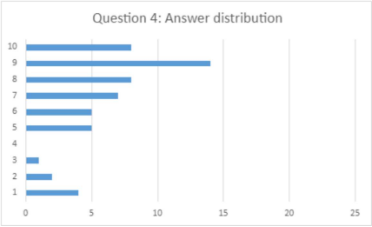
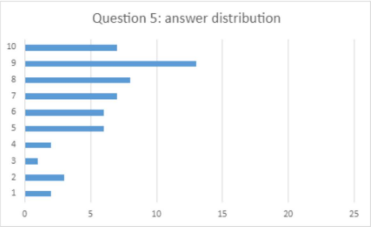
Participants also noted that one might understand the wider determinants of health and current advice, but not necessarily able to act on it. 'Honesty with oneself' and motivation were key factors, but so were access, affordability, availability, mental health etc. Healthy living was understood to be a multi-layered concept, that could be affected by a multitude of variables.

The mapping exercise elicited surprised responses in most groups with regards to how much data is routinely collected by public and private institutions. Particularly emotional responses were received from those who were not particularly active online. It also transpired that the apps and services people used most were the ones they were most likely to forget about when considering how their data was being tracked (email, phones, digital maps).

Those more aware of the situation were also more likely to consider how the system could be improved for greater transparency:

> *"Being born in 2021 you are both a human being and a source of data in everything you do. Therefore governments, private sector etc need to have a conversation about how we need to live and think of data flows as being just as important as health flows, employment flows and so on."*

The survey responses corroborated these findings, with an average score of 9 (1-10 agreement scale) to the statement: "I know about the different things that influence my health". The average score for both "Having more information about my **health** helps me stay well" and "Having more information about my **lifestyle** and **habits** helps me stay well" was 7.

I know about the different things that influence my health. Average score: 9	Having more information about my **health** helps me stay well. Average score: 7	Having more information about my **lifestyle** and **habits** helps me stay well. Average score: 7
		

3.1.2 What information do people collect and hold themselves on wider determinants of health? Why do they do it?

The lifestyle and personal circumstances of the person seemed to dictate what information, if any, they actively and consciously collected about themselves. In most cases where participants said they did collect information, it was related to activity levels or symptoms, with the direct aim of benefiting their health.

People with long term conditions were likely to collect more data than others, and in a more structured way, which was a necessity rather than choice. Most often this information was for self management or for sharing with health and social care professionals. While some collected raw data (activity, glucose, diet etc – mostly using digital) others collected more general information (appointments, journaling etc – mostly using paper, but also digital).

However, participants noted that gathering this type of data can feel like cumbersome admin work, whereas marketing data is collected seamlessly in the background. Moreover, for some, personal experience was perceived to be more valuable than data. All the participants living with long term conditions had developed their own approaches to self management, informed by their experiences over the years.

Participants living with sensory loss were also highly likely to collect information about their daily habits, meetings, and commitments. This was due to the nature of living with sensory loss, which made them more reliant on technology to take part in everyday activities. This in turn also meant there were more data flows and integrations to consider. A large proportion of participants living with sensory loss also tracked health and fitness data. While fitness data was mainly tracked and recorded for motivation, lifestyle and diary data was captured to help them keep track of appointments, help with memory issues and to 'keep busy'.

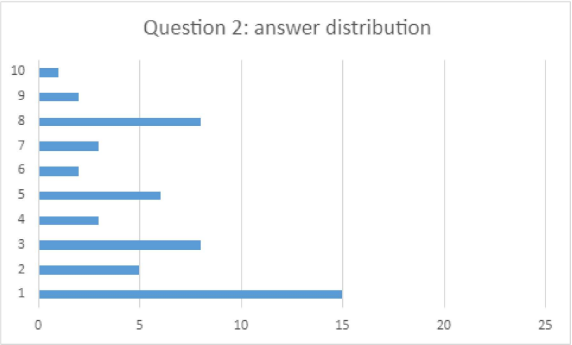
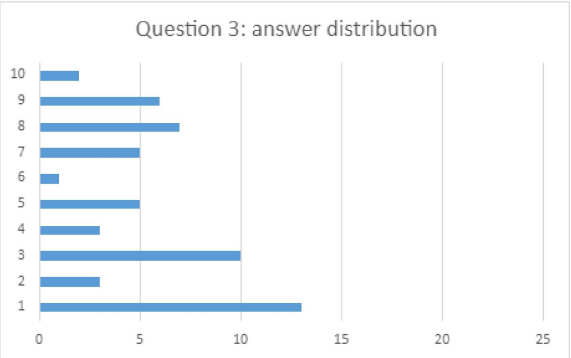
Where people did not collect any information, the barriers cited were:

- Saturation: a few individuals felt they knew enough already due to having to manage long term conditions and did not want to be overwhelmed by more data
- Skills / confidence: some participants said they did not know how to use data to inform their wellbeing
- Availability of software / hardware: while one participant noted that there were no digital tools specifically designed for their condition, another individual highlighted that wrist-worn wearable devices were uncomfortable or even painful to wear if you lived with certain conditions

Some participants noted that they did not diarise their wellbeing through digital means or paper records, but instead kept 'mental records' of their habits. They were also more likely

to trust their own intuition or consult a health professional in the first instance if they had any health or wellbeing concerns.

The survey responses reveal that people are slightly more likely to collect lifestyle and habits data digitally rather than on paper. However, neither constituted a significant practice in our survey respondents.

I collect information about my lifestyle and habits **through paper diaries or in other written form.** Average score: 4	I collect information about my lifestyle and habits **through digital apps and websites**. Average score: 5
	

3.1.3 With whom do people currently share data they collect?

As already mentioned, **those who collected information mostly shared it with health professionals and friends or family**, although there were variances between the groups. For example, in the LGBTQI+ participants seemed more comfortable sharing information with health professionals in comparison to friends or family. In the ethnic minority workshops the opposite applied. However, in both these communities there was increased concern that prejudiced or biased professionals might misinterpret data and offer inadequate treatment in response.

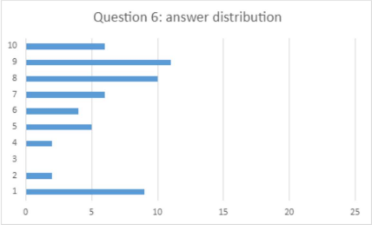
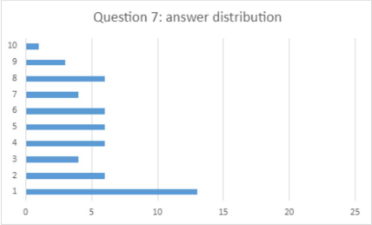
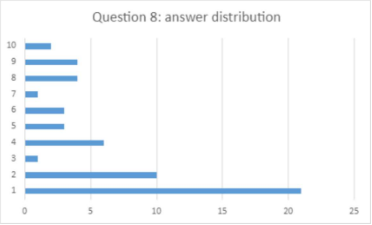
There was a strong sense across the board of the **importance of sharing personal experiences for peer support, advocacy or to effect change in policy and practice**. While this is not the type of 'raw' data sharing that the project set to explore, it is worth noting that individuals seemed more open to sharing their stories rather than their data. Looking at the controls and assurances that participants called for during engagement, it is likely that this preference is linked to issues of control, authorship, and empowerment.

The COVID-19 pandemic was brought up in most conversations and it was recognised that it posed both barriers and opportunities for sharing information; people might be less likely to contact their GP, but more likely to be open about their health with friends and family. However, it was noted that those at risk of isolation might not do the latter and therefore be at risk of 'falling through the gaps'.

With regards to barriers to sharing data, participants in the sensory loss workshops mentioned the barriers they faced in trying to communicate their situation with health and public services. Stories of having to share information repeatedly with local and national authorities, often during the same year, for the renewal of entitlements were common amongst this cohort. The fact that health professionals are unlikely to be able or willing to make sense of large sets of personal data was also brought up in various workshops.

Other examples of sharing personal health and wellbeing data were for research purposes (clinical trials) or with private companies in exchange for personalised customer service or support. In the latter example, the participant felt they were getting 'more understanding treatment' if they were open about their health conditions with these companies. It is worth noting however that these were Scottish companies that the participant trusted, admitting that they would have not felt the same way about multinational companies.

The survey responses highlighted surprisingly low scores with regards to sharing data with health and social care professionals. Although more respondents shared information to some degree with health and social care professionals compared to other agencies, the scores tended to be lower than expected across the board.

I currently share some information related to my health, lifestyle and habits **with friends and family**.	I currently share some information related to my health, lifestyle and habits **with health or social care professionals**.	I currently share some information related to my health, lifestyle and habits **with other agencies**.
Average: 6	Average: 4	Average: 4
		

3.2 Future visioning: aspirations and concerns

Through our workshops, survey, and interviews, we also aimed to determine how participants felt about the potential of sharing data linked to wider determinants of health with a range of services. We wanted to ascertain whether people saw any potential benefits to this, whether they had any concerns and how these might be addressed.

3.2.1 Would people like to see different data sets brought together?

One of the strongest themes under this question was that **participants overwhelmingly wanted better integration of data flows within health and social care**. Joining up this information was seen as having the potential to create better communication within the health and social care system, addressing current inefficiencies which can lead to repetition, frustration and barriers to treatment and support.

Some participants felt positively about the potential for bringing more data into the NHS, such as that linked to activity, lifestyle, and wider circumstances. This was moderated by an acknowledgment that NHS professionals might struggle to process all this data. This was backed by the experiences of participants who tried to bring data from digital trackers, letters, printed lists of medications etc into consultations. The responses from health professionals varied: some were happy to accept the information where it offered more context, while others were wary of accepting data collected in a non-medical setting.

Related to the above theme was a sense that **linking data sets could enable a more holistic view of the person and provide more opportunities for involving them in their own care and treatment**. Participants noted that because the person and their family know the person's situation better than a healthcare professional, they should be able to input information they feel is relevant into their own medical record. Respondents also argued that requests from a healthcare professional to access a person's data should require permission from the person.

Despite being able to see the added benefits of sharing additional data sets with NHS professionals, **most participants preferred relationships based on trust where they were empowered to share such information themselves when relevant**. It was noted that health professionals should be encouraged to ask question on the broader determinants of health in their consultations, as some respondents argued that only using a few medically based indicators was misleading about a person's true health and wellbeing. It was argued that inputting data in partnership with the healthcare professional would be a more inclusive approach and give people greater ownership of their own health and wellbeing.

Participants in the sensory loss workshops were also in favour of better data sharing between local and national authorities for routine processes (applying for PIP, blue badge etc). There was a strong desire for information on accessibility requirement to be routinely and automatically made available, so that the individual does not have to always repeat what their accessibility needs are and how information should be communicated to them. The WelcoMe app[6] was mentioned here as an example of good practice.

Better sharing of information between third sector organisations was another recurrent theme, noting that better information could lead to improved signposting and earlier interventions. It is worth noting however that there wasn't a full consensus for data sharing amongst workshop participants, as some participants were very reticent and very private, emphasising the importance of allowing individuals to opt in or out of any such systems.

It was also noted **that data collection should not be used as the sole basis or replacement for targeted social interventions**. While discussing scenarios where social media was tracked to prevent risk of isolation for community members or bullying for children, it became clear that there is a strong preference for personal approaches, involving face-to-face outreach and education, rather than relying on data collection to identify risky situations. This was partly due to concerns around unwarranted surveillance and partly due to participants feeling that data can be easily misinterpreted.

Some participants argued that too much information, or imperfect data sets, could create a lot of "noise" and end up being unsuitable for all practical purposes. There were also concerns around the authenticity of data if people self-report, or the reliability of tracking devices that might break or malfunction. It was noted that if people thought they were being monitored 24/7, it could provide them with a false sense of security that could lead to unintended harms. Finally, others felt that data sets could easily be presented out of context, therefore providing misleading information.

A common thread in the survey responses was a concern that there is a risk of disempowerment inherent in bringing data sets together. This was due to the perception that **data could strengthen paternalistic approaches or weigh the balance of power further in the favour of professionals or the 'state', rather than individuals themselves**. Interestingly, one workshop participant noted that already in some instances such as to do with insurance or credit scores, there is already data in the 'system' that we cannot override or affect by adding our own personal data. This raised questions about the level of empowerment a data-enabled future could offer.

Another theme that came out of the survey respondents was a **suspicion of what personal data would be used for**. Many expressed concerns about the idea of commercial companies having access to their data and the uses that these data would be put to. In some instances, they felt that other forms of measurement would be more

[6] https://www.wel-co.me/visitors

appropriate than individualised data. Some participants also expressed concern about the level of individual information that the NHS or the government would have on a person and queried whether it was necessary to share this amount of data.

3.2.2 Which data sets do people want to keep private?

The following types of information were regarded as particularly sensitive by participants and survey respondents, listed from most sensitive to least sensitive (Figure 5):

- Financial data (both general and detailed)
- Sexual health data
- Mental health data
- Data on medication
- Equality data (ethnicity, gender, disability etc)
- Data related to health conditions or symptoms
- Location data
- Detailed dietary data
- Employment data
- Gender

During a workshop aimed at people from ethnic minority communities, participants discussed the persona of an asylum seeker and noted that there were particular sensitivities in such a scenario, as sharing the wrong or misleading data could have life-changing consequences. Therefore, **while data sets can be sensitive in themselves, context can also add layers of sensitivity.**

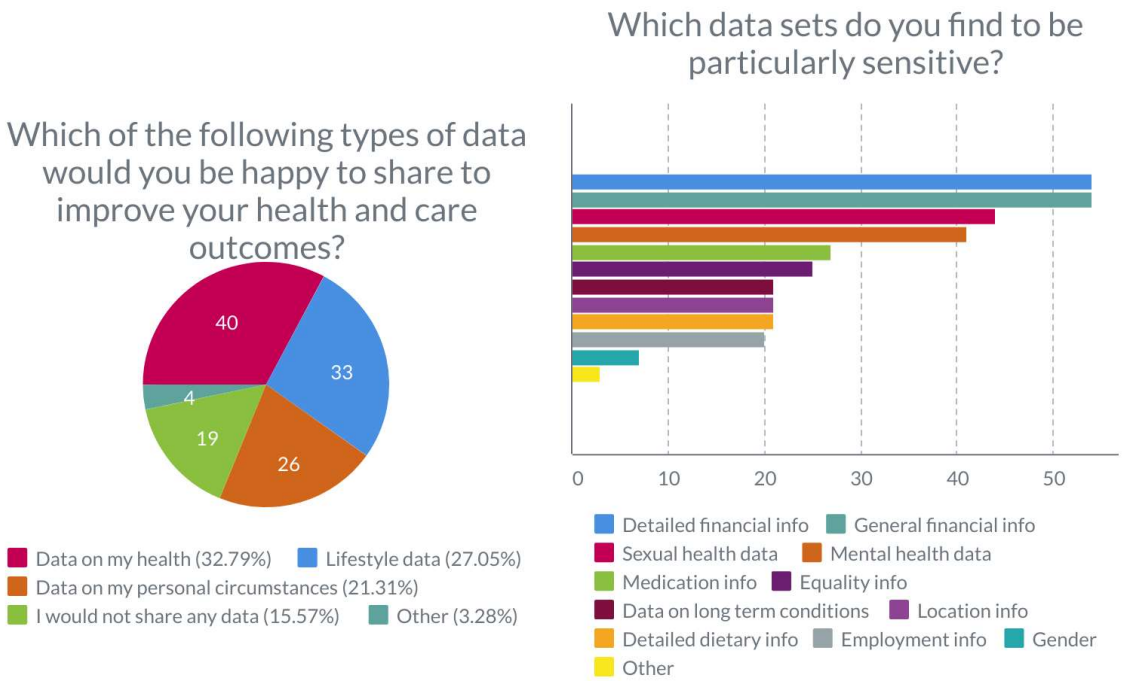


Figure 5

While there were general concerns around sharing data that could lead to serious harm, such as fraud or identity theft, **many of the conversations were framed around fear of stigma and discrimination.** This was even more evident when the interpretation of sensitive personal data could be affected by bias, particularly when based on opinions rather than facts (such as in the example provided in the gender transition scenario in the survey, see Appendix 2, page 55). There were also fears that if people were forced to share sensitive details about their personal circumstances, other bodies could act against them or discriminate based on the information.

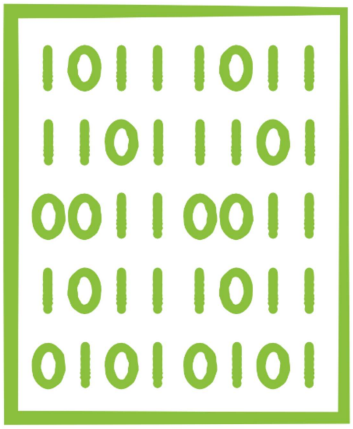
There were strong responses in the survey that raised concerns about the infringement of privacy, linked to the fear of a 'Big Brother' state. While some respondents felt that only sharing some types of data would be such an infringement (finances, home tracking etc), others felt that any kind of monitoring and sharing of data, including aggregate population data will lead to an almost Orwellian society. There were also enhanced concerns around sharing information with insurance companies, due to fear of increased premiums and unequitable approaches.

3.2.3 Do people want some of their data collected and analysed for prevention and public health outcomes?

There were mixed views across the board in relation to whether collecting and processing data for prevention purposes was reasonable.

Some participants and respondents felt that such an approach could **support joined up services and guarantee continuity of care for at-risk individuals, as well as support tailored interventions**. It was argued that linking data between the third and public sectors in particular could lead to such benefits. There were also suggestions that automatic prompts might get people to check in with support services or GPs, particularly in the current circumstances.

However, many felt the risks outweighed the positives. The greatest concerns were linked to the potential misuse of data by insurance companies or health providers, bias inherent in data collection, disempowerment (focusing more on sharing data instead of supporting individuals through their journeys) and concerns about privacy and mistrust of sharing information. There was also a comment that in a truly equitable society there would be more equal opportunities and we would not need to resort to tracking the population to solve systemic issues.



3.2.4 What trade-offs are people willing to make around data and health and wellbeing?

Participants were more likely to consider data sharing if there was a clear benefit to themself, others or wider society. However, there were also discussions around scenarios where potential benefits could come with associated risks. One such example

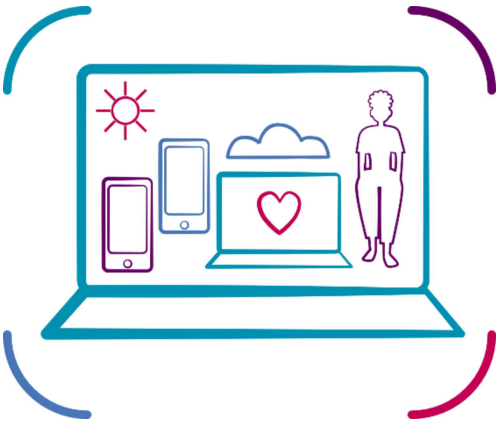
brought up in the workshops was that of connecting an individual's gambling account with their bank account; this could raise an alarm if gambling spend got out of hand, but it could also lead to negative credit scores with the bank. It was noted that in these situations balancing risks was important and no 'rule' could be created, but it should instead be up to the individual to weigh the risks against the benefits and make an informed decision.

Survey respondents were also more likely to respond positively to the scenarios where they could see how the use of data would improve continuity of care for at risk-individuals, bring benefits to individuals or wider society, support personalised and preventative interventions or holistic approaches to health and wellbeing. For example, people argued that digital solutions could prevent people from 'vanishing from services' and falling through the gaps in the welfare state. In several responses, even if respondents were not necessarily pro-data sharing, if they saw the potential benefits as outweighing the risks to health, they were more likely to accept the scenario as positive.

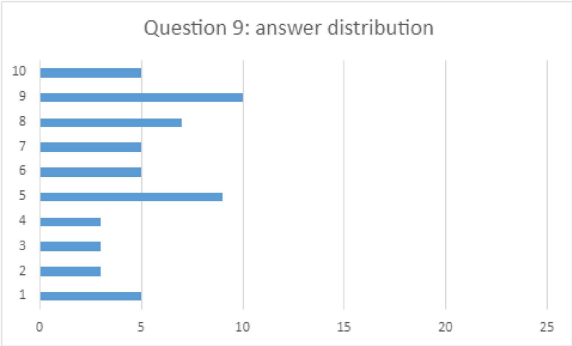
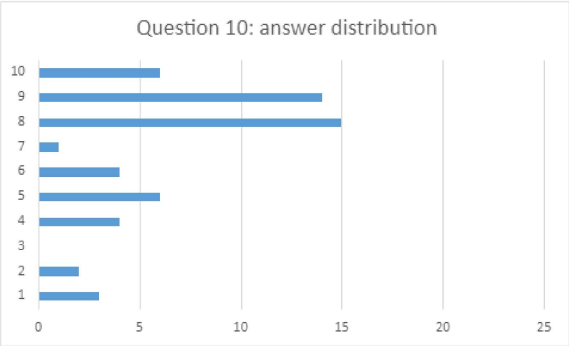
Other situations in which participants were more willing to consider sharing sensitive data included scenarios where the data was anonymised, collected and shared with explicit agreement of the data subject, used within a closed community only or to evidence a need for support and avoid abuse of the system. Moreover, for some receiving better treatment or understanding from service providers was seen as enough of a benefit to warrant them sharing potentially sensitive data.

In some cases, the 'proximity' of the individual or agency accessing data was also an important consideration. While sharing financial information with a social worker raised red flags, there were other services participants identified as more trustworthy for handling this type of data, such as Citizen Advice Bureaus or banks' debt services. The reasons given here were that the individuals working in these services were further removed from the personal situation of the individual who was accessing support.

In the sensory loss workshops, **many participants felt like data and technology came hand in hand and the latter wasn't optional**: "For me as a deafblind person I think technology has potential. I feel that what it does is it levels the playing field so that no matter what impairment you have the technology brings you on a par with everyone else." This highlights the importance of ensuring that individuals' rights are safeguarded in a data-enabled future and that the trade-offs individuals end up making are fair.



The data from the survey shows a slight rise in acceptability of data sharing where there are benefits to wider society compared to benefits to self, with the average score raising from 6 to 7. This highlights the importance of social capital in individual's considerations.

I would be more likely to share information related to my health, lifestyle and habits if I could see **direct benefits to myself**. Average: 6	I would be more likely to share information related to my health, lifestyle and habits if I could see **benefits to wider society (i.e., research purposes).** Average: 7
	

3.2.5 Who should hold responsibility for data sharing?

Survey and workshop consensus was largely that people should be in control of their own data: "This is an opportunity to create individual ownership of data and shift the paternalism of social services in our society. We must enable people to use the data to foster individual control and autonomy and responsibility. Autonomy, privacy and independence should be at the heart of data collection."

The issue of disempowerment applies to this consideration too, as we need to ensure that in giving people ownership and control of their data they are empowered and enabled to take informed decisions. It was also suggested that both professionals and the public need further training and education on how data is or could be used, including the implications of data sharing. Conversely, participants felt that if an individual did not want to share data, even if it were for their benefit, that was their right and it should be respected.

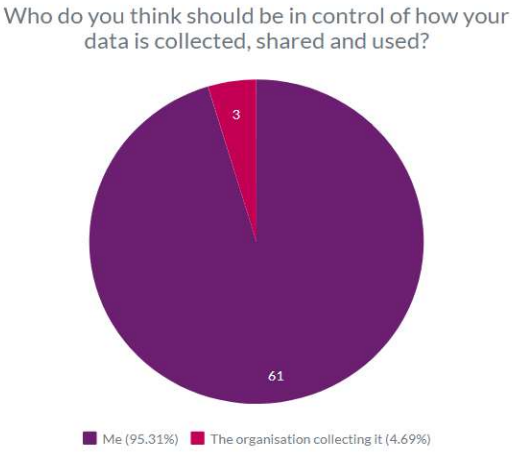


Figure 6

Most participants agreed that once data is shared with another agency it was that agency's responsibility to keep the data safe and secure, particularly within the NHS. Participants also felt that organisations should have a responsibility to make their Terms and Conditions more accessible and easier to understand.

3.2.6 What safeguards do people want around data collection and sharing?

Throughout the engagement, participants asked for a wide variety of controls and assurances to be put in place to protect individuals' data and right to privacy. While these

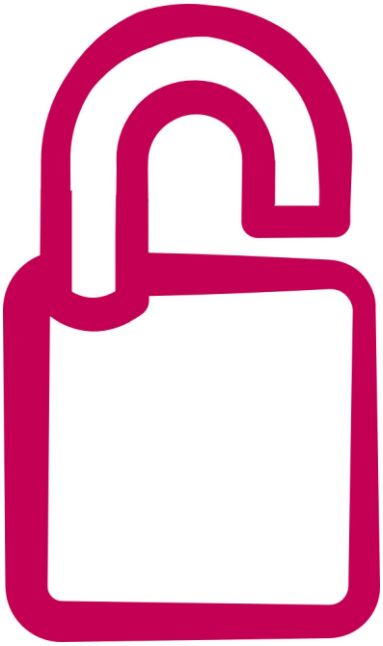
have been summarised and interpreted practically under the 'Core principles for data sharing' chapter, the following paragraphs provide a more in-depth exploration of these requirements.

The strongest recurrent themes were those of informed consent and freedom to choose. Participants argued that **individuals should be in control of their data and how (or whether) it is collected, processed, or shared.** Core prerequisites for this are better transparency within terms and conditions and privacy notices, allowing individuals to make informed personal choices.

There was a strong focus on the importance of empowering the data subject to understand and make decisions with regards to data sharing, creating 'mutual trust and respect' between systems and citizens. It was noted that there is a substantial need for education, transparency and open two-way communication around data sharing to build a more equitable system. **We need to ensure that we co-create clear processes and systems based on empathy and human relationships.**

Protecting individuals' right to privacy was another key requirement. Participants felt strongly that individuals should be allowed to decline sharing data at no detriment to them in terms of the quality of the public and health services they were accessing.

It was also highlighted that **there needs to be rigour in the use of data, in line with the individual's consent.** There should be no collection, use and processing of personal data that individuals in question are unaware of and individuals should not be stigmatised or discriminated if they chose not to opt-in to data sharing.



Participants noted that the purposes for data collection, use and sharing should be clear and transparent, while also benefiting the individual, community, or wider society. This also includes an element of **building trust in systems and professionals**, as there were comments linked to distrust towards both private and public bodies surfaced in our engagement. "Folk need to know exactly where that information is being taken and how it's used to their benefit, not the agency's benefit".

Furthermore, it was felt that those with access to sensitive personal data should be trained to ensure that no discrimination, shaming, or prejudgements were passed. Similarly, **there should be no adverse effects to individuals due to either computer error, human prejudice or malintent resulting from the processing of data.** As a participant noted, you "can't teach a computer nuance, but human interpretation is open to bias also."

Or as another participant observed, human bias could become part of digital systems themselves: "The way data is shared means that potential human bias is being replicated, amplified and passed on. Doctor may feel that they can't think outside of the box. There are

human biases in digital systems that can limit the action that can be taken." This related to issues of power dynamics and guidelines based on technological process.

Security of data was another key consideration and a principal source of fear and concerns. All participants felt strongly that personal information must be kept secure, with special care given to sensitive data or that relating to more at-risk groups. It was seen as particularly important to ensure that no unauthorised access to data was permitted, and that it should only be collected through trusted tools.

Finally, some of those we engaged with told us that consideration needs to be given as to whether data is accurate. Do people have the devices, skills or connection required to gather it? If the data collected affects any benefits or sanctions, will self-reporting be influenced? We must also ensure that the balance between facts and personal stories or opinions is right, with the two complementing and reinforcing each other.

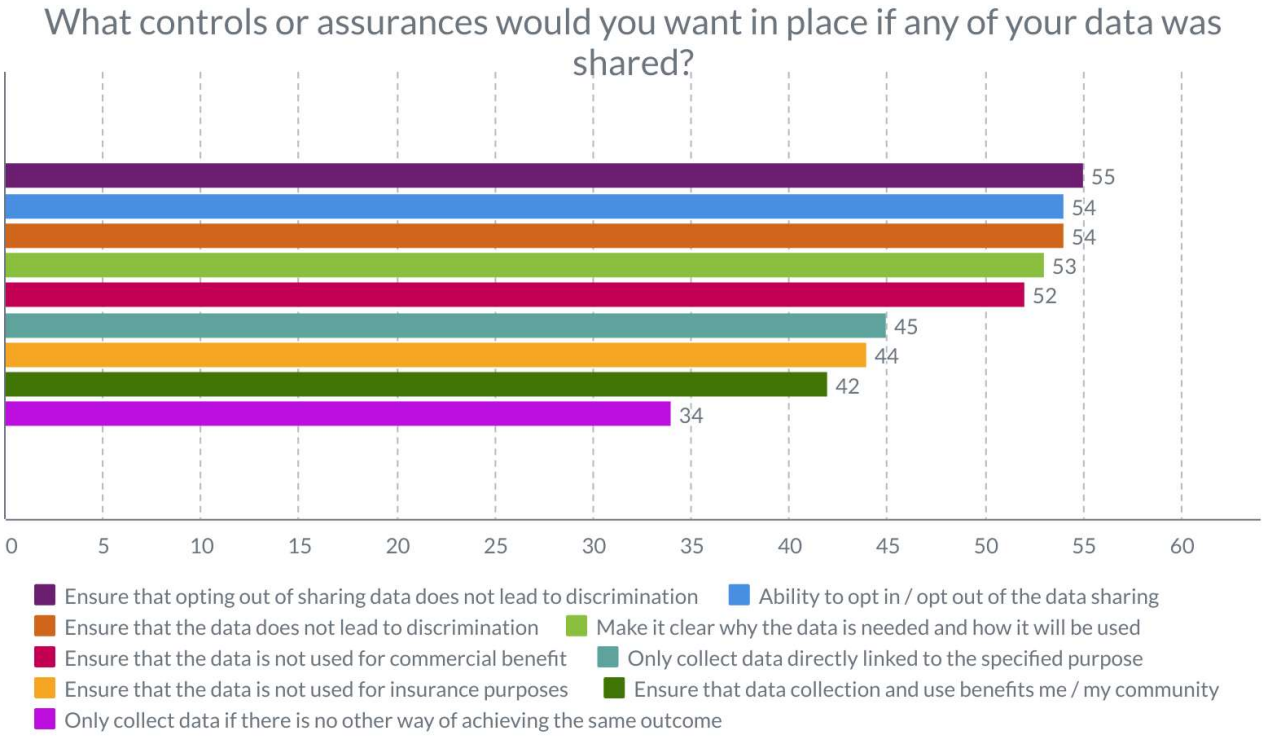


Figure 7

3.3 Attitudes to data sharing

The findings described in the previous chapter can give us a good understanding of the wide spectrum of attitudes to data collection, use and sharing that are currently present amongst the Scottish public. Reflecting further on the responses we received to the six fictional scenarios presented in the survey (see Appendix 2 pages 54-55), it is striking that no one scenario was accepted as overwhelmingly positive or overwhelmingly negative (Figure 8).

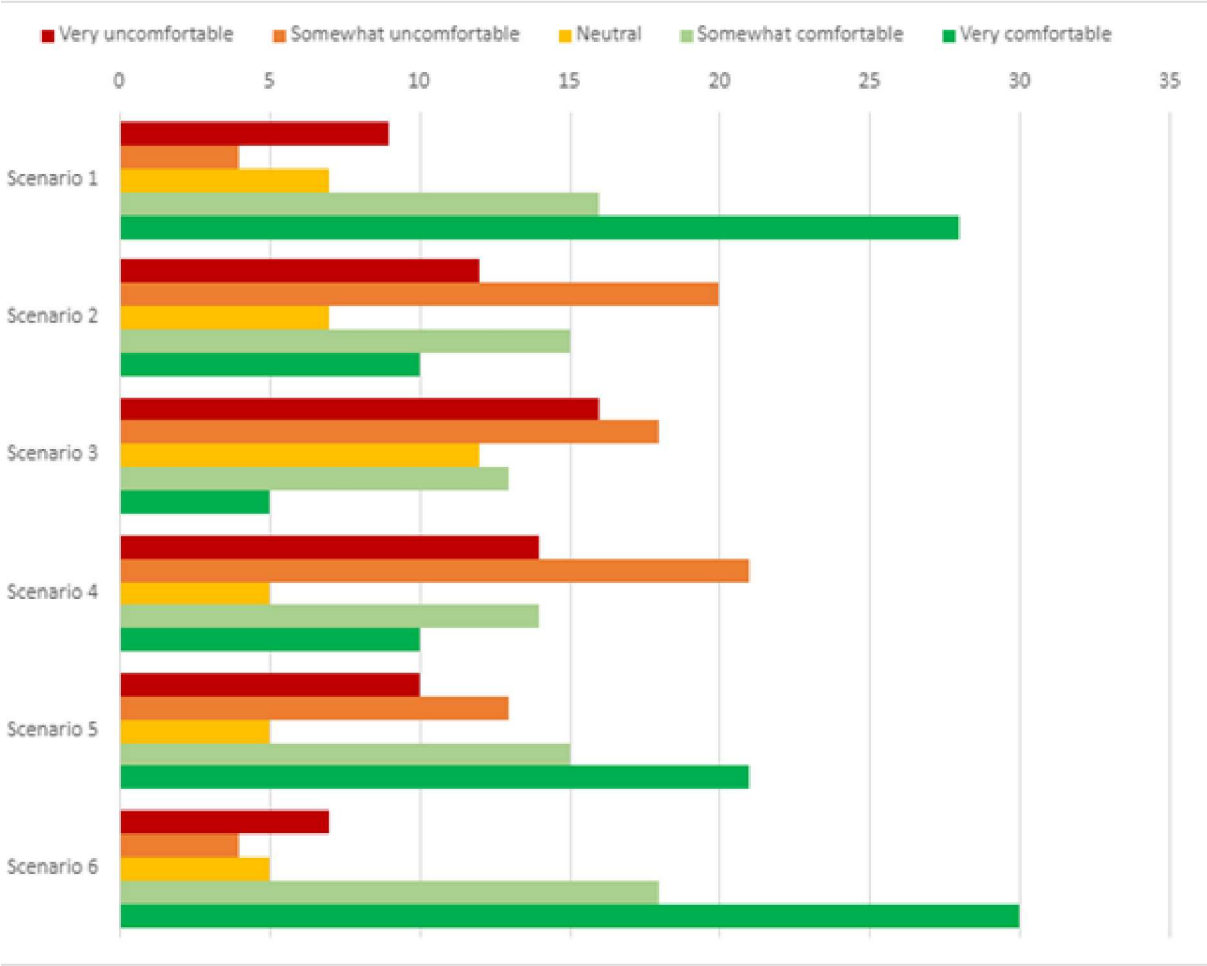


Figure 8

While scenarios 1, 5 and 6 (sharing anonymised utility data, home remote monitoring and sharing homelessness data between nursing teams) were viewed more positively than negatively, with the rest (sharing financial data for gambling safeguarding, peer references in support of gender transition and sharing information on employment gaps) eliciting a majority of negative responses, often the same scenario could be interpreted either way by different respondents, depending on their current attitudes and perceptions of data sharing practices. It became apparent that there were different respondent profiles with regards to their attitudes to data:

1. Those unwilling to share any information under any circumstances, who also claimed that they did not share any data (low scores across Q6 to Q9).

2. Those unwilling to share any information under any circumstances, but who admitted that they were currently sharing some information (medium to high scores across Q6 to Q9).
3. Those worried and concerned about data sharing, but who could see benefits for self / common good in the right circumstances and with adequate safeguards.
4. Those positive about data sharing, who could see benefits for self / common good in the right circumstances and with adequate safeguards.

It seemed that where respondents were positive about the scenarios, they either had similar personal experiences that had been positive (employment help, visualising utility data) or saw the risk of not sharing data as being more significant than the risk of doing so (homelessness and COPD example in particular).

The scenarios linked to gender transition and employment gap saw the least consensus in the responses. Reasons given were often linked to the fact that sharing 'opinions' rather than 'facts' was open to more abuse and misinterpretation. This is interesting if considering that workshop and interview findings saw people as being more likely to want to share stories than data. This helps clarify the importance of personal authorship and the ability to tell one's own story, rather than deferring this responsibility to others.

Where respondents were against the sharing of data, their reasons were most often linked to:

- Concerns that digital services or data collection will replace face-to-face services and personal touch points
- Fear of misuse or abuse of data
- Concerns that data sharing is being used to "address" wicked societal problems superficially rather than considering the root causes
- Fears that power imbalances will become inherent in digital systems
- Concerns around the autonomy of individuals to consent

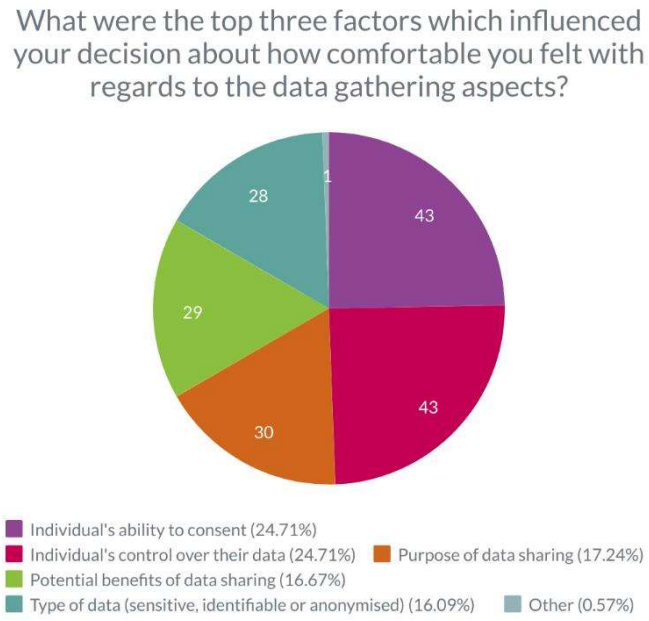


Figure 9

Participants who were wary of data sharing were also more likely to interpret the scenarios as being detrimental to the individuals in question, for example thinking that the air monitoring for the person with COPD was to catch them smoking rather than prevent exacerbations due to humidity or pollutants. There were also vocal concerns raised about paternalism and the "nanny state" stripping individuals of their autonomy and disempowering them from taking their own decisions.

4. Alternative futures

Throughout the project, we identified strong themes with regards to the use of data on the wider determinants of health in wellbeing services, as evidenced in the previous chapters. The views were spread across a spectrum of attitudes, ranging from those who were greatly concerned about data-enabled futures to those who were positive about data's potential to bring benefits to individuals and societies.

Despite this variety of opinion, we believe that with the right controls, assurances and transparency, a future where data does play a positive role in our lives can be achieved. Building on the insights gained in the dialogue enquiry, we created a set of nine guiding core principles that can enable such a future to be built. However, rather than presenting the principles as abstract themes from the outset, we wanted to interpret them first through the prism of 'alternative futures' - a set of fictional scenarios that illustrate how this future could look in practice for Scotland's people.

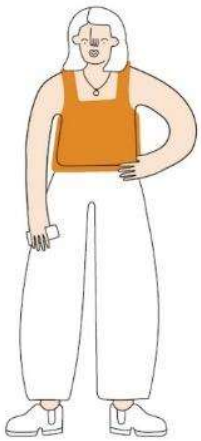
4.1 Scenarios

The scenarios are built based on five personas that were initially co-created in the project workshops. They have been amended slightly to be more representative of the core groups we engaged with and of the conversations that we facilitated. The scenarios are followed by a summarisation of the nine core principles we identified.

The scenarios introduce concepts that present potential ways of embedding the principles in future systems. These are highlighted within the text and explained in more detail in the 'Art of the Possible' chapter.

Meghan

Meghan is a young woman from Luss, currently living in Glasgow where she is studying. She lives in a student flat and is in a bisexual polyamorous relationship.



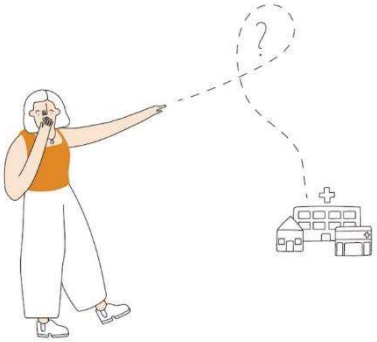
She likes hillwalking, nature and animals, but dislikes climate change and pubs. If you asked her what her ambitions were, she'd say: "I like my freedom and I would really like to make a difference in the world!"

When she went away to University, Meghan kept her GP at home for convenience, but registers as a visitor with a local Glasgow GP practice during term time. She accesses counselling through Student Services.

Meghan is quite active and likes to use a few fitness apps and websites. In doing so she tracks a certain amount of information about her fitness, which she is aware of.

However, Meghan is also aware of the concerns around data sharing. Like many of her friends she was shocked by the Cambridge Analytica scandal and has since become more aware of how she shares her data online.

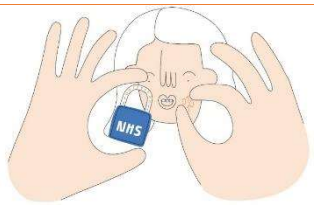
Meghan's top concern is around stigma surrounding her relationships. She has good friends at Uni that she trusts but she is still hiding her sexuality from her parents and older brothers, so she tends to keep some things quite private. She wouldn't share on Facebook what she shares on TikTok.



Meghan wants to ensure that she is in control of information that is private to her.

As she changes flats yearly and also spends considerable time in Luss, it is important to her that she can quickly change her communication preferences and that her GPs, university counsellor or other health and care professionals know how and where to contact her confidentially.

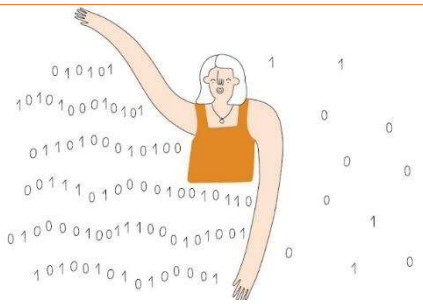
It is also important to her that her records are secure and that she is in control of who has access to her information.



Meghan uses a **personal data wallet** to control the flow of her information.

She holds all her own data such as contact details, student registration number, National Insurance Number, Community Health Index number and medications **on her personal cloud**, which she can access through her phone.

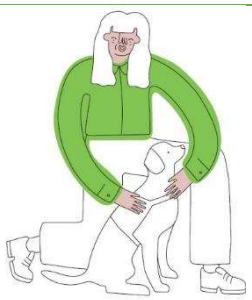
When needed, she can share bits of information with relevant parties to confirm her identity, change her preferences and so on.



For example, if she changes her address in her data store, she can then also share this with SAAS, her GP or Uni counsellor at the click of a button.

She can also review permissions. If Meghan were to decide she wanted to change counsellors, she could remove access to her address, biography and other data that she chose to share (such as sexual preference, interests, medications, emergency contacts) and then re-share these with her new preferred support provider.

Joanne



Joanne is a 71-year-old retired midwife who lives in Castle Douglas. She has started experiencing sight loss about 8 years ago and is now registered blind.

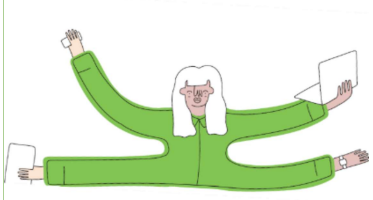
She likes animals, the outdoors and being near water. She is known to say how much she loves talking to her children and grandchildren who now live in England.

Joanne has had to make quite a few changes to her lifestyle in response to her sight loss. She has now had house adaptations installed, accesses non-residential care and has a guide dog to help too.

Her sight loss also made her appreciate how difficult a change in circumstances can be to cope with and communicate.

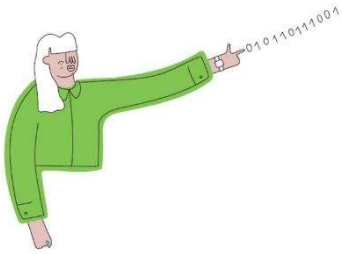
She found that she had to repeat her health story a lot. For example, every year since her sight loss started, she has had to reapply for Personal Independence Payments and a travel pass, despite her condition being permanent.

Every time she accessed services, she had to make them aware of her sight loss and sometimes even verify it.



Joanne used to have a largely off-line lifestyle but now she is finding she is using lots of gadgets to stay independent. She is therefore collecting and sharing a lot of data with private companies, which she is aware of.

While Joanne is not overly concerned about data sharing, she would however like to better understand how this information is being used and how it might benefit her or the wider sensory loss community.



To address these issues, Joanne chose to use the personal data wallet. By keeping all her own data, **she can confirm her identity with statutory sector services** so that they can see that her situation has not changed and auto-renew her entitlements.

She can also choose to use this system to share data on her sight loss with her utility providers and other services she interacts with, so that they are aware not to contact her by post, for example.

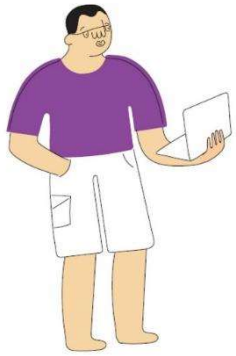
She prefers to access the wallet through her voice-enabled tablet, but it is linked to her smartwatch so she can grant permissions on the go.

Furthermore, Joanne's house is now a smart home. She has learnt how to control her environment using her tablet, but **she has also agreed to share some of the data from her home sensors with her children**, who get an automated alert if the front door isn't opened at agreed intervals.

As Joanne needs to take her dog out regularly, this can be a sign that she has experienced a fall. This alert can prompt them to contact Joanne or her neighbours to check on her.

While Joanne is keen to protect her own sense of independence and not burden her children with lots of data at the moment, she is aware that in the future she could give them or other carers access to more data if she felt the need to. This helps her feel reassured that she will be able to continue living in her own home in older age.

Cameron



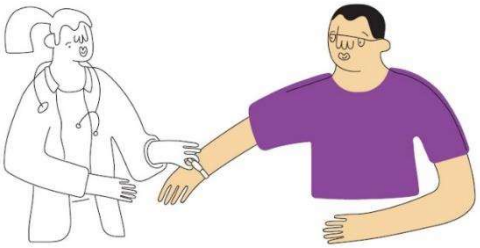
Cameron is a 29-year-old man living in Govanhill in Glasgow. He lives with his partner and studies part time.

He likes tech, as well as food and cooking. He dislikes exercising.

Cameron is ambivalent about data sharing as he doesn't really think about it. Although he likes gadgets, he doesn't use any data collecting wearables as he's really not into fitness.

Because Cameron lives in a SIMD area where life expectancy for men is quite low, he is invited to a routine GP appointment designed to spot any worrying health signs.

During the appointment, Cameron's GP advises him to change his sedentary lifestyle and food choices as he is showing warning signs of pre-diabetes.

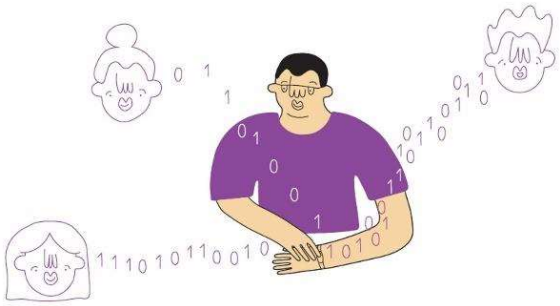


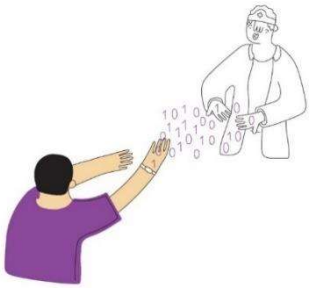
As a result, Cameron is referred to a wellbeing programme delivered through a partnership between the NHS and a local third sector organisation. He also gets a free wearable device to track his steps and help with motivation issues.

Through the wellbeing programme, Cameron can access both clinical and behavioural change support. He attends regular appointments but can also track and share his activity and nutrition data in between appointments using his device and app.

He can choose which data he wants to share and with whom.

For example, he develops a very good relationship with the weight management specialist so **he feels comfortable sharing more detailed data on meals and his personal notes (captured in the diary function of the app) with her**, while he only agrees to share high level steps and calories data with his GP.





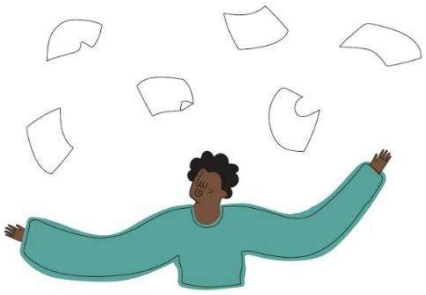
After completion of the programme, Cameron also accepts to share his anonymised data for research into behavioural change and the impact of targeted health interventions.

Alimatou

Alimatou is a 42-year-old woman living in Springburn, Glasgow. She has arrived in Scotland four months ago and is currently an asylum seeker waiting for the outcome of her application.

She lives with her husband and four children, aged 15, 12, 10 and 2. She likes walking, going to church and growing her own food. She dislikes the weather in Glasgow.

You're likely to hear her say "my present ins not my future" as she's an ambitious and forward-looking person.



With regards to data sharing, Alimatou is afraid of any stigma that might result from data being shared without consent, the wrong data being shared or even data that could be interpreted in the wrong way.

However, when Alimatou first arrived in Glasgow, she was helped by an organisation supporting asylum seekers to create her personal data wallet.

This helped her collate information on her residence, volunteering status and attestations from the local council and her children's school to confirm her identity.

Alimatou was involved in every step of this, and she was offered training and education on data protection and her rights.

Alimatou chose to gather this information on paper, but once she became more confident, she was happy to switch to the online model, using the charity's offices and support to get online.

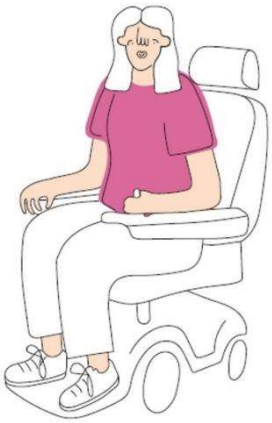
Alimatou can also use this system to seamlessly share data, to confirm her identity and status.

Alimatou can also **choose to give certain permission to those she trusts**, so for example should a request come in from the Home Office when Alimatou cannot get online, her trusted charity support worker can respond on her behalf.

However, other elements of her wallet such as details on her children or her health information are more private, in line with Alimatou's preferences.

The data wallet can also be used to refer Alimatou to specific services that she might need, such as food banks or other sources of local community support.

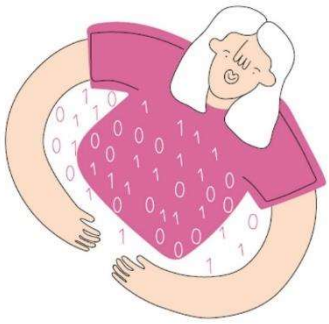
Sonia



Sonia is a 35-year-old woman who works part time in the third sector. She is also training to be a teacher and she lives near Aberdeen.

Sonia lives with fibromyalgia and is very involved in self managing her condition.

She likes reading, chocolate and long walks with her dog, although she has recently purchased a power chair to manage her energy on challenging days.



Sonia understands the sensitivities around data sharing, particularly concerning vulnerable groups, due to her work in the third sector. She is therefore very concerned about data sharing and tries to keep it to the absolute minimum.

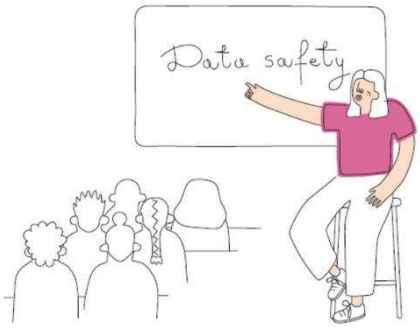
Since she has a long term condition that flares up unexpectedly, she often ends up disclosing information to her employer. It's important to her that she can do this confidentially and securely.

Since Sonia works with vulnerable groups, she has agreed to undertake a full PVG check.

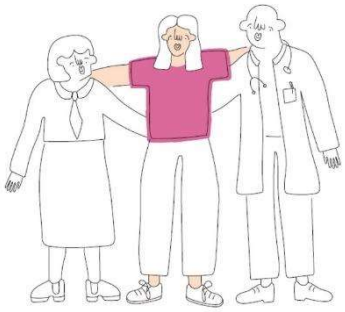
However, she was able to do this through the personal data wallet using a **'disclosure without exposure' model**.

This means that she was able to confirm her eligibility for working with vulnerable groups without sharing all her personal sensitive information with a central body.

Instead, all her individual data sets were confirmed separately by those holding the information already to confirm her identity and suitability for this work.



This way, Sonia can protect her privacy whilst also not missing out on any opportunities that those keener on data sharing might access, such as following her dream of becoming a teacher.



Sonia also has a great healthcare team who know her and support her.

She opted out of sharing health and lifestyle data with them digitally but knows she can still access the same quality service when she needs it by simply picking up the phone.

4.2 Core principles

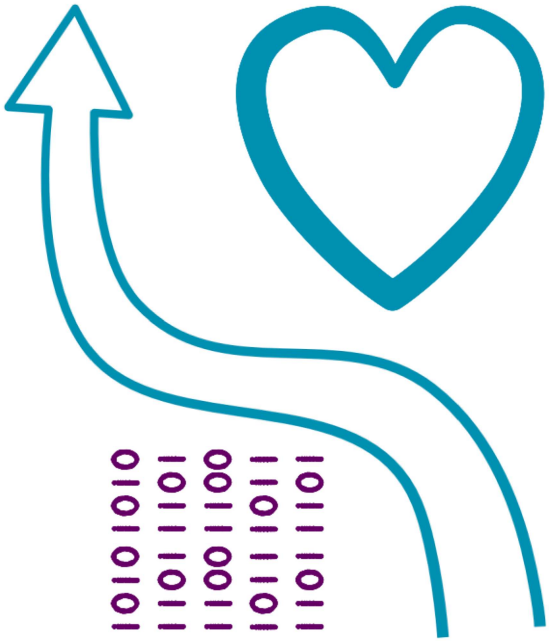
As mentioned previously, from the engagement we carried out, we developed nine core principles which we feel are essential to building a future where the potential of data is harnessed in positive ways. These are detailed below, alongside references to how they have been embedded in the previous scenarios.

	Data should only be collected, processed and shared in line with the GDPR key principles of: Lawfulness, fairness and transparency; Purpose limitation; Data minimization; Accuracy; Storage limitation; Integrity and confidentiality; Accountability. GDPR adherence should constitute the bare minimum standard for the development of any future data systems. *This principle was implied in all scenarios described in 4.1.*
	Individuals should be empowered to make **informed** decisions about any uses of their personal data. Consent should be given **freely**, without any pressure, repercussions, or fear of discrimination. When developing consent processes, we must ensure that we are taking into consideration cultural and contextual factors and that people are at the centre. *This principle was implied in all scenarios, but more obvious in Alimatou's case, who was supported to understand the implications of the process she was undertaking.*
	In addition to the GDPR principle of purpose limitation, the purpose for any type of data processing must be **clear, transparent and for the benefit of either the data subject or wider society**. Personal data should not be collected, used and shared for commercial gains unless informed consent for this specific purpose has been granted. *This principle was implied in all scenarios, but more obvious in Cameron's case, when he agrees to use the wearable device for his own benefit and then share anonymised data for research.*

	Data processing should not replace opportunities for people to **share their own stories and experiences with those involved in their care.** Data might be used to complement and provide evidence in support of one's narrative but should not replace it fully. *This principle was more obvious in the following scenarios:* • *when Cameron uses data from his wearable device to support him in his consultation with his weight management specialist.* • *when Sonia chooses not to share data with her health team but instead communicate with them directly.*
	Care must be taken to ensure that **if individuals do not want to opt-in to data-enabled processes there are no negative consequences** to them because of this. Quality of care and service provision should be agnostic of people's data related attitudes, skills, or confidence. *This principle was implied in all scenarios, but more obvious in Sonia's case, when she chooses not to share data with her health team, but still receives the same quality service.*
	Data subjects should have the right to own and control their own data unless they take an informed decision to pass this responsibility to someone else. Owning their information, individuals can amend it, grant and remove access permissions as necessary. This can help build one-source of truth whilst also empowering individuals to control their own information. *This principle was implied in all scenarios, but more obvious in Meghan's and Joanne's cases, where they control the information in their respective data wallets and grant access to other parties as necessary.*

	Consideration needs to be given to whether data is accurate. Do people have the devices, skills or connection required to gather it? If the data effects any benefits or sanctions, will the quality of self-reporting be influenced? We must also ensure that any data which will affect decisions is validated and interpreted without biases or prejudices. *This principle was implied in all scenarios, but more obvious in Alimatou's case where she builds her data wallet to prove her identity with information from trusted sources. She also accesses support, training and physical assets to enable her to do this.*
	Data education is needed for members of the public, professionals and support workers to ensure that • those whose data is collected, processed, and shared fully understand what they are consenting to and are empowered to make decisions with regards to their own information. • those using data understand its potential uses and can maximise on the opportunities provided, while ensuring the safety and privacy of those they are supporting. *This principle was implied in all scenarios, but more obvious in Alimatou's case where she accesses support and training in relation to data protection and her rights.*
	Data must not be used to stigmatise or discriminate against individuals unfairly. We must ensure that decision making processes, whether automated or made by individuals, do not have inherent biases that could be detrimental to individuals' wellbeing. Steps must also be taken to ensure data is not misinterpreted or used for malicious purposes. *This principle was implied in all scenarios.*

5. Digital 'Art of the Possible'



This chapter has been provided by colleagues at the DHI. It describes how available and maturing digital products and platforms can help meet the needs highlighted in the possible futures inspired by the engagement undertaken with citizens by the ALLIANCE.

The project findings describe several possible future state scenarios. Some of the most common high-level requirements emerging from these scenarios include:

As a person empowered to use my personal data, I want to:

a) Manage my own data, bringing together different attributes (e.g., national insurance number, age) for easier reuse (Meghan)

b) Grant access to these attributes to others in a way that they can trust, so they can give me access to the support I need (Joanne)

c) Grant access to these attributes in a way that people I trust (e.g., a guardian, link-worker, or navigator) can reuse on my behalf (Alimatou)

d) Access tailored recommendations based on the attributes I share (Alimatou)

e) Disclose proof of eligibility without unnecessarily exposing my personal data (Sonia)

f) Add data to my patient-held medical record from personal devices (Cameron)

g) Self-monitor and share this with my support team to help me stay healthy and independent (Joanne)

This chapter will use examples of technologies that could support someone with these needs. Most of these requirements relate to how data is stored and shared (the 'data layer'). The focus will be on platforms that work underneath/across many applications and devices. Section **5.1 Emerging capabilities** will describe these platforms with reference to individual products (the 'experience layer') when illustration is required. Section **5.2 How these capabilities help meet needs** will relate the capabilities to the different user needs outlined above.

5.1 Emerging capabilities

This section will describe the new types of digital infrastructure that can help change the way we design new services and experiences. These technologies are foundational and described regarding the capability they introduce, rather than an overt focus on individual apps or devices that already exist. Understanding how these 'data layer' technologies work can help us understand what is possible and change the rules regarding how we might design a new service or experience.

The capabilities come under two main categories: digital wallets and patient-held health records.

5.1.1 Digital Wallets

There are generally three types of technology available today that could support some or all of the needs related to managing identity and security data identified through the *My World, My Health* engagements with citizens.

i. *Consumer Digital Wallet / Password Manager*

Digital Wallets or Password Managers are smartphone-based applications that allow users to gather personal data for easy reuse when using online services. Several wallets or password managers are available on the open market for free and, in some cases, with paid-for upgrades. Apple and Google have wallets built into their phones' operating systems. Online payment systems like PayPal also offer digital wallets. Password managers like Lastpass, Dashlane and Keychain all offer wallet-like functionality.

These are the most accessible options to start using as an individual. They do not require other services and systems to change to bring value. However, as a result, they are also the most superficial in their impact. Because these tools are offered by commercial companies, your privacy and security protections may vary.

For example, in the password manager model, you can store passwords, contact details, payment details and other commonly used data either on your phone or online with access via an application on your phone. In this model, data may be stored anywhere, subject to the terms and conditions of the individual provider. Then, when you interact online via an app or web browser, the wallet prompts you to login automatically to sites and gives you the option to pre-populate forms or payment information.

While this service is very convenient and accessible, this is traded for reductions in privacy and security. Any model that gathers data in one place is almost always more vulnerable to misuse, creating trust issues. Commercial companies may not always be upfront about how they use or reuse personal data, and the legal rules vary depending on which country the company is based in.

Another downside is that it does not give the user any extra authority or ability, i.e., you are not able to 'prove' any of the information you provide, and you still have to share lots of personal data when filling out forms to access to the things you need.

ii. *Self-Sovereign Identity Wallet (SSI)*

SSI is a method of establishing trust in an interaction. You can download a digital wallet to store and give attributes or 'proofs' (i.e., information about your status, e.g., that you hold a clean and current driving licence) to an organisation (e.g., a car rental company) who may use them to make decisions about whether you are entitled to access a particular service (e.g., to hire a vehicle). The organisation can verify that the attributes were given by an issuer that they trust (e.g., the DVLA). In this way, the care hire company's trust in the DVLA transfers to you as the attribute holder.

For an identity system to be 'self-sovereign', you control the verifiable attributes or proofs you hold. Your consent is required to use those attributes, reducing the unintended sharing of your personal data. In this model, the personal data is held in either a Personal Data Store (PDS) or locally on your phone in a digital 'SSI' wallet, such as the one provided by Evernym.[7]

One of the benefits of SSI models are that data do not need to be stored centrally and controlled by one organisation to monitor the exchange of data and maintain trust. The data is distributed across different organisations and attribute providers, reducing the risk of misuse. The person has complete control over the use and reuse of their personal data because they hold their own 'keys' on their phone (stored on the phone itself and not online). Only the person can access these keys, and they make any decisions about whether to share personal data.

The main weaknesses of SSI models are:

- The dependence on the physical phone, which could be lost or stolen. However, there are mitigations available (e.g., using biometric technology or other security measures to verify you are the data owner and enable you to recover access).
- This highly distributed model can make it hard to use the data without accessing your phone.
- It tends to focus on holding and reusing proofs but does not generally handle your broader data, e.g., blood pressure readings or diary entries.

iii. *Personal Data Store (PDS)*

A Personal Data Store supports citizen-controlled, online storage and exchange of personal data and proofs in a safe, secure, and straightforward manner. A PDS allows users to have complete control over their data and reuse it as they move between services. Other

[7] www.evernym.com/products

platforms or applications can seamlessly integrate with the PDS to access your information with your consent. The PDS acts as a 'single source of personal truth' to empower you and reduce the friction, effort, risk and cost for both you and the organisations you interact with. The PDS does not hold all the data - but instead pulls this together from different sources so that it feels to users like it is a single record.

A PDS can handle standard data or the 'verified attributes' (described under *ii. Self-Sovereign Identity Wallet)*. You can hold a version on your phone if needed, and it can hold the keys described in the SSI model. A PDS is more vulnerable to the types of attacks any service which uses the internet to store data might suffer. However, a PDS can contain a wide range of different types of information and proofs from across all aspects of your life. Having access to this online and in one place can be very useful.

Generally speaking, there is a trade-off between privacy and convenience in most digital interactions. The consumer wallet or password manager is highly convenient and available but with higher privacy and security loss. The SSI wallets are at the other end of the spectrum, being harder to use and not as widely accepted yet, but highly controllable and secure. A PDS sits somewhere in the middle of this spectrum.

Specialist providers of PDS, such as Mydex CIC[8] or Solid,[9] prioritise privacy, security and user control. This focus on giving the PDS owner full control of their data, alongside transparent information and policies can help to reassure and build trust. Mydex CIC takes this a step further than most by using an 'asset and mission locked' Community Interest Company (CIC) model – which prohibits them from commercialising or reusing personal data in any way, investing profits back into the CIC to further their mission to empower people to control their own data.

5.1.2 Patient-held health record

There are generally three types of technology available today that could support some or all of the needs relating to managing health-related data identified through the My World My Health engagements with citizens.

iv. *Consumer Health Record*

Most smartphone operating systems have built-in capabilities to allow connected applications and devices to gather data within a single place on the phone. For example, Apple HealthKit can allow blood glucose, blood pressure, step count, sleep and other quantitative data from apps and devices to be brought together and visually presented. These visuals can help you to identify trends and support self management.

[8] mydex.org
[9] solidproject.org

However, these smartphone records do not typically integrate with information from NHS systems. The data can't be routinely shared with health and care professionals (though there are some initial examples of this working in the US).

v. *Personal Health Record*

Personal Health Records[10] (PHRs) allow patients to view records held by health and care services and write in their own information, creating a more comprehensive shared record. Importantly, they usually work across conditions, groups, and services, enabling more holistic care and more active co-management by the citizen. A PHR can also help people share essential information with a broader support network, like family and carers, if they choose to. In many cases, devices might integrate with the PHR to allow data sharing with professionals. Examples of PHRs include eRedbook,[11] COHESION Life Wallet,[12] and Patients Know Best.[13]

vi. *Health Data Exchange*

A Health Data Exchange (HDE) supports people to generate, reuse, and control the flow of their personal health data. A HDE enables data to be shared across new patient-professional co-management applications, devices, PDS and consumer services (e.g., Fitbit). It can reduce the challenge of managing all these different services, letting you control them all in one place.

A PHR might integrate with a HDE to support broader data sharing and cooperation with different systems (e.g., NHS records). The HDE might also connect to commercial applications like Apple Healthkit and Google fit, and allow the smartphone record to integrate. Examples of a Health Data Exchange include Lenus,[14] Validic[15] and HDX.[16]

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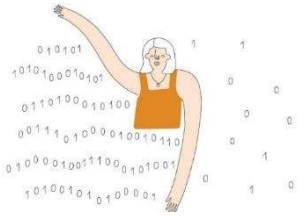
[10] digital.nhs.uk/services/personal-health-records-adoption-service/personal-health-records-adoption-toolkit
[11] www.eredbook.org.uk
[12] www.cohesionmedical.com
[13] patientsknowbest.com
[14] lenushealth.com
[15] validic.com
[16] www.hdx.live

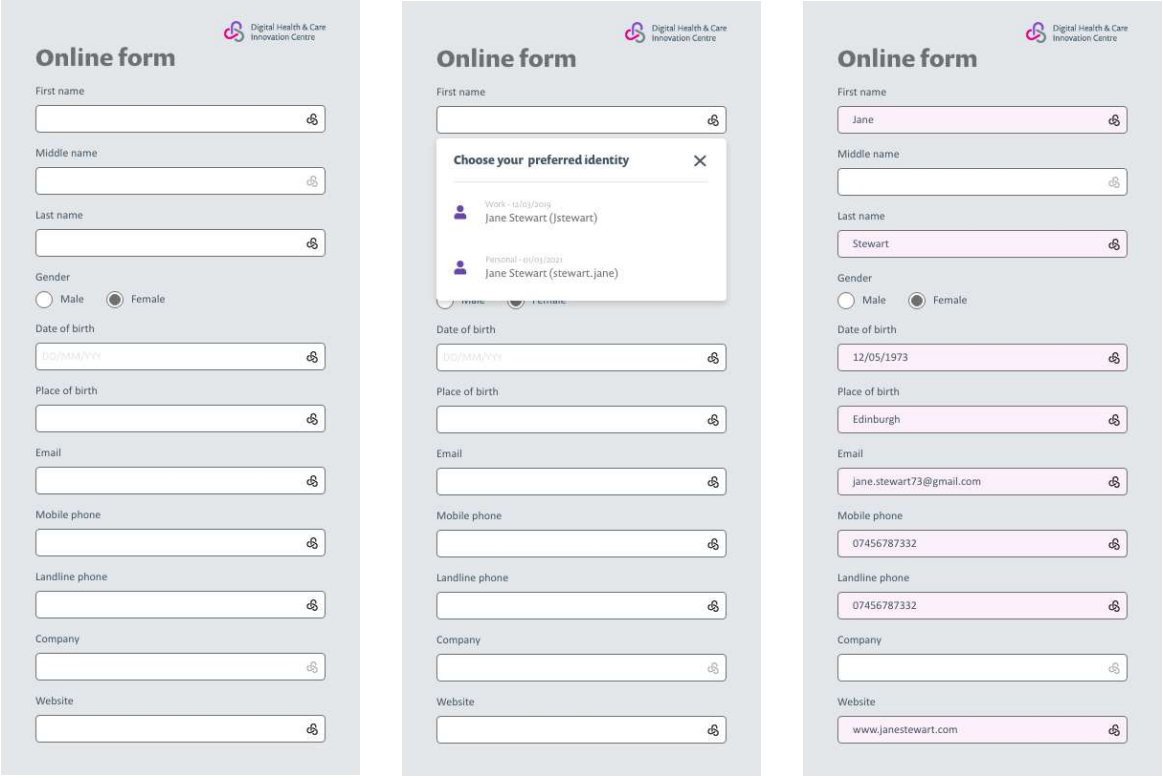
5.2 How these capabilities help meet needs

This section returns to the high-level requirements drawn from the future scenarios at the start of this chapter, and shows how the capabilities listed in Section 5.1 could help to meet these needs.

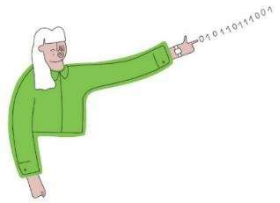


a) ***As a person empowered to use my personal data, I want to…*** **manage my own data, bringing together different attributes (e.g., national insurance number, age) for easier reuse.**

Meghan's requirement could be satisfied by any of the digital wallet options listed in section 5.1. She can choose which type of digital wallet to use based on whether privacy or convenience is more important for her. The consumer wallets could make it easier for Meghan to store and reuse numbers, contact details and other answers to typical online form questions. Below are screens showing how Meghan would be able to use the wallet. She sees an icon when her wallet or PDS has answers to the field requested. She clicks on the field and is asked which 'profile' she wants to use – in this case, 'personal' or 'work'. The form then autocompletes based on the information held in her wallet.

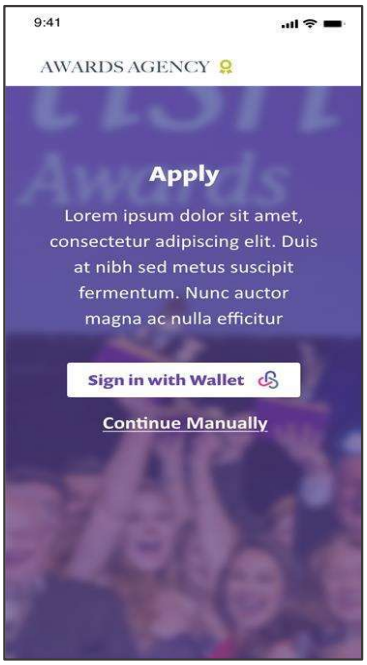


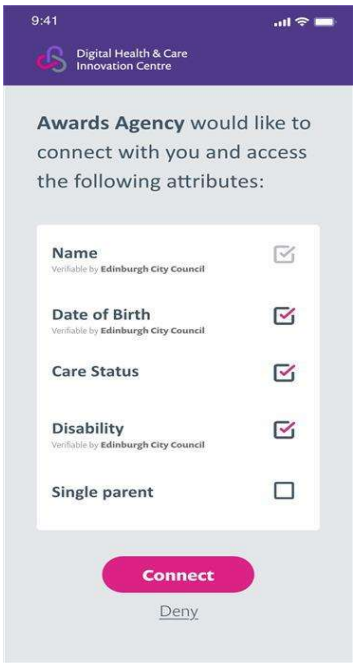
This type of wallet would provide a convenient initial solution. Still, Meghan's acceptance of this model would depend on her tolerance for and trust in the organisation providing the wallet, and the privacy and security choices they allow.

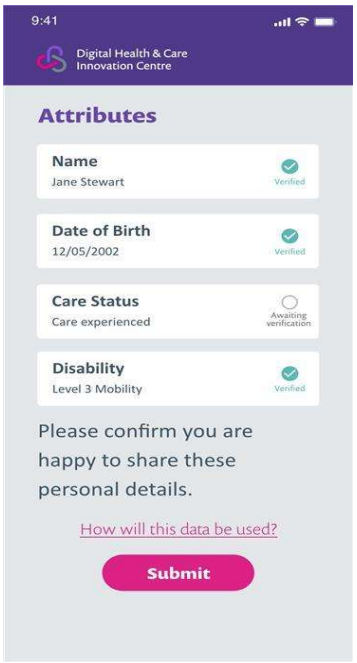


b) ***As a person empowered to use my personal data, I want to…*** **grant access to these attributes to others in a way that they can trust, so they can give me access to the support I need.**

Joanne's requirement could be satisfied by the SSI wallet or PDS outlined in the previous section under the digital wallet description. Either would allow a professional or organisation to 'verify' the validity of the attribute Joanne holds, creating a verified attribute (e.g., her GP could verify that she is living with sight loss). Access or eligibility decisions depend on whether the person or organisation trusts the professional or organisation that gave Joanne the attribute. For a non-digital example, off-licences and the police trust the driving licence a person holds because it is effectively 'verified' by a government body - the DVLA.







The screen images above show how Joanne might sign in with her wallet or PDS account instead of filling in a form to register or apply manually. She is alerted to the type of data the organisation may want to access from her wallet. She can review this and decide to give consent to share attributes from her wallet. If the organisation who gave Joanne the attribute has verified it, Joanne could expect it to be quicker and more seamless for the application to be processed because there would be no need for further checks and other inter-organisational communication.

The Scottish Government has recently successfully prototyped this approach and plans to use it going forward as part of an attribute store strategy[17] for identity assets in Scotland.

[17] www.gov.scot/policies/digital/digital-identity-scotland

c) ***As a person empowered to use my personal data, I want to…*** **grant access to these attributes in a way that someone I trust (e.g, a guardian, link-worker or navigator) can reuse on my behalf.**

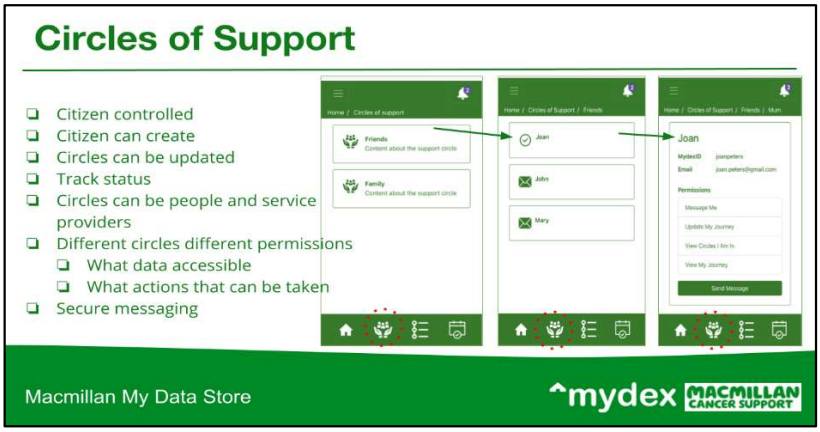
There are several digital wallet options available that might support Alimatou's requirement:

- **Consumer wallet (described in 5.1.i) -** The password managers and consumer wallets would allow Alimatou to share her passwords with trusted people. There is also an option to set up the password manager so that it would automatically grant access to a trusted person in case of emergency.

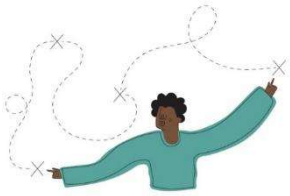
- **SSI wallet (described in 5.1.ii) -** SSI is typically a technology focused on the private, individual use of attributes through local storage on the phone rather than online. This technical method makes It more challenging to delegate access to another person or organisation without physical interaction. It is unclear if there is a technical solution for this, but there has been recent discussion and development around a 'guardian'[18] concept. The development of this concept could allow people to share verified attributes between themselves so that they could grant someone a 'guardian' status and allow them the reuse of their attributes.

- **Personal Data Store (described in 5.1.iii) –** Alimatou could create a 'circle of care' detailing all the people involved in keeping her well, storing their contact details, roles and data access permissions in her PDS. One of these roles could be nominated as a 'guardian'. This person could have delegated authority to use her attributes to help her access services and navigate the available support pathways.

An example of this working in practice is the Macmillan My Data Store[19] project. Macmillan and Mydex have developed a 'circles of support' model that allows someone to delegate this authority e.g., for lasting power of attorney.



[18] sovrin.org/on-guardianship-in-self-sovereign-identity
[19] medium.com/macmillan-my-data-store-pilot/introducing-macmillan-my-data-store-365359c692c8



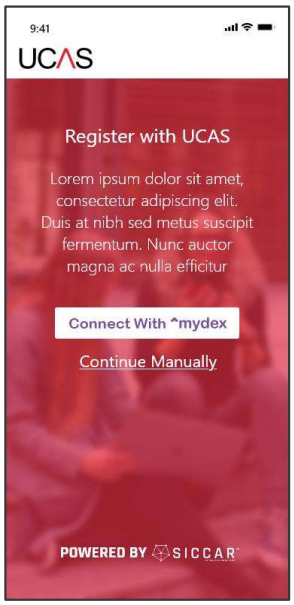
d) ***As a person empowered to use my personal data, I want to…*** **access tailored recommendations based on the attributes I share.**

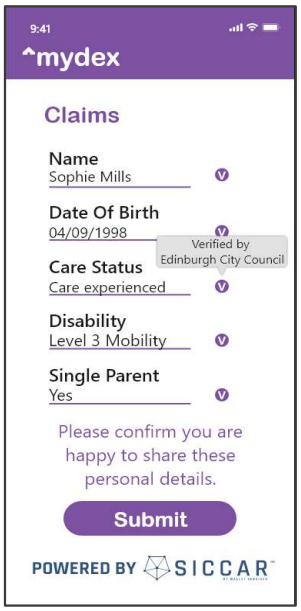
An SSI wallet or a PDS could satisfy this requirement for Alimatou, but further work would be required to automatically match her personal data and attributes to the different criteria used by services to determine what services or benefits she is eligible for.

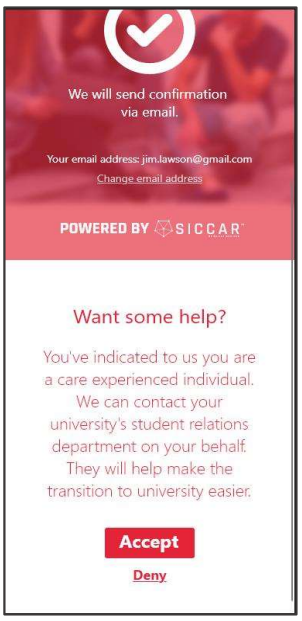
DHI partnered with the Independent Care Review and Siccar to explore the needs of young people who have experience of care, and understand how verified attributes might support the way they want to access services. We learned that some young people may be reluctant to share information about their experience of care in order to access help they are eligible for (e.g., accessing bursaries when applying for university).

The prototypes below were developed to demonstrate how a young person with an experience of care could use their verified attribute to demonstrate they are entitled to support without explaining why they are eligible. The system automatically recognises that they are entitled and offers this as an option. This puts the power in the young person's hands to activate the support if they want it, without sharing any personal details about their experiences.

This is linked to the 'disclosure without exposure' concept described in Sonia's future scenario – no one sees the data shared, and no one is aware that the young person is offered support or why.







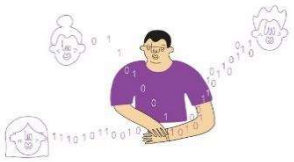
Lastly, if Alimatou trusts the organisation in question, she could allow them to continuously read the attributes in her PDS and then proactively update them when the attributes change over time, e.g., if her asylum claim is granted and she is able to access different forms of support.

e) ***As a person empowered to use my personal data, I want to…*** **disclose proof of eligibility without unnecessarily exposing my personal data.**

The concept of 'disclosure without exposure' is also achievable through the SSI wallet and PDS.

The organisation who needs to process Sonia's disclosure form can reach an agreement with the organisation who provide verified attributes to ensure that they can trust the processes used to verify and award the attribute. This means that they do not need to see the reason why Sonia is eligible, just that she has been awarded the attribute by a trusted organisation.

The simplest example would be if we moved away from a system where a person has to show a birth date to prove their age, e.g., when buying alcohol at a supermarket. Instead of showing e.g., a driving licence with their date of birth at the supermarket checkout, the person could present the wallet app on their phone to the supermarket scanner and give consent to share the 'proof of age' attribute. The system then checks it against the minimum age for the transaction. The member of staff sees a green tick or a red cross – that is all they need to know to do their jobs.



f) ***As a person empowered to use my personal data, I want to…*** **add data to my patient-held medical record from personal devices.**

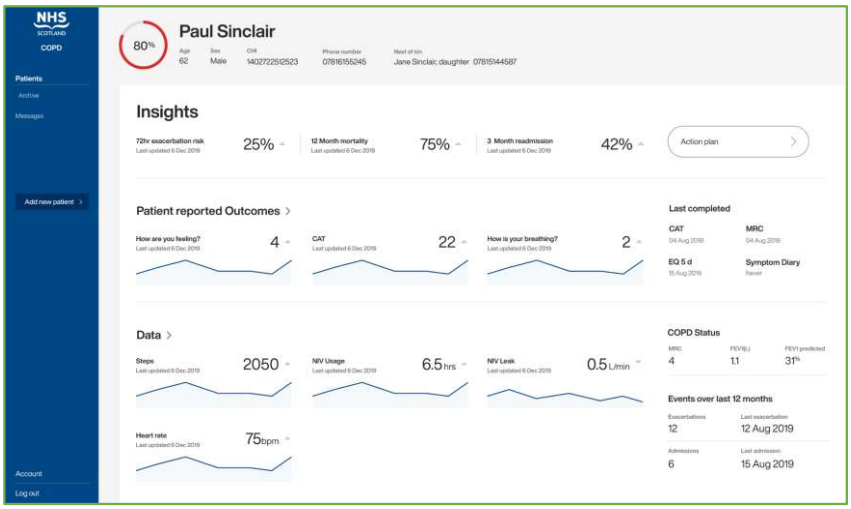
Cameron's story is about wellbeing, lifestyle and weight management. DHI are currently working in partnership with NHS Grampian and people living with diabetes to co-design new ways of supporting self management. The new concept being developed uses a PHR (described in 5.1.2). With this concept:

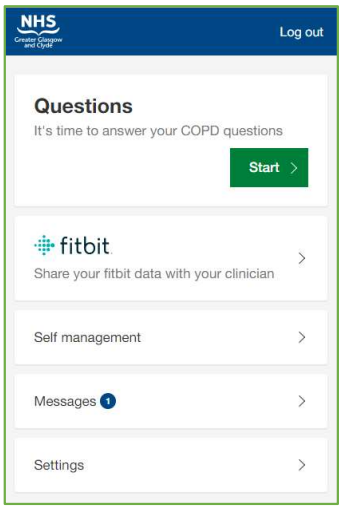
- Cameron would be sent a link to register for a Personal Health Record.

- He can add people to his 'circle of care' and set permissions around access to his data.
- The PHR connects to NHS systems via a Health Data Exchange. Cameron can consent to his health psychologist accessing his Fitbit data and his diary, where he reports progress, events and other things affecting his journey.
- Cameron has fewer appointments, as he communicates with his support team using online messaging. They send him tailored advice based on the data he shares and offer encouragement or follow up with a phone or face-to-face conversation if he is struggling.
- A summary of the interactions can be shared with his GP as needed because the Health Data Exchange connects to GP systems.
- Cameron could reuse the data he collects in his PHR if he ever needs support with other conditions or services (e.g., diabetes or preoperative assessment).

g) ***As a person empowered to use my personal data, I want to…*** **self-monitor and share this with my support team to help me stay healthy and independent.**

DHI is collaborating with NHS Greater Glasgow & Clyde, and Storm ID on the Dynamic-Scot[20] project. This is deploying digital remote monitoring and co-management of Chronic Obstructive Pulmonary Disease (COPD). This service is currently being used in Glasgow.





[20] www.dhi-scotland.com/projects/dynamic-scot

Although Joanne's future scenario relates to sight loss rather than COPD, we can illustrate what is currently possible for self-monitoring using the COPD co-managed care tool as an example:

- Joanne registers for the new service, downloading an app onto her phone.
- The app connects to a Health Data Exchange, which allows her to consent to link her app to her COPD specialist and GP.
- The app also makes it easy to connect her Fitbit and home ventilator to the Health Data Exchange. Joanne can share her physical activity, sleep and respiratory data with the clinical team.
- Joanne also fills in a Patient-Reported Outcome tool in her app every so often, which helps her report her experiences using a format the health professionals can use to make their assessments – e.g., shortness of breath, fatigue, etc.
- All this data feeds into a team of health professionals, who are alerted if Joanne starts to deteriorate. The team can proactively visit her to prevent her condition worsening – with the aim of avoiding the need for Joanne to be admitted to hospital. With her permission, Joanne's GP is updated whenever anything significant happens.
- This service reassures Joanne that she is 'always assessed' and spends less time in and out of the hospital and more time living her life, feeling secure that her GP and specialists are well informed and can support her very responsively.

This model could be developed further, linking to two earlier elements in this paper:

- Joanne could connect her Personal Data Store to the Health Data Exchange. Her doctor could 'verify' her COPD status, which could then be used as a verified attribute to support her application for a Personal Independence Payment.
- Joanne could connect a PHR application to the Health Data Exchange, replacing the COPD application and covering more than one condition. This application would allow her to name and share data with her circle of care, including friends, family, and neighbours, to help her remain independent and reassure or equip those around her as needed.

6. Recommendations for future work

Scotland's people want to take part as equal partners in Data Dialogues

It is clear from the engagement that we carried out that data sharing can be a very emotional issue for many people. Attitudes to data sharing vary greatly, having been influenced positively or negatively by recent experiences, personal circumstances and access to information. However, the quality of the engagement and the range of responses described in previous chapters are testament to the fact that there is an appetite for holding these conversations.

Create opportunities for more dialogue in the future

As noted in the 'Project limitations' sub-chapter, online engagement over six months can only reach a limited audience. As society begins to open up again in the wake of the COVID-19 pandemic, Scottish citizens and residents should be given new opportunities to have their voices heard with regards to the future of data in Scotland.

Context is as important as the conversation itself

In our experience, survey responses tended to be more one-sided than the conversations we held during interviews and workshops. We therefore believe that in-person conversations are a better medium for discussing complex themes of this sort, as they allow two-way dialogue and opportunities to probe where people's attitudes stem from for deeper insights.

Clarity, trust and transparency

If we are to consider a data-enabled future, clarity, trust and transparency around any type of data sharing will be important, as well as a focus on real empowerment of individuals. How can we ensure that consent processes are truly informed and that individuals agree because they want to, not because they have to? This is an ethical question that needs to be at the very foundations of data systems and strategies.

Person-centred technologies

We can see from the examples presented in the 'Art of the Possible' chapter that technologies that could meet some of people's needs already exist. However, they offer varying levels of control and some options trade security for convenience. While there are examples of solutions that have been designed in a person-centric way, this needs to become the norm in both public and commercial

sectors. We must acknowledge that current data systems are built on existing culture and power imbalances that need to be addressed.

Ensure that no one will be left behind in a digital Scotland

We need to ensure that we do not build a two-tier system where if people choose to opt out of a service or agreement, they will be at a disadvantage compared to those who opted in. This is in line with current ambitions and must hold, regardless of whether they choose to embrace new technologies or not. We must also consider the rights of those who need to use technology or rely on services due to living with long term conditions, sensory loss, or disability.

Processes and systems to ensure that future services will be accessible and inclusive

If we are to consider moving towards a data-enabled future, support must be put in place to ensure that those who want to be part of this system can do so regardless of their cultural background, digital skills, or access to technology. We must consider creating new support roles and focus on cascading awareness and learning across communities. A data-enabled future should be accessible and inclusive of all people living and working in Scotland.

Take time to acknowledge and understand the current state of play and contributing factors

It is also worth noting that as a society we need to recognise where we currently are with regards to data sharing. This involves accepting that there are good and bad practices linked to data sharing and that there are both benefits and risks inherent in the use of data. Therefore, it is unsurprising that we come across both positive and negative attitudes towards the use of personal data by wider services, such as local government or the NHS. Taking our time to scan and make sense of the current landscape will provide a better position for having more open and transparent participatory conversations on the topic in the future.

Moving towards a data-enabled future that is built on empathy and person-centredness

The concerns around data sharing will not disappear unaddressed and the potential benefits that data can bring are not guaranteed. We need to continue work on the topic, involving all stakeholders and building participatory processes to ensure better understanding, awareness and engagement with the topic. The aim is to move towards a co-created, empathic, person centred data-future in Scotland.

Acknowledgements

The **My World, My Health** project was funded through the Nesta Data Dialogues programme. We would like to thank Alice Clay and Kyle Usher for their support throughout the process and their flexibility in light of the COVID-19 pandemic.

Special thanks also go to the team at the Digital Health & Care Innovation Centre (DHI). The participatory engagement methods were designed with invaluable input from Gemma Teal and Dr Kate Mark. Chal Chute provided extensive technical knowledge and advice, as well as co-authoring this report through the provision of the 'Art of the Possible' chapter.

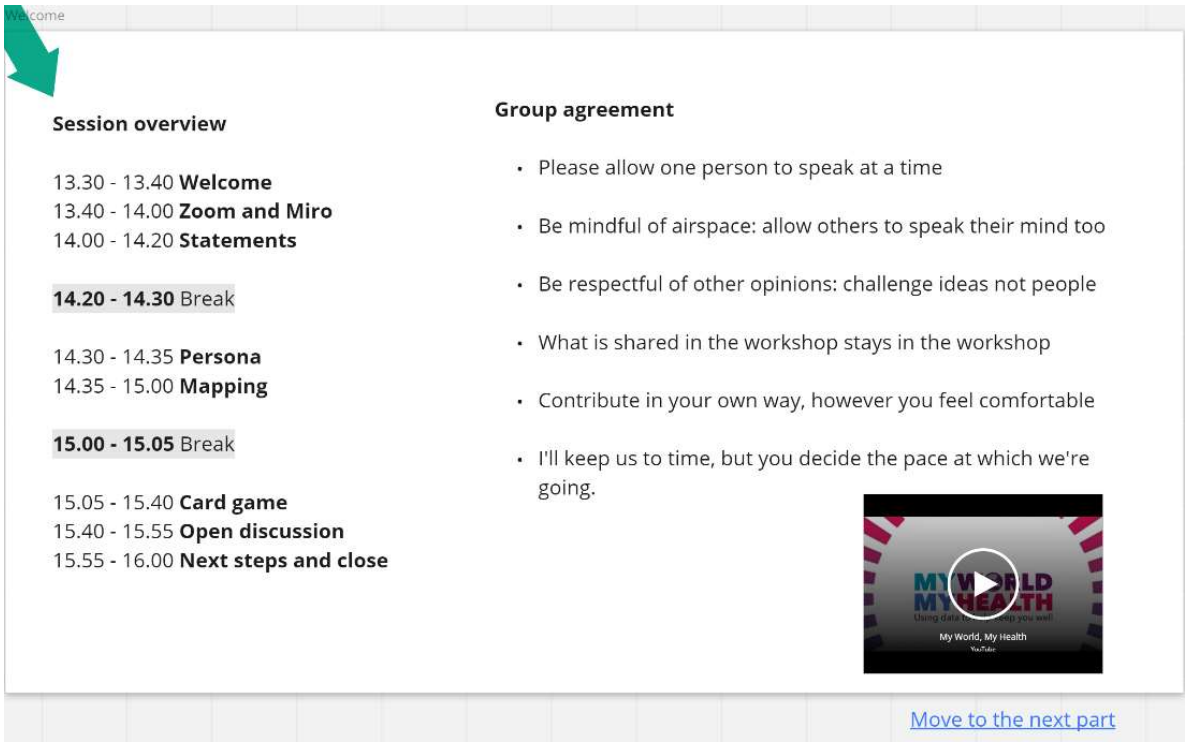
This project drew on the support and advice of several ALLIANCE colleagues, who have helped with the project planning, promotion, facilitation, delivery, administration, analysis and reporting. Each contribution has been invaluable and have contributed to the success of the project overall.

We would also like to thank the creatives that have contributed to the visuals of this report, Olga Mrozek and Steven McGreggor.

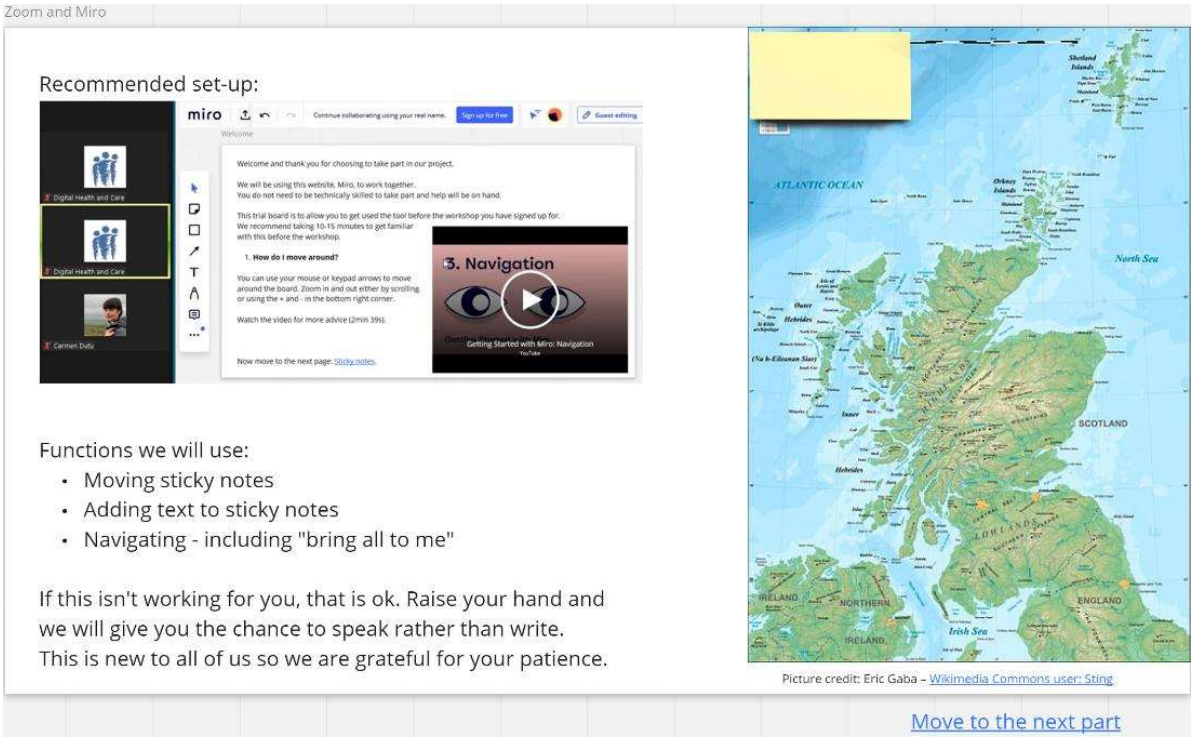
Last but not least, we would like to thank each and every one of the 125 participants that took part in a workshop, interview or completed the online survey. The insights and contributions we have received make up the foundations of this report and its recommendations.

Appendix 1: workshop structure

1. **Welcome:** scene setting, agenda and group agreement.

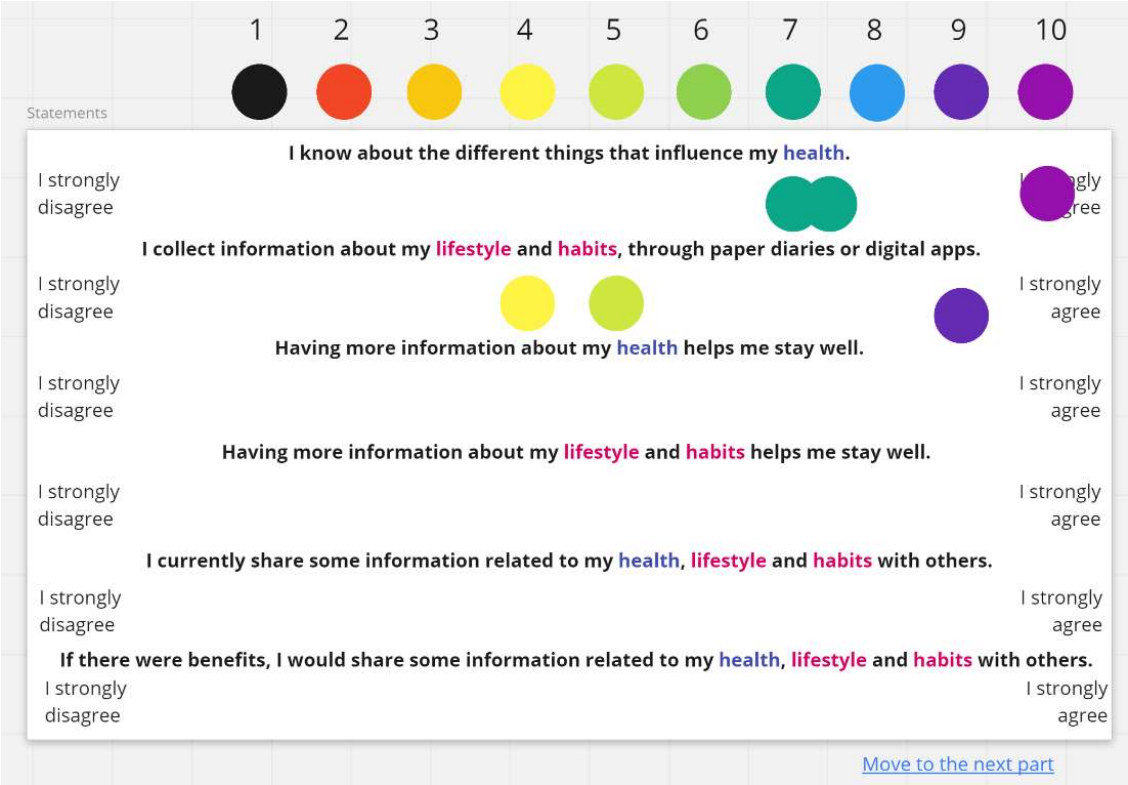


2. **Zoom and Miro:** protected time to demonstrate how the tools work and ensure participants were comfortable with the online medium.



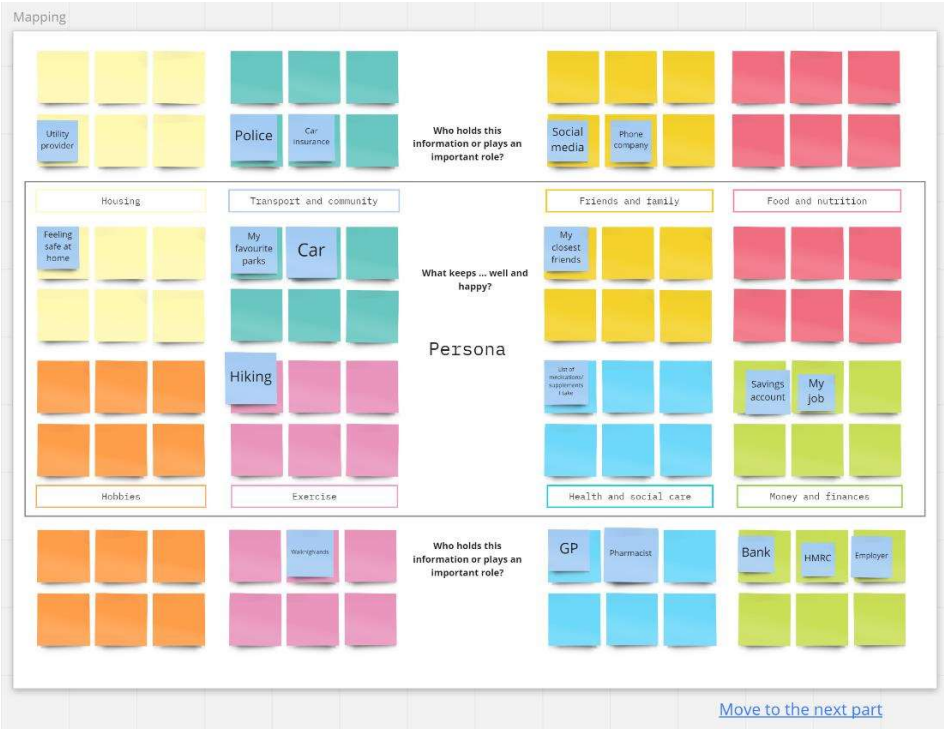
3. **Statements:** a series of six statement were read out to participants and they were asked to state whether they agreed or disagreed with them on a scale of 1-10.

Coloured dots were used to map the responses for a quick visual interpretation of that particular group's baseline attitudes and practices.

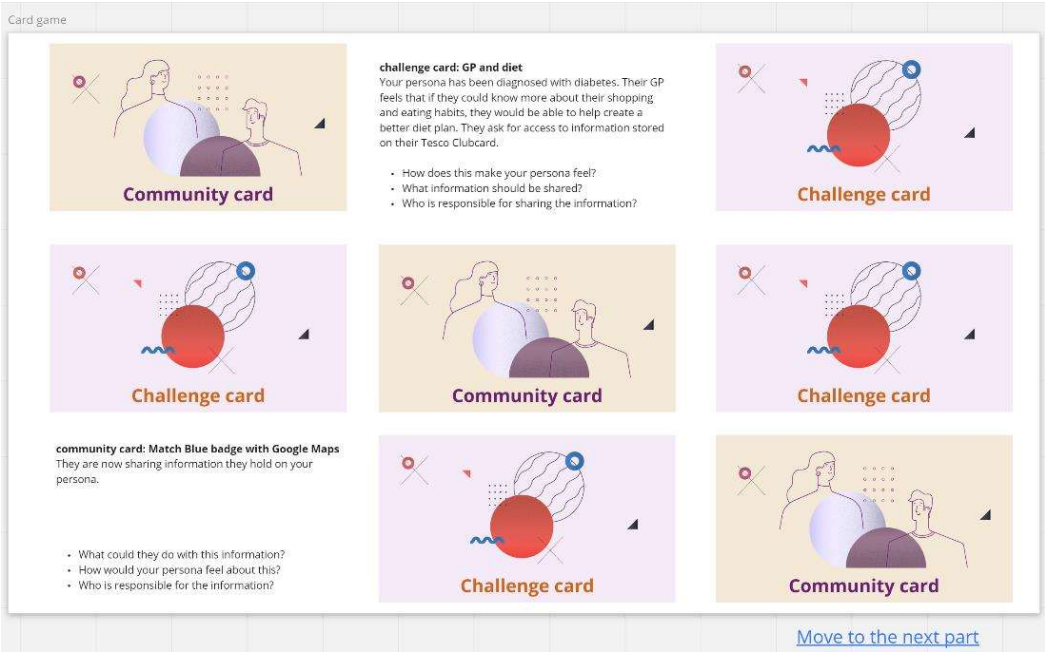


4. **Persona building:** in collaboration, the group participants were asked to help build a persona representative of their group by choosing a picture from a set of stock photos of individuals and offering information such as name, age, likes and dislikes, personal circumstances etc.

5. **Persona mapping:** based on the persona built in the previous exercise, participants were asked to think of what might keep that particular individual well, mapping determinants of health against eight separate categories: housing, transport and community, friends and family, food and nutrition, money and finances, health and social care, fitness and exercise, hobbies.



6. **Card game:** based on the mapping exercise, participants were asked to consider two types of data sharing fictional scenarios. Community cards presented scenarios where organisations or bodies identified in the previous exercise were force-paired to share data. Challenge cards presented scenarios where something happened in the persona's life that triggered an opportunity for data sharing. These scenarios were selected at random and were used to dive deeper into the participants' feelings towards data sharing.



An illustrative example of the template we used can be viewed at:
https://miro.com/app/board/o9J_IY5zSSI=/

Appendix 2: survey structure

1. **To learn more, listen to our project podcast, which will tell you all you need to know about the project and this survey: *My World, My Health podcast with Chal Chute and Dr Kate Mark*.**
   - Thank you, I have listened to the podcast.
   - I'll listen to it later.
   - No thanks, I'm not interested in the podcast.

2. **Did you take part in one of our My World, My Health workshops or interviews?**
   - Yes (skip to Q4)
   - No

3. How do you feel about the following statements?
(1-10 scale; 1 = I strongly disagree, 10 = I strongly agree)

a. I know about the different things that influence my health.

b. I collect information about my lifestyle and habits through paper diaries or in other written form.

c. I collect information about my lifestyle and habits through digital apps and websites.

d. Having more information about my health helps me stay well.

e. Having more information about my lifestyle and habits helps me stay well.

f. I currently share some information related to my health, lifestyle and habits with friends and family.

g. I currently share some information related to my health, lifestyle and habits with health or social care professionals.

h. I currently share some information related to my health, lifestyle and habits with other agencies.

i. I would be more likely to share information related to my health, lifestyle and habits if I could see direct benefits to myself.

j. I would be more likely to share information related to my health, lifestyle, and habits if I could see benefits to wider society (i.e., research purposes).

4. Scenarios: how comfortable are you with the data sharing aspects of the following scenarios?
(very comfortable / somewhat comfortable / neutral / somewhat uncomfortable / very uncomfortable; each scenario followed by a prompt to detail why they chose a particular level of comfort)

S1: Utility companies have data on fuel use within households. Imagine if they shared anonymised data (at a neighbourhood level) with the local council to identify areas of fuel poverty and target interventions to ensure no one goes cold this winter.

S2: Consider someone who is recovering from a gambling addiction. Imagine if access to their financial data was shared, with their agreement, with their social worker so that they could keep an eye on their spending and help them avoid relapsing.

S3: Consider someone who is about to go through a gender transition. Imagine if references from their friends and family were shared with their health team, so that they could understand their situation without the need for a mental health assessment?

S4: Consider someone who has had a considerable gap in their employment due to bereavement and ill mental health. Imagine if their community support worker could share data with prospective employers to explain the gap, thus helping the individual avoid disclosing information they feel anxious about.

S5: Consider an older person who is diagnosed with chronic obstructive pulmonary disease (COPD). Imagine if their care provider fitted their home with sensors to detect air quality, but also how they move around and what they get up to. This could help prevent falls and worsening of their condition.

S6: Consider someone who has just been made homeless. Imagine if their district nurse was able to share information on the individual's situation with other nursing teams in the area, to ensure that their care in the community can continue despite potential changes in address at short notice.

5. What were the top three factors which influenced your decision about how comfortable you felt with regards to the data gathering aspects?
(choose up to three)

- Individual's ability to consent
- Individual's control over their data
- Purpose of data sharing
- Potential benefits of data sharing
- Type of data (sensitive, identifiable or anonymised)
- Other

6. Which of the following types of data would you be happy to share to improve your health and care outcomes?
(multiple choice)

- Data on my health (symptoms, medications etc)
- Lifestyle data (habits, personal preferences, dietary etc)
- Data on my personal circumstances (who I live with, family situation, employment etc)
- I would not share any data
- Other

7. Which of the following types of data do you consider to be particularly sensitive?
(multiple choice)

- Detailed financial information (transactions, shopping habits etc)
- General financial information (credit score, earnings etc)
- Sexual health and sexual preference data
- Mental health data
- Medication information
- Equality information (ethnicity, disability etc)
- Data on long term conditions
- Detailed dietary information (what I eat on a daily basis)
- Location information
- Employment information
- Gender
- Other

8. What controls or assurances would you want in place if any of your data was shared?
(multiple choice)

- Ensure that opting out of sharing data does not lead to discrimination
- Ability to opt in / opt out of the data sharing
- Ensure that the data does not lead to discrimination
- Make it clear why the data is needed and how it will be used
- Ensure that the data is not used for commercial benefit
- Only collect data directly linked to the specified purpose
- Ensure that the data is not used for insurance purposes
- Ensure that data collection and use benefit me / my community
- Only collect data if there is no other way of achieving the same outcome
- Other

9. Who do you think should be in control of how your data is collected, shared and used?
(single choice)

- Me
- The organisation collecting it
- The organisation using it
- Other

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of nearly 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

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Health and Social Care Alliance Scotland alliance.scotland
www.alliance-scotland.org.uk

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The ALLIANCE is supported by a grant from the Scottish Government.
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About the DHI

The Digital Health & Care Innovation Centre is a national resource, funded by the Scottish Government and the Scottish Funding Council.

We are a collaboration between the Glasgow School of Art and the University of Strathclyde with a focus on innovation in digital health and care to help the people of Scotland live longer, healthier lives while providing sustainable and inclusive growth for our economy.

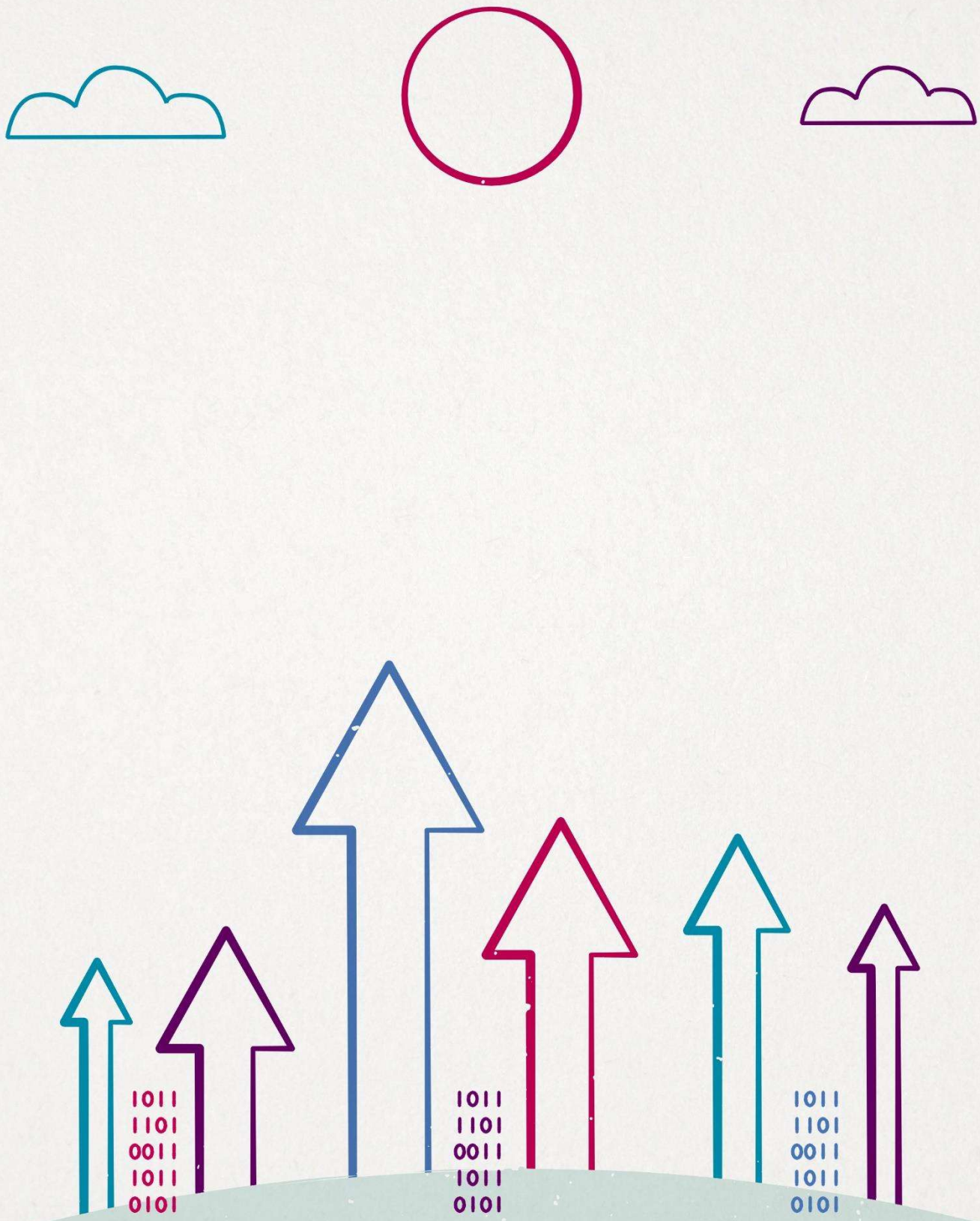
We collaborate, co-design and transform great ideas into real solutions that have benefits to the system and Scotland's citizens. We have a number of key assets open to our partners including our Demonstrator and Simulation Environment, which includes access to open architecture to quickly prove data integration, this can often lead to the opportunity to gain access to a variety of Real-World Environments and living lab testbeds.

We work extensively with the Scottish Government, NHS, Local Government, Academic Institutions, Commercial organisations (SMEs through to Enterprise-level organisations) and our Citizens, who are at the heart of what we do and why we do it.

We have a proven track record on the delivery of next-generation digital services focussed on empowering citizens to make better health and wellbeing choices, accessing services on their own terms and delivering more of their own care.

We provide a range of services to increase individual and organisation readiness to harness digital innovation for impactful results.

Learn more: www.dhi-scotland.com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