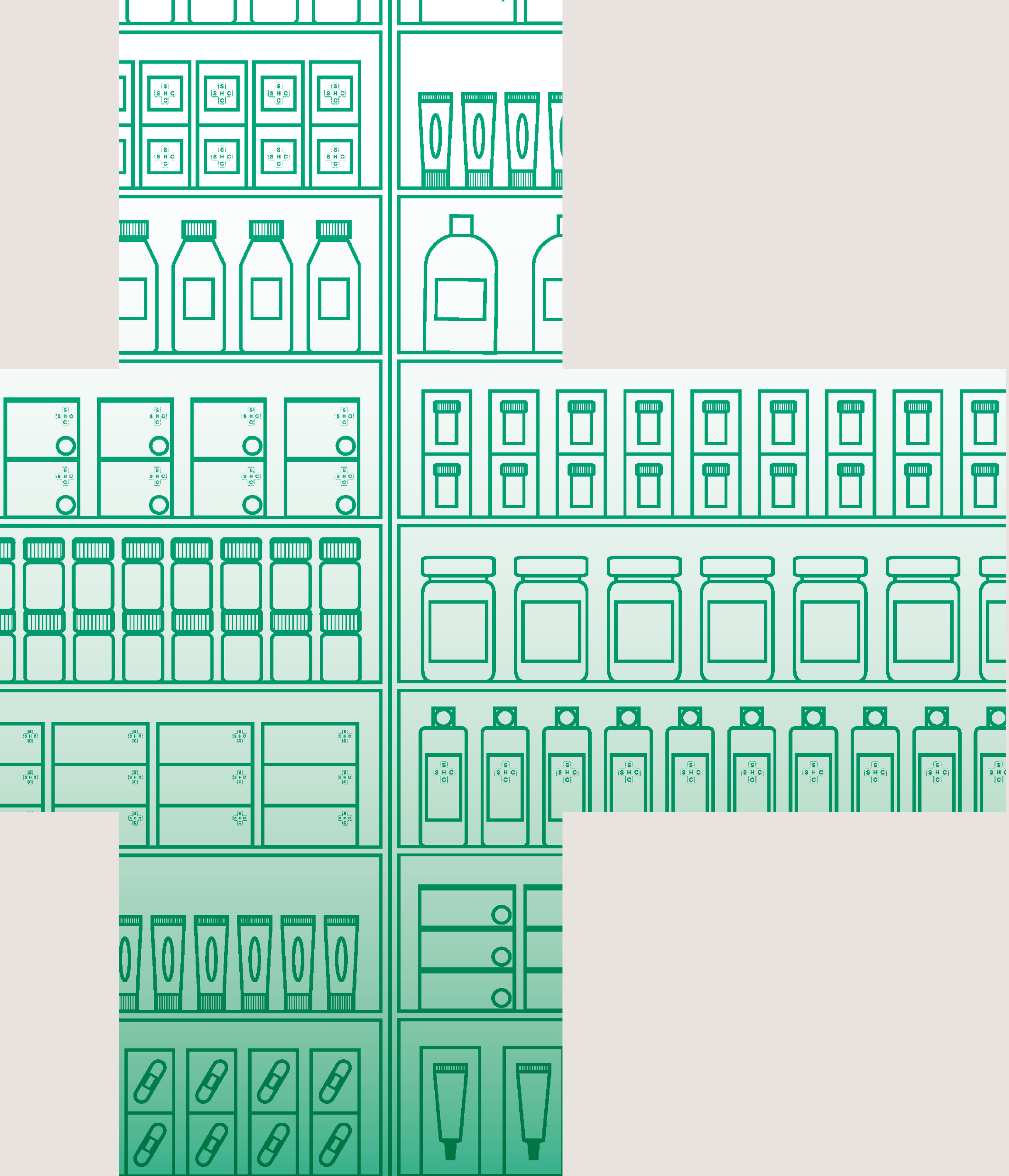


Data Dialogues 2

March 2022

The Liminal Space

Contents

Introduction

This report was produced in March 2022 as part of the engagement relating to the development of Scotland's first Data Strategy for Health and Care. The project was commissioned to build on the original Data Dialogues programme and other literature and research exploring the public's relationship with their health and care data.

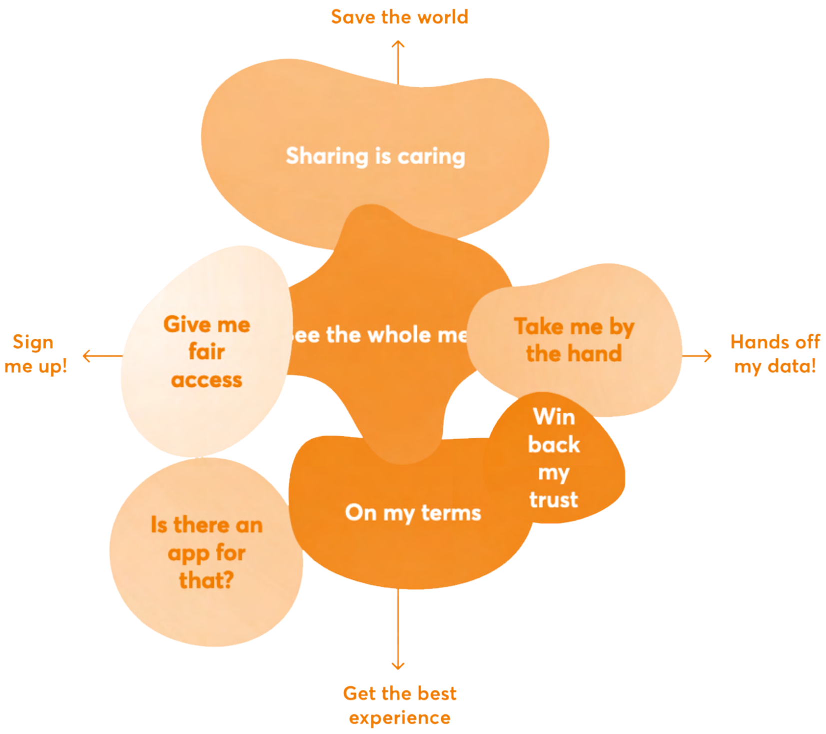
In 2019, Nesta and the Scottish Government embarked on a dialogue with Scottish citizens to understand their opinions and ideas for the use and sharing of health and care data, and to explore possible futures that improve outcomes for everyone. The aim of this dialogue was to inform the development of Scotland's first Data Strategy for Health and Social Care and ensure that Scottish citizens' voices were at the heart of this strategy. The programme was called Data Dialogues.

Background

The original Data Dialogues programme included four funded projects, the findings of which were synthesised into seven data relationships. These have been arranged by people's willingness to share data and whether they were driven by personal or societal concerns (see diagram). An immersive dialogue that communicates each relationship more fully is available in the summary report.

A note about these relationships: a data relationship includes both the way that a person shares and benefits from data as well as their attitudes, understanding and beliefs around data sharing. These relationships were not intended to be exhaustive but describe the most interesting and surprising relationships that were unearthed from the consultations. It should be noted that one person might not have only one relationship with the data, but they might adopt a number of different relationships in different circumstances. Similarly, while each relationship is informed by insights from a few specific groups, these relationships could be adopted by many different people.

Details of the seven data relationships can be found in Appendix A.



Method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How proactive wou
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ANTI-AGING MELANOMA PREVENTION CREAM - 25ML
You have been using this cream and tracking your skin health on your DataPassport for over 6 months now. Remember to log in to see how your health is improving - and how to look after your skin over the summer months.
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SCOTTISH HEALTH CONNECT
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Purpose and Themes

The purpose of this follow-up work was to gain a deeper understanding of how Scottish citizens, whose voices are often not heard, view the notion of managing and sharing their personal health and care data.

The aim was to map these responses onto the data relationships included in the original summary report.

Themes for the follow-up work include:

- Data and Inequalities – to be addressed through who we engaged with and how we engaged with them
- Citizen Ownership and Navigation of Data
- Data Quality

Method

In order to obtain findings that could be mapped onto the seven data relationships, we built on our fictional pharmacy concept used in the original Data Dialogues programme.

As before, the experience again involved three parts: personal exploration, collaborative engagement and self-reflection.

In this case, each stage involved the following:

1. Personal exploration

As in the main programme, each participant started their experience by engaging in an online quiz, designed to elicit responses that shared their current understanding of the health and care data landscape in a non-judgemental way. The quiz was developed to concentrate on the core themes of this stage including citizen ownership, navigation of data and data quality.

2. Collaborative engagement

As before, participants were then invited to a choreographed hour-long online session on Zoom where they engaged in a series of conversations and exercises around the benefits, risks and trade-offs of data sharing, as well as delving into choice, trust, value and ownership. This time the groups were smaller to engender a closer, more intimate space for discussion. To aid the conversation, the facilitators in each group were from each specific community – we used this participative approach to help ensure that the discussion and insights reflected the views of these participants, as opposed to pre-conceived ideas of the attitudes of any particular group of people. The fictional pharmacy pack was sent to the group facilitator as opposed to each individual participant.

3. Self-reflection

Once the session had ended the group facilitator was asked to record in writing their views around the key themes coming out of the session and to include their own personal reflections.

More details on the experience process can be found in Appendix B.

Recruitment

The Liminal Space team ran 10 online sessions over the week commencing 24th January 2022. All groups had between three and five participants.

Group participants

All participants lived in Scotland and were recruited from the following categories: LGBTQIA+ (four participants); Transgender (three participants); East and South-East Asian heritage (three participants); Indian or Pakistani heritage (five participants); Black people (five participants); disabled (eight participants); and people with a non-professional carer responsibility (eight participants). In the analysis, the responses from East and South-East Asian, Indian and Pakistani heritage and Black participants were grouped together as Black and Minoritised Ethnic (BAME). As in the recruitment for the previous work, the majority of participants were light users of health care services, excluding the transgender and disabled participants and unpaid carers.

All participants were paid £65 after completing both tasks. In total, 44 people were recruited, 42 people completed the quiz, and 36 participants plus seven facilitators joined an online session.

Group facilitators

The Liminal Space team researched advocates with facilitation experience in the various community spaces and reached out to recruit them to take part in the programme. Each was paid £300 for attending a briefing session, facilitating one group and writing up their reflections after the session, and £400 for facilitating 2 groups.

Reflections on the method

Overall we believe this method resulted in these participants sharing their true feelings about data and data sharing.

It is important to note, however, that these findings are indicative of samples not representative of these groups in Scotland, and we did not ask the participants or the group facilitators to speak on behalf of their community. Further research, ideally quantitative, would be required to validate these findings.

As in the original work, the participants appeared positive about the process – in the workshops themselves the participants all appeared engaged and gave thoughtful and considered feedback. The group facilitators gave mostly positive feedback. One would have liked a longer induction process and felt unsettled by the process itself, although they found it "fascinating".

Feedback from the group facilitators

"Really enjoyed it. Participants were well selected for their enthusiasm. Although geographically could have been better for this workshop (all women from Edinburgh). It was a pleasure working with the Liminal staff. Well organised, knowledgeable, thorough and imaginative."

Disabled facilitator

"I genuinely really enjoyed it from start to finish, but especially the session as it turned out (despite being somewhat nervous beforehand). A really interesting topic, and a lovely group of people to work with (The Liminal Space folk and the workshop attendees too)."

Transgender facilitator

"I really enjoyed being part of the project – it gave me a lot of food for thought. I enjoyed working with the team from The Liminal Space, who were helpful and supportive. I enjoyed being able to connect with carers who were not necessarily being supported by our organisation and who gave different perspectives on the subject matter." **Unpaid carer facilitator**

Feedback from the group facilitators

"This was a fascinating project to take part in. I learnt a great deal from the workshop and the participants. I found the prescription exercise quite unsettling as it made me feel like my agency and bodily autonomy about my health care was being taken from me by these medications being given to me without adequate explanation or even consent. I think a bit more induction would have been helpful, maybe by spending a bit more time with The Liminal Space staff, having the opportunity to practice some of the facilitation with The Liminal Space staff, and developing FAQs asked by participants based on past workshops to support the facilitation."

East and South-East Asian heritage facilitator

"I really enjoyed participating in this session, the group who were recruited were a fantastic, chatty bunch who made it an easy discussion. I also really appreciated the highly organised approach by The Liminal Space team who made everything clear, easy to follow and enjoyable to deliver." **LGBTQIA+ facilitator**

"Experience was good and an important project to be a part of. The Liminal Space team provided an adequate briefing, technical support and resources."

Black facilitator

Summary Insights and Learnings

‘Ownership’ and control of data

To what extent do the public want ‘ownership’ and/or control of their own data?

Overall the insights in this report indicate that the question of control is more important than ‘ownership’. Our participants do not want the responsibility of ‘owning’ their data per se – and by this they mean they do not want the responsibility of storing and looking after their data. For most of these participants, the NHS is seen as the most suitable organisation to do this. It is trusted and also, as Health and Care Professionals are seen as the most important recipients of shared information, it is the most relevant organisation – with years of experience of storing personal health care data securely.

It is important to note, however, that this positive view of the NHS is not held across all participant types – the first-generation immigrant and transgender participants in our sample do not hold the same positive views about the NHS. They are suspicious and assume commercial motives would underlie any organisation’s health care data strategy.

Key to control for the participants in our sample is:

- Visibility of all data held about them
- Translation/interpretation so that they know what the data means
- Ability to update data where incorrect/discriminatory/out of date
- Ability to control who has access and for how long

Our participants talk about ‘necessary’ data, i.e. the data that needs to be shared to optimise the health care they receive. All our participants are happy for this ‘necessary’ data to be shared with Health and Care Professionals to ensure that their health care is as joined-up as possible. Beyond that, however, they want to retain the ability to withhold consent from the NHS sharing their data for wider reasons.

What are the perceived benefits of this ‘ownership’?

As stated above, ownership when defined as storing and looking after their data is not seen as a benefit. Control of data is seen as much more important. The benefits of control include: convenience – the ability to give data to those that need it; time-saving – can give relevant people access so you don’t need to repeat your health care story every time you see a Health and Care Professional; make corrections – these participants would value the opportunity to check and ensure their data is up-to-date and correct.

What are the perceived drawbacks?

While these participants would like control, they recognise that they might not understand the data included in the record (therefore they would like interpretation/explanations). They also think the management of their data might be onerous. These participants are open to the idea of technological solutions making the control of their data manageable, and also making the data understandable. Apps were frequently mentioned in these sessions as the primary data management tool – having access to their health care data on their phone is seen as the best, most efficient solution for the majority of these participants.

What parties would they be comfortable sharing this data with?

These participants are happy to share their data with Health and Care Professionals to aid their health care. Most would be happy to share with pharmacists, though there are some concerns about other people in the pharmacy gaining access. Many are happy for researchers to access their data anonymously, though they would like control over what is shared and with whom and for what purpose. The vast majority of this sample would not be happy to share their personal health care data with other organisations unless there were strict controls/regulations to ensure the sharing was for ethical reasons. There was an overwhelming perception that their health care data has value and should be shared for the benefit of all e.g. to develop innovative new drugs, and not ‘nefarious’ purposes such as marketing, stopping benefits or targeting of unnecessary tests or drugs.

And for what purposes?

The sharing of health care data to support their own health care is always perceived as fine (and for the most part, these participants are surprised it doesn't happen more often currently). These participants are also generally positive about the use of their health care data in an anonymous form to support the development of better science, drugs and so on. Fewer are happy if their data is used to highlight preventative health care e.g. tests and drugs – there are widespread concerns that this will lead to raising unnecessary fears about health, wasted resources, the over-commercialisation of health care (like the US) and add strain to an already under-resourced NHS through overdiagnosis.

How would they want to access (and administer control of) their data?

Technology was seen as the future by these participants with apps seen as the main way forward. Most of these participants could imagine using an app to 'toggle' users on and off across different levels of access, vary control for different types of data and obtain translations/interpretation of what their data means.

Are there any groups (perceived to be or otherwise) at a disadvantage with this 'democratising approach' to data?

Across this sample, the issue of what would happen to people with reduced capability and capacity was raised. Who would manage their data? It was seen as ironic that these people, who are probably most in need of joined-up data solutions, would be the least empowered to use them. There would need to be a provision in place for these people.

What does 'ethical data collection' look like to the public?

What information is considered 'sensitive'?

While these participants think that 'sensitive' data includes anything that is potentially stigmatising – such as HIV status, wider sexual health issues, substance abuse – they also understand that any data can be sensitive if it can be used against you in the wider world e.g. blood pressure data could impact your ability to get insurance, or information about your musculoskeletal health might impact your ability to get a job. Overall, these insights highlight that sensitivity depends on the circumstances of the individual as opposed to the type of data per se.

Who are they comfortable handing over data to? (e.g. is the involvement of the private sector in the collection and use of data on behalf of the public sector acceptable to the public?)

The vast majority of these participants would not see it as acceptable to involve the private sector in the collection and use of data even if it was on behalf of the public sector – if this was done then strict controls would need to be put in place to ensure that data was not used unethically. These participants, for the most part, would only want the NHS or a separate public organisation that specialises in storing and looking after the data to be involved.

On what grounds could data be shared?

Across this sample, the issue of what would happen to people with reduced capability and capacity was raised. Who would manage their data? It was seen as ironic that these people, who are probably most in need of joined-up data solutions, would be the least empowered to use them. There would need to be a provision in place for these people.

What checks/balances need to be in place?

These participants want transparency – this includes being able to see their own data and having the ability to make corrections if necessary. They would also like strong regulations in place to ensure that data is not used for non-altruistic reasons.

Should the default be to opt-in or opt-out?

This varied from participant to participant with no pattern across the sample. The most common view is that Health and Care Professionals should get blanket access when necessary for an individual's health care, but in all other cases they would like to maintain control – ideally, this would be made simple using new technology. The ability to change their mind about access was also seen as important.

Are there groups (perceived to be or otherwise) at a disadvantage when data is routinely collected?

Some participants from the transgender, BAME and disabled groups all raised discriminatory practices as a potential concern. This area needs more research to explore more fully.

Stakeholders

BAME participants

> "There is a perception that there are ethnic differences in the approach to personal health data."

We spoke to people with East and South-East Asian, Indian and Pakistani heritage and Black people. We found that issues around discrimination and potential stigmatism were raised by these participants. We also saw that among the first-generation immigrant participants there was less trust in the NHS. Also this group had issues around coming into the NHS and not having NHS data protocol explained to them, which resulted in confusion and further loss of trust. These participants had also witnessed the perceived negative consequences of data sharing for profit in other countries and, as a result, were concerned/sceptical about data sharing for research and development.

LGBTQIA+ participants

> "Sexuality flagged as 'sensitive data' and also the longstanding fear of data being used against you."

Among the participants in our sample, this was raised as an issue but was not seen as a reason not to share data, except among the transgender participants.

Disabled participants

> "A group that is very much impacted using health and care services."

Overall, while these participants could see the benefits of a joined-up system saving them time and being more convenient, and being better for their overall health care, they were also worried about ethical issues around data sharing and the potential for negative impacts of sharing data impacting their wider life.

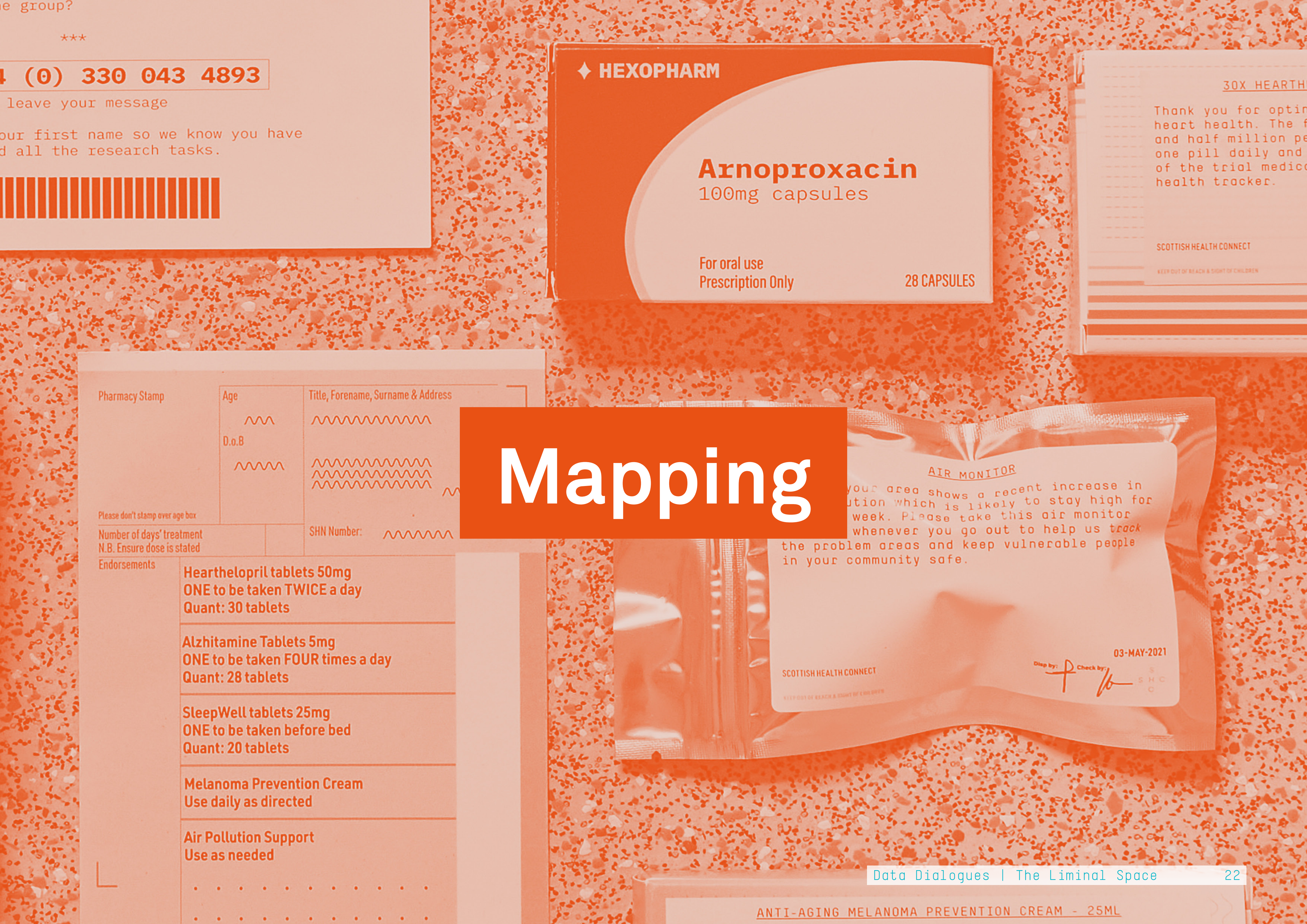
Unpaid Carers

> "Will need to address how data flows might support the transition from child to adult care services and its challenges."

Carers are supporters of wider data sharing of health care data of the person they are looking after – and not just restricted to Health and Care Professionals but also people across the wider community such as the police. But these participants are much more reticent when it comes to their own health care data – they become similar to other groups in the population and are less keen on their data being shared, unless it is among Health and Care Professionals around a specific health issue.

It should be noted that none of the participants in our sample were asked to speak on behalf of their communities and the sample was not 'representative' of each of these communities in Scotland.

Mapping



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4 (0) 330 043 4893

leave your message

our first name so we know you have
d all the research tasks.

HEXOPHARM

Arnoproxacin
100mg capsules

For oral use
Prescription Only

28 CAPSULES

30X HEARTH

Thank you for optin
heart health. The f
and half million pe
one pill daily and
of the trial medic
health tracker.

SCOTTISH HEALTH CONNECT

KEEP OUT OF REACH & SIGHT OF CHILDREN

Pharmacy Stamp

Age

Title, Forename, Surname & Address

D.o.B

Please don't stamp over age box

Number of days' treatment
N.B. Ensure dose is stated

SHN Number:

Endorsements

Hearthelopril tablets 50mg
ONE to be taken TWICE a day
Quant: 30 tablets

Alzhitamine Tablets 5mg
ONE to be taken FOUR times a day
Quant: 28 tablets

SleepWell tablets 25mg
ONE to be taken before bed
Quant: 20 tablets

Melanoma Prevention Cream
Use daily as directed

Air Pollution Support
Use as needed

AIR MONITOR

your area shows a recent increase in
ution which is likely to stay high for
week. Please take this air monitor
whenever you go out to help us track
the problem areas and keep vulnerable people
in your community safe.

03-MAY-2021

SCOTTISH HEALTH CONNECT

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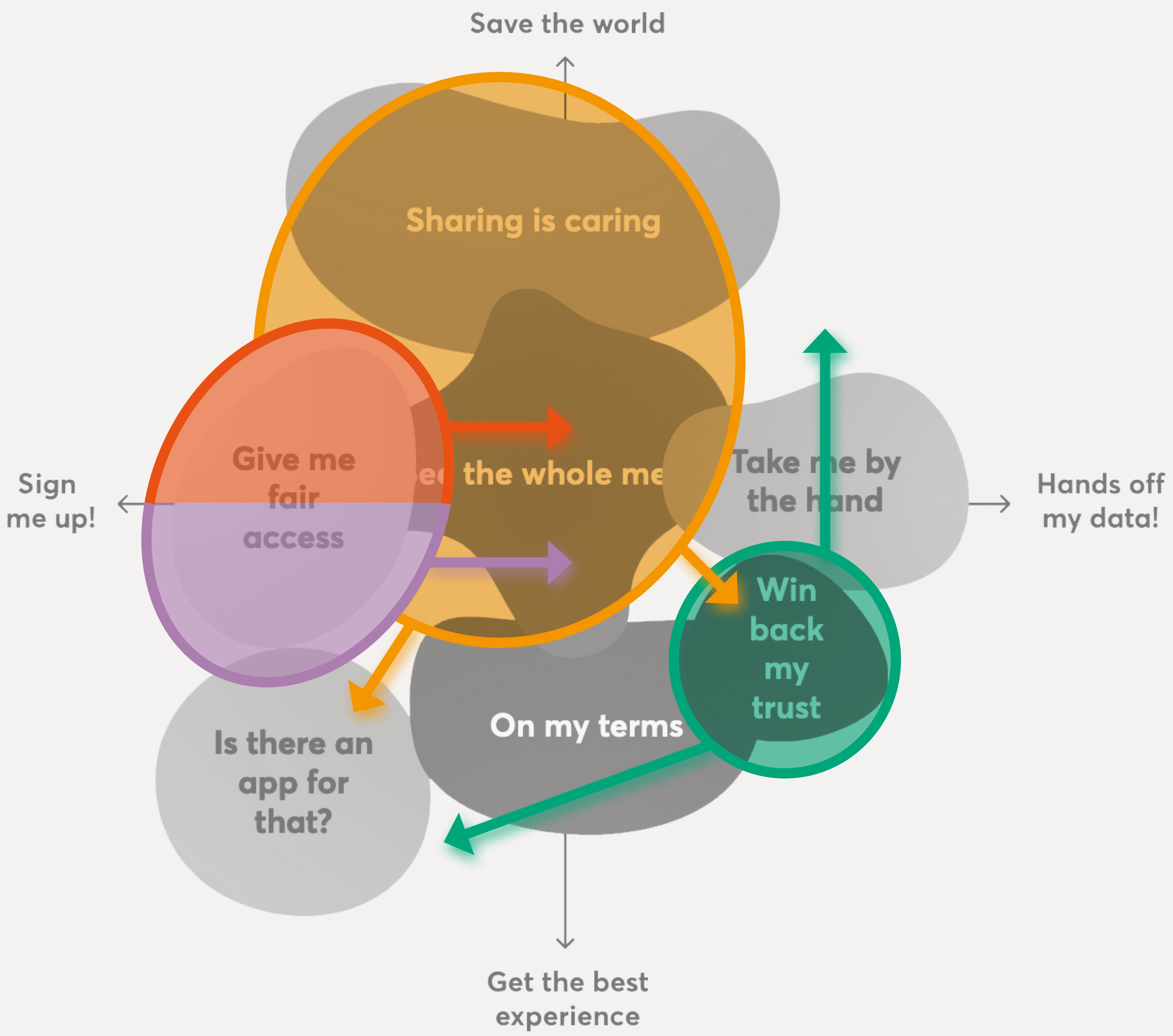
KEEP OUT OF REACH & SIGHT OF CHILDREN

ANTI-AGING MELANOMA PREVENTION CREAM - 25ML

This image summarises how these participants map onto the existing data relationships. Details of the original data relationships can be found in Appendix A.



Category of Participant	Data Relationship in original report	Data Relationship of participants in stage 2	Comments
BAME participants	• Win back my trust	• Win back my trust • Is there an app for that? • Sharing is caring	
LGBTQIA+ participants	• Sharing is caring • See the whole me	• Sharing is caring • See the whole me • Is there an app for that? • Win back my trust	
Disabled participants	• Give me fair access	• Give me fair access	• But with concerns about data storage and use
Unpaid Carers	• N/A	• Give me fair access	• But only when discussing the data of the person they care for • These participants map onto ‘On My Terms’ when discussing their own data

Detailed Findings

You have been using this cream and tracking your skin health on your DataPassport for over 6 months now. Remember to log in to see how your health is improving - and how to look after your skin over the summer months.

BAME participants

Data relationships

Across the BAME participants, views were reflected that mapped onto the following data relationships:

- Is there an app for that?
- Sharing is caring
- Win back my trust

What we found:

There was a fear that data could be used for unethical purposes if shared beyond medical service providers. For example, some BAME participants mentioned the risk of pharmaceutical and insurance companies gaining access to and using the data to fearmonger about ill health or increase the price of medication or insurance for specific individuals. The security of any centralised database was critical for many of these participants.

Discrimination was raised by many BAME participants as being a potential issue. There was also a fear that their medical profile might lead to discrimination in the workplace (e.g. companies won't want to hire someone with chronic or long term health issues) or might contribute to discrimination in the form of homophobia, medical racism, or broader institutional racism.

At the same time, convenience for the individual was also a top priority, but without sacrificing control and consent over medical treatment, medication and diagnosis. Apps were mentioned spontaneously by some BAME participants as being an appropriate way to make it easy to access and look after their own data.

Most BAME participants were also keen to share data if they felt it contributed to an objective 'greater good' such as improving health outcomes of the community, contributing to medical research on medication or disease, or being able to give back e.g. being alerted to an increased need of blood or organ donation that matches your medical profile.

> "[Data collection] is good...it can create analysis, create action and a response for people."

Ownership and management of data

There seemed to be a general consensus that an integrated approach is needed and overall there was a preference for individuals being able to manage their health care data and opt-in, rather than opt-out of the management of their own data. Indeed, some participants were frustrated that this was not already happening as it can be inconvenient to have to keep repeating health issues to different Health and Care Professionals and also can cause negative outcomes for care if Health and Care Professionals work in silos.

> "It puts individuals at risk if the doctors aren't talking to each other."

Some BAME participants were sophisticated in their views about data sharing and highlighted the difference between 'necessary' data that needed to be shared for their own convenience and to optimise the health care they receive – such as medications, test results and diagnoses – and other data that they felt was personal e.g. HIV status, alcohol consumption, weight and so on. They wanted to retain the ability to give blanket consent to health care providers sharing the necessary types of data to support their individual needs, but anything beyond that they wanted to be asked for explicit consent. They also wanted to be able to review and manage what health and care data was stored about them, with relevant interpretations and translations so they could make sense of it.

Others said they didn't feel like they were informed enough or couldn't take the responsibility to make decisions about their health care and what data should or shouldn't be used or shared. Many agreed that medical expertise are needed to know what information is relevant and necessary and so they were not comfortable with taking over the management of their data.

Most BAME participants were comfortable with NHS Scotland looking after and managing their data – there was an inherent trust of the NHS and also an accountability of the NHS to get it right – "we're paying in, they should be doing a good job". This however was not true for those participants who were first-generation immigrants to Scotland, who did not view the NHS in the same light.

Exploring what 'ethical data collection' might look like

A number of issues were raised including:

- **The exploitation of data by the private sector** – there was widespread concern about data being leaked, in the case of a centralised database being hacked or sold to pharmaceutical, insurance, tech and other companies. There was recall of examples like Cambridge Analytica as cases showing the terrible consequences of data collection and breaches. Some participants demonstrated good knowledge of how personal data can be used for marketing purposes.
- **Accountability of organisations following data breaches** – some BAME participants felt the government should feed back how such organisations were sanctioned in order to instil trust in the public, and put regulation in place to force organisations to prove they can anonymise data completely before sharing it with wider parties.
- **Stigmatising information such as mental health conditions or other stigmatised disorders e.g. HIV and alcoholism** – many participants felt that this information should not be accessible to pharmacists or researchers for fear that it might be used in an unethical way, particularly if linked to a specific characteristic.
- **Fear of waste and fearmongering** – there were concerns that using data sharing could result in potential waste of medication or treatment that is not needed or appropriate, or fearmongering about health issues without cause.
- **Clearance levels for different types of data –** there was a widespread view that some data should be available to all e.g. allergy information, but other information e.g. HIV status or other potentially stigmatising data should be restricted on an 'at need' basis
- **Transactional approach to data –** one participant felt that Health and Care Professionals or others should only get access to an individual's data for a defined period of time.

> "Not blanket access, not all NHS need to see everything."

- **What happens if someone can't give consent? –** there were widespread concerns around older people or ill people not being able to give their consent or being able to decide what levels of information could be used in a useful way. The perception among most was that Health and Care Professionals should be trusted in those cases to make decisions on the individuals' behalf based on medical need/ expertise, though once again first-generation immigrants had a less positive view about the NHS.

Reflections of BAME facilitators

The BAME facilitators' reflections included the following:

Concerns about data security

> "I know GPs are already independent private companies. There has been a longstanding culture of complete security over people's data within health institutions – they have data and its use hammered into them as part of working within that culture. How secure would it be within another service?"

Positive outcomes of data sharing

> "A local pharmacy having access to my health data might actually reduce the potential risks of a GP or other health professional not picking up on key signs or symptoms, so it kind of spreads the risk? The example in the media recently highlights this when a little boy had a specific illness and when his parents phoned 111 and NHS 24, they didn't have the Key Information Summary meaning this was a contributing factor to his death. That's an extreme example, but would the sharing of some key data within our disciplines prevent things like this happening?"

Concerns around medical racism

> "The issue of medical racism is very important and warrants further exploration. Medical science and science more broadly have long been used as justifications for racism and explanation for inferior health outcomes, physical health and mental health of people from the Global South. Collection of personal medical records might lead to falsely racialised medical profiles being built, leading to overdiagnosis or underdiagnosis of medical conditions in certain ethnic groups. There are also issues with UK ethnic categories, for example, Asian refers to an extremely wide group of people with different lifestyles and health conditions. There needs to be further thought and consideration on this as correlation with ethnicity and race can be useful, for example, with sickle cell disease."

Concerns around private data being seen by colleagues

> "As someone who works closely with Health and Social Care services in North Lanarkshire, [if my health data is shared] could my colleagues potentially see my underlying health conditions?"

A different perspective – first-generation immigrants

Some of the BAME participants were first-generation immigrants, having arrived in Scotland in the last five years. These participants did not show the same level of trust in the NHS as those in our sample brought up with the idea/concept of the NHS. This group was equally distrusting of health care providers in other countries – they tended to assume that commercial opportunism is behind all health care systems.

They had also assumed before this research that data sharing was already happening to a much greater extent within GP practices, hospitals and pharmacies in the UK. This highlighted for them a lack of adequate communication on behalf of NHS Scotland when you become an NHS patient about what kind of data they store for patients and if, or when, it is shared.

Some of these participants also asked questions about what might happen if data needed to be shared internationally? How would this be controlled or managed safely?

Also, from their experience there have been problems where certain care in the UK requires certain vaccinations which aren't mandatory "back home", and how proving their vaccinations has been difficult as they don't have access to their old records, and there is a disconnect between NHS and overseas services – so what does this mean if the NHS has a "gold standard" but people feeding into this system from other countries don't have the same quality of information?

There were additional reflections from our BAME group facilitators on the issue of those without regularised immigration status – this was not a focus of this research, but we include their views here for information.

> "I think prior negative experiences with the NHS would significantly affect a person's trust in the NHS's handling of their data. This could be negative experiences through misdiagnosis, malpractice, long waiting times or health care surcharges and having NHS debt, which many of my service users experience (sometimes up to £10,000). This debt impacts their ability to regularise their immigration status, as this information is shared with the Home Office, therefore, the NHS is not seen as a trusted repository of data."

> “Many of my service users (undocumented migrants or migrants with no fixed address) have had very bad experiences with trying to access primary health care through GP surgeries as information about their visa or address is often asked, even though it is not required. Passed data sharing between the NHS and Home Office for the purpose of immigration enforcement also actively discourages migrants from receiving health care, even in the context of a pandemic. Some only received their COVID jabs through community-based pop-up vaccination clinics as they were so scared of data sharing with the Home Office or police. Again, this might lead them to not trust the NHS with their data.’

LGBTQIA+ participants

Data relationships

Across the LGBTQIA+ participants, views were reflected that mapped onto the following data relationships:

- Is there an app for that?
- Sharing is caring
- See the whole me
- Win back my trust

What we found:

Overall these LGBTQIA+ participants were positive about the idea of sharing health and care data for the benefit of society e.g. to help develop preventative medicine. There was a strong preference for public management of data (via the NHS) and little or no involvement from private companies who could potentially misuse data. They wanted any use of their data to be not for profit, and for improving their own or others health care only.

Whilst they were happy for the NHS to look after their data, they also want control – they want to be able to access their files, to see everything that Health and Care Professionals can see and to be able to choose what they do with their data. This visibility of their data would also be useful – allowing them to see what decisions were made about their health care when they were children which might have impacts now, and also as an aide for reminding them to get tests, vaccines and so on. They saw technological solutions such as apps being the best way to do this.

It was very important to these participants that data collection and sharing was done in an ethical way – transparency was seen as being at the heart of the issue. Without transparency, there could not be trust, and trust in the system was seen as fundamental by all.

Ownership and management of data

This group was generally happy for their data to be looked after centrally by the NHS in a centralised, connected version of everyone's data, as long as they were able to view and challenge the data held. As stated, they liked the idea of being able to easily view their data via an app or similar. These would potentially be convenient and easy to manage – simplifying currently laborious tasks and fitting in with busy lives. They would need to be user friendly and jargon-free.

> "It would be great to get out your phone and activate someone like your optician to see your record."

There were divergent thoughts on whether the system should be opt-in or opt-out, but overall the main unifying wish was for visibility and the ability to correct if needed – transparency was seen as critical for any system moving forward. In terms of providing consent each time for the use or sharing of data, some would be happy with a one-time consent rather than regular updates (as long as this could be reversed at a future point), others wanted a more involved management approach with explicit consent asked for each time their data was shared for anything other than their own health care.

Exploring what 'ethical data collection' might look like

Once again transparency was seen as key to creating trust in the process – ethical data collection for them was defined as honesty and openness about how the data would be used and why this is relevant to them. They proposed a notification and agreement process using jargon-free, simple language that outlined why the data was being shared. So as long as a notification or an agreement outlined why, and with whom, the data was being shared, they would probably give consent. If this transparency was in place they would be happy to share personal data collected through wearables etc. with the organisations that needed it for altruistic reasons.

A different perspective – transgender participants

While this group understood the benefits of sharing data, their prior experiences with the health service, especially during and after transitioning, have led them to be more wary about the potential for discrimination and inaccuracies in their health records. This appears to be a factor making them less positive about data sharing overall than the wider LGBTQIA+ group. They had all experienced discrimination by Health and Care Professionals and were worried about inflammatory, stigmatising comments in their records. While they still felt the NHS was the best place for data to be stored centrally, they did not have the same level of trust in the NHS as other participants. Extra work needs to be done to ensure these participants feel safe and secure with the sharing of their data. Efforts need to be made to win back their trust – this can be done through allowing complete visibility of information held about them and the ability to correct potential inaccuracies on their files.

The transgender group facilitator shared some additional reflections that captured the detail of issues that arise specifically for this group when sharing data:

> "There were some really interesting thoughts and points made around presumptions being made in hospitals etc. – one participant was a transgender man who volunteered the information that he wasn't medically transitioning [because of other health issues] and so can be read as a woman by others [being called 'she' etc.] when information isn't shared in advance; but when his title and name are shared without asking in advance, he prefers that."

> "Also, the condoms being used as a theoretical product came up in the group with the tiniest bit of annoyance it seemed, essentially, for not knowing who has what genitals etc."

Disabled participants

Data relationships

The views of disabled participants could not be mapped onto any existing data relationship exactly – the closest fit was Give Me Fair Access. With these participants there were significant concerns about how their data is stored (need to keep it safe) and used (not for unethical reasons).

What we found:

This group all immediately saw the benefits of sharing data – indeed, many had already shared data in trials or as part of their treatment (e.g. one participant downloads data from wearables and other monitoring technology they use and shares with their GP). They also saw that joined-up data resulted in better (and more convenient) health care. But at the same time, most had significant reservations about the wider use of data in research or by private companies, and about how their data was stored and potential security risks.

The closest data relationship out of the seven available was 'Give Me Fair Access' – these participants really wanted a joined-up health and care system. They didn't want to have to constantly repeat their stories and disability needs, but for them to be easily shared (among Health and Care Professionals), many were already using surveillance methods in their health care, and they are reassured that they are being looked after. But at the same time, they were nervous about sharing their data and wanted controls to ensure that their data is only used for ethical reasons.

Ownership and management of data

Overall this group believed that there should be absolute patient choice and control about how data is looked after and managed. There was an expectation that this would look different for everyone, based on their specific health issues and comfort levels around data – they want a personalised approach.

This group was reluctant about one organisation looking after all health care data – while the NHS is seen as the most obvious place to store the data, there were concerns about how this would be vulnerable to hacking. There were also concerns about the NHS being privatised in the future so that their data could be sold to commercial organisations and used for unethical reasons.

There was a desire for data to be continued to be stored in multiple places, but with systems that can talk to each other to ensure joined-up care, and with multiple layers of consent to ensure the right people have access at the right time but to prevent the use of data for the wrong reasons.

Exploring what 'ethical data collection' might look like

There was a widespread perception among these participants that there needed to be safeguards in place to assure security and confidentiality. The importance of data protection rules was cited as critical. Overall, any system should be transparent, and flexible, granting granular access to information to those that need it – no blanket 'one size fit all'. It should also be easy to use.

An example from the group of potential unethical use of data was the DWP using health care data to decide who is fit for work:

> "I'd also be concerned that the DWP would abuse access to these records. We've all seen the headlines of them telling someone they're fit for work when they've already died or are not far from it."

There were also issues raised around anonymity and how it is difficult to enforce when you have a rare condition.

Many of these participants were also reluctant about taking more drugs – they felt that some issues don't need intervention and data sharing with "big pharma" could result in the further medicalisation of health care:

> "All of this is intrusive and unnecessary as far as I'm concerned. When it comes to the medicines, it feels like big pharma are just trying to push their products and ply us all with pills we don't need."

Reflections from the Disabled facilitator

The Disabled facilitator’s reflections included the following:

Mental health issue

> “One person in the group said ‘you don’t have to take the medicine’. However, in my experience in mental health, some people are compelled (by legal compulsory treatment orders under the Mental Health Act) to take their meds or coerced into doing so (e.g. threat of detention, withdrawal of services).”

What happens to those who can’t control their data?

> “Not everyone will be able to manage their own data. Will people be able to nominate a proxy (like a digital advocate), and how will that be governed? Is there potential for abuse?”

Unpaid carer participants

Data relationships

The carer participants could be mapped onto the Give Me Fair Access data relationship when discussing the data of the person they are looking after, but they are closer to the On My Terms relationship when reflecting on their own health care data.

What we found:

When talking about the data of the person they cared for, this group were the most positive about data sharing and were confused that data wasn't shared more already among GPs, hospitals and pharmacies, as well as other key health professionals. They found it onerous to keep having to tell the health care story of the person they cared for again and again, and they would appreciate having a simple joined-up system that would be more convenient.

> "Anything to stop me having to repeat myself…some of these forms take hours to fill out."

> "With my son, it's already stressful visiting or engaging with these services [he has severe autism and cannot be in public spaces too long] so anything to make it easier."

There was also a perception that a joined-up system would be safer for the person they cared for. They mentioned agencies – such as the police – who would benefit from health care data to provide better care for people living with dementia who go missing, or autistic children.

> "This could help keep people safe in the community."

The role of the pharmacist was also picked up on – carers have really regular contact with their pharmacist and felt that many of them know them and the person they are caring for better than the GP. They said they would like their pharmacist to have more power e.g. for repeat prescriptions and the ability to help them when they can't get through to the GPs, who are so busy. Also to ensure that multiple drugs prescribed at different times are safe if taken in combination with each other.

There were multiple examples given of how better sharing of data would improve the health care of the person they look after.

- One woman's uncle was an alcoholic. When she has to take him to A&E (which happens often) she has to tell the Health and Care Professionals about this – it is embarrassing for her uncle, and also potentially dangerous - what if she wasn't there?
- One woman's daughter has ADHD. The dentist had no record of this, and when she had to have an extraction, the dentist did not treat her in the way one would expect with her condition. This caused a huge amount of anxiety which could have been avoided if they had known about her condition beforehand.
- One woman with a son who has autism took him to see the audiologist for a hearing test. The doctor asked him to do lots of things that he couldn't understand. Again, it would be better if the audiologist had known beforehand about his autism and had been able to prepare.

When they turned to a discussion of the sharing of their own data, however, the participants were much less positive about the benefits of sharing and more concerned about the security risks and who had access to their data. There was widespread negativity about the private sector having access to their data.

Ownership and management of data

When thinking about the data of the person they were looking after, simplicity and convenience were critical. Their care duties already mean that they have to do a lot of administration for the people they are looking after and so they would not want to have to give permission every time data was being shared as that would be too onerous – blanket, 'one size fits all' permission would be best.

> "I would like to see a passport or a journal where it is all collected together."

> "I wouldn't imagine having any role inputting the data or giving separate permissions."

When it came to thinking more widely, however, they did want to retain more control. They personally would like to be able to opt-in and out depending on whether or not they saw the relevance of sharing the data.

The issue was also raised about people who are unable to make decisions about their health and care data, but who were likely to have the most need for it to be connected. If there is no guardian or carer with the permissions, how would this data be managed if it all became about individual control?

Exploring what 'ethical data collection' might look like

Ethical data collection seemed to mean for most that they should be able to give their permission, through an agreement, so that they were aware of what was being shared and with whom. They would be likely to give blanket permissions for the health care data of the person they are caring for but want much more control over the permissions for their own data.

Whilst they wanted the data of the person they cared for to be shared more widely across Health and Care Professionals and relevant bodies in the community, there was widespread negativity in this group about the private sector using their data on behalf of the public sector.

They were also worried about non-professional caregivers having access to this data, e.g. carers that come into the home having too much information on the people they care for, or people who work in a pharmacy (not including the pharmacist).

> "There are some things you don't want them to know."

Also there were concerns about wider groups such as potential employers being able to look at the data and the fact that they are a carer having a negative impact on their wider lives.

> "I would be worried about people applying for jobs, for example what if you applied for a job in the NHS - you wouldn't want your employer to be able to look at all this information."

They also pointed out that it was only ethical or relevant to use this data if it is kept up to date as situations can change rapidly, and they asked how this would be managed.

> "It takes a lot of manpower."

Reflections of Carer Facilitator

The Carer facilitator's reflections included the following:

Carers undervalue their own health need

> "Carers often don't think much about their own health as they focus more on the health of the person they care for. It could be helpful in the future for carers' health support to be available through pharmacies that are accessible and visited regularly by them – often to pick up meds for the people they care for. The notion of the fictional pharmacy could be an important measure that would help to 'care for the carer' without them having to actively seek a GP appointment to deal with their own health issues."

Carers need to be seen as equal partners in care

> "Although things are getting better now, carers need to be seen by Health and Care Professionals as equal partners in care and involved in the information that is being shared about them and the person they care for. They often hold key data/information about the cared-for person that only they are aware of, as they care 24/7."

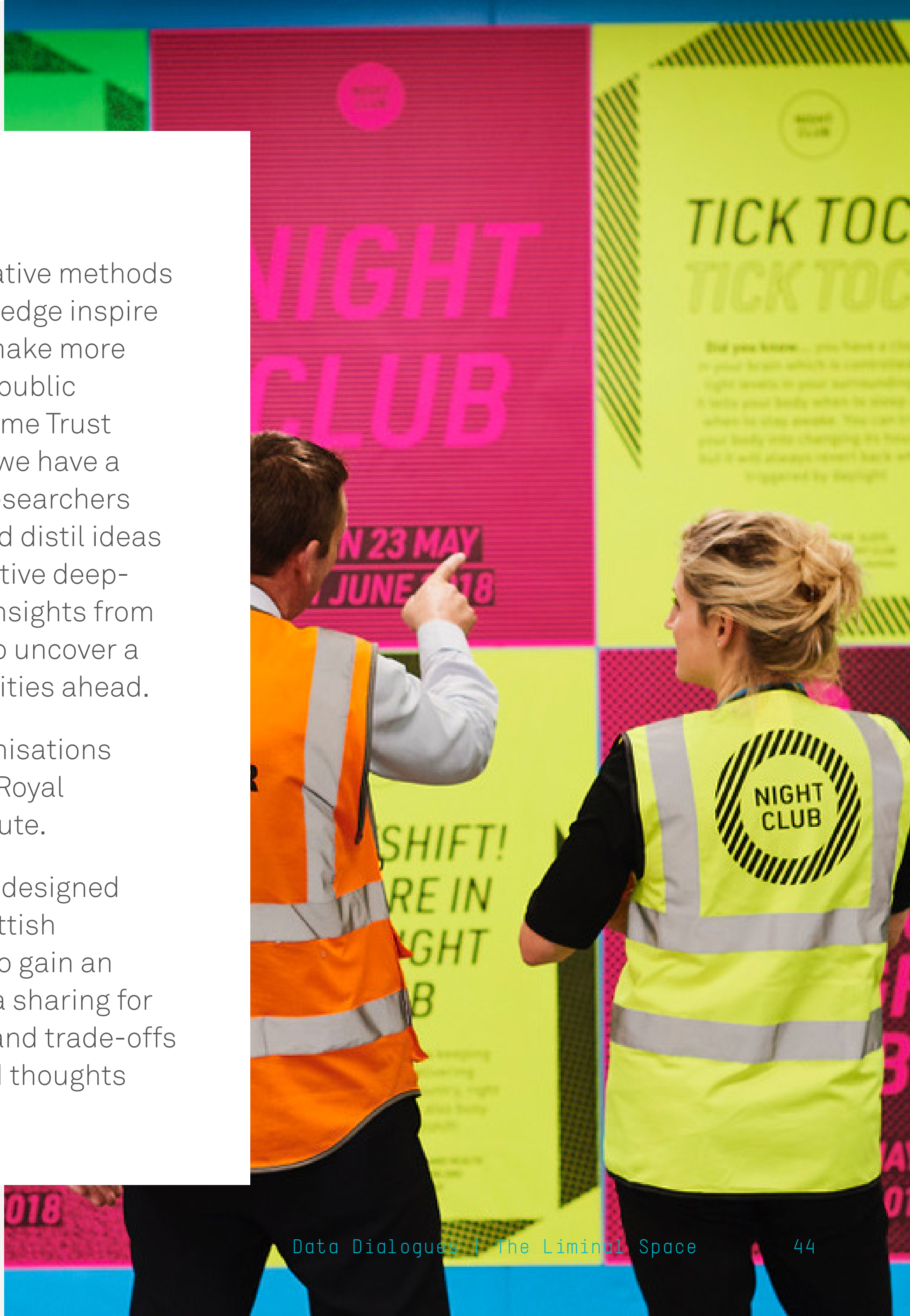
Appendix

Appendix A: The Liminal Space

The Liminal Space uses people-centred design and novel creative methods to engage and empower people, and by deepening their knowledge inspire them to affect change. Our mission is to empower society to make more evidence-informed decisions and actions and our pioneering public engagement work has recently been recognised with a Wellcome Trust Sustaining Excellence Award. As a purpose-led organisation, we have a strong track record of working with leading institutions and researchers using people-centred design approaches to bring together and distil ideas that can be used to create meaningful outcomes. We use creative deep-listening methods to surface and capture the most valuable insights from stakeholders, taking a lateral and holistic approach in order to uncover a more nuanced understanding of the challenges and opportunities ahead.

We have delivered projects for and with a wide variety of organisations including Wellcome Trust, The National History Museum, The Royal Academy of Arts, Selfridges, UKRI and The Francis Crick Institute.

For the original Data Dialogue programme, The Liminal Space designed and delivered an online and physical experience for 100+ Scottish citizens based around a fictional pharmacy concept in order to gain an understanding of their current level of knowledge around data sharing for health and social care, to enable discussion around benefits and trade-offs of data sharing, and hear their individual hopes, concerns and thoughts around possible futures.



Appendix B: The Data Relationships

See the whole me

People might be part of several communities that intersect to give them a unique set of experiences that influence the care they want and need. They want to be understood holistically, be treated without judgement, and receive tailored support. They would like to be taken care of by a support network that can include AI, specialists, and peers that share their experiences. We've heard this from LQBTQIA+ people, young people, and people with a named condition.

People with this data relationship said:

- They often want a more holistic approach to their health, being acknowledged as a whole person rather than treated only for specific conditions.
- They worry that their data will be inaccurate, used out of context or misunderstood. They want authorship over their own healthcare information.
- They want their data to be used by specialists – whether in a sensitive topic or simply in avoiding bias.
- Many young people don't feel understood by doctors and would rather interact with online communities, or even an AI.

Give me fair access

We heard this from people with disabilities or chronic health conditions and people who need some level of care. The lives of people with sensory loss, dementia or different abilities can be transformed by data sharing. However, accessible technologies are often unavailable, or people lack choice over how they share their data. Nonetheless, these services can offer a radical benefit, improve lives and are often positively viewed by those who use them.

People with this data relationship said:

- They really want a joined-up health and care system.
- They don't want to have to constantly repeat their stories and disability needs, but for them to be easily shared.
- Many of them see surveillance as a means of safety and support – it reassures them that they are being looked after.
- They want access to inclusive technologies but also a fair choice over what data they have to sacrifice in order to participate.

Is there an app for that?

We heard this from young people and people from the general public. Many people are interested in getting the best health and care service they can. In this relationship people might be active internet users, where they already share a lot of data. The most important thing in this relationship is for people to be able to personally use the data or feel its benefit in an improved or personalised experience.

People with this data relationship said:

- They will share their data if it improves or personalises their own experience.
- They might not mind sharing data with private companies if they are offering a great service.
- They want access to their own data so they can manage their own health.
- They want more convenient data collection: *“Why do we have to input data ourselves when there is tech to get it so seamlessly?”*

Take me by the hand

We’ve heard this from older people and people in care. A lot of people value health and social care practitioners for not only medical care but also human connection. They might resist data-enabled technologies, fearing that they will replace the human connections they already have. They value familiarity and require personal guidance on sharing and benefiting from data.

People with this data relationship said:

- They just want to feel cared for and listened to by another person. They want health care with a human touch.
- They worry that data-enabled health care will replace, rather than enhance, face-to-face interactions.
- They should be able to opt out of data sharing without getting worse quality care.
- Having someone take the time to talk to them face to face about data sharing is really reassuring and helps them to trust the system.

Win back my trust

We heard this from minority groups, people in care and people receiving Universal Credit. Many people think that data will only be used against them. In some cases this fear is abstract, but others have suffered at the hands of the system, have experienced prejudice in health and care services and feel the system isn't designed to help people like them. These people are wary of sharing data. The first step to improving this relationship is to acknowledge the existence of these fears and to address them in a genuine way.

People with this data relationship said:

- Many of them have experienced judgement and discrimination at the hands of the health service. Their negative experiences are real, and they stay with their communities.
- Trust will need to be earned before they would be willing to share their data. First and foremost they want to be listened to and acknowledged by those in power.
- People who haven't experienced discrimination find it impossible to imagine that it exists.
- They are most concerned about where the power lies: *"What happens when people are mistreated, and things go wrong? How do we get justice?"*

On my terms

We heard this from a broad cross-section of society. Many people don't have a strong need for data sharing health and care solutions, and they don't recognise a radical benefit to their lives. They are concerned with more abstract issues of autonomy and worry about losing control of their own decisions. This tends to be an uneasy relationship but can be improved by transparency over data use and the provision of simple data controls.

People with this data relationship said:

- They want to be in control of their own data sharing.
- They don't understand how it benefits them to share their data. This makes them nervous and much more critical of sharing.
- Some of them are concerned about preventative care. It will only increase the burden on the NHS and increase their fears when they are actually well.
- They are most worried about the future: *"What if we are ruled by a Big Brother government? Or what if our data is misused in the future?"*

Sharing is caring

We've heard this from a broad cross-section of society, but particularly young people, LQBTQIA+ people and people with a named condition.

In this relationship, the primary motivation for sharing health care data is to help the greater good. These people feel well informed about the risks and benefits, either through their own research or through their own experiences. It is important to them that they know how their data is being used to help people and that proper protections are in place to ensure an ethical and equitable system.

People with this data relationship said:

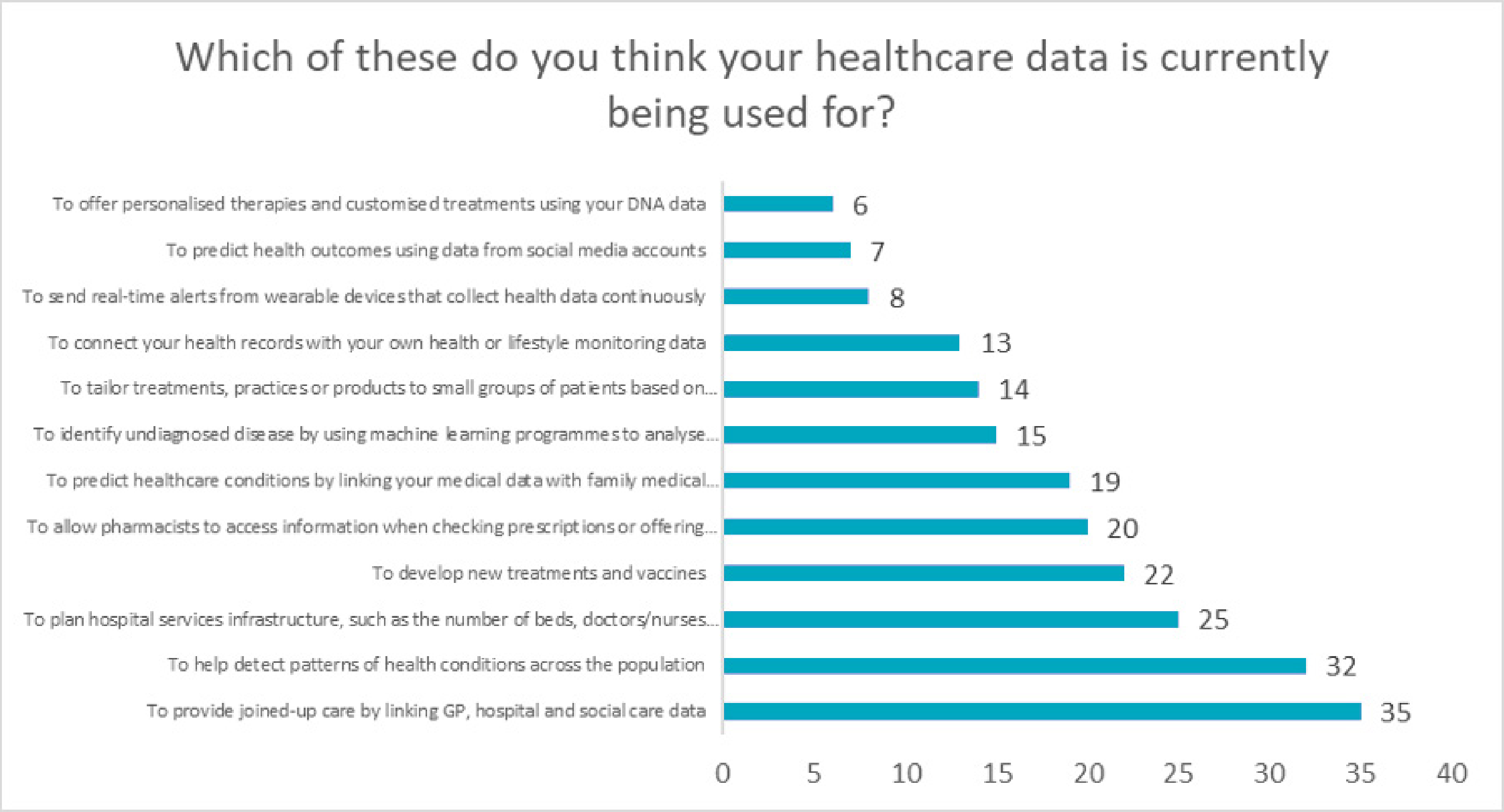
- Many of them are happy to share their data if it will help people with similar conditions or experiences.
- They are more willing to share their data if there is a clear benefit to society, and if they think the data will actually be acted on.
- They don't trust the intentions of private companies and are not very willing to share with them.
- It's nice to be appreciated when they share their data. Even a simple thank you helps them to feel they are doing good.

Appendix C: The Participant Experience

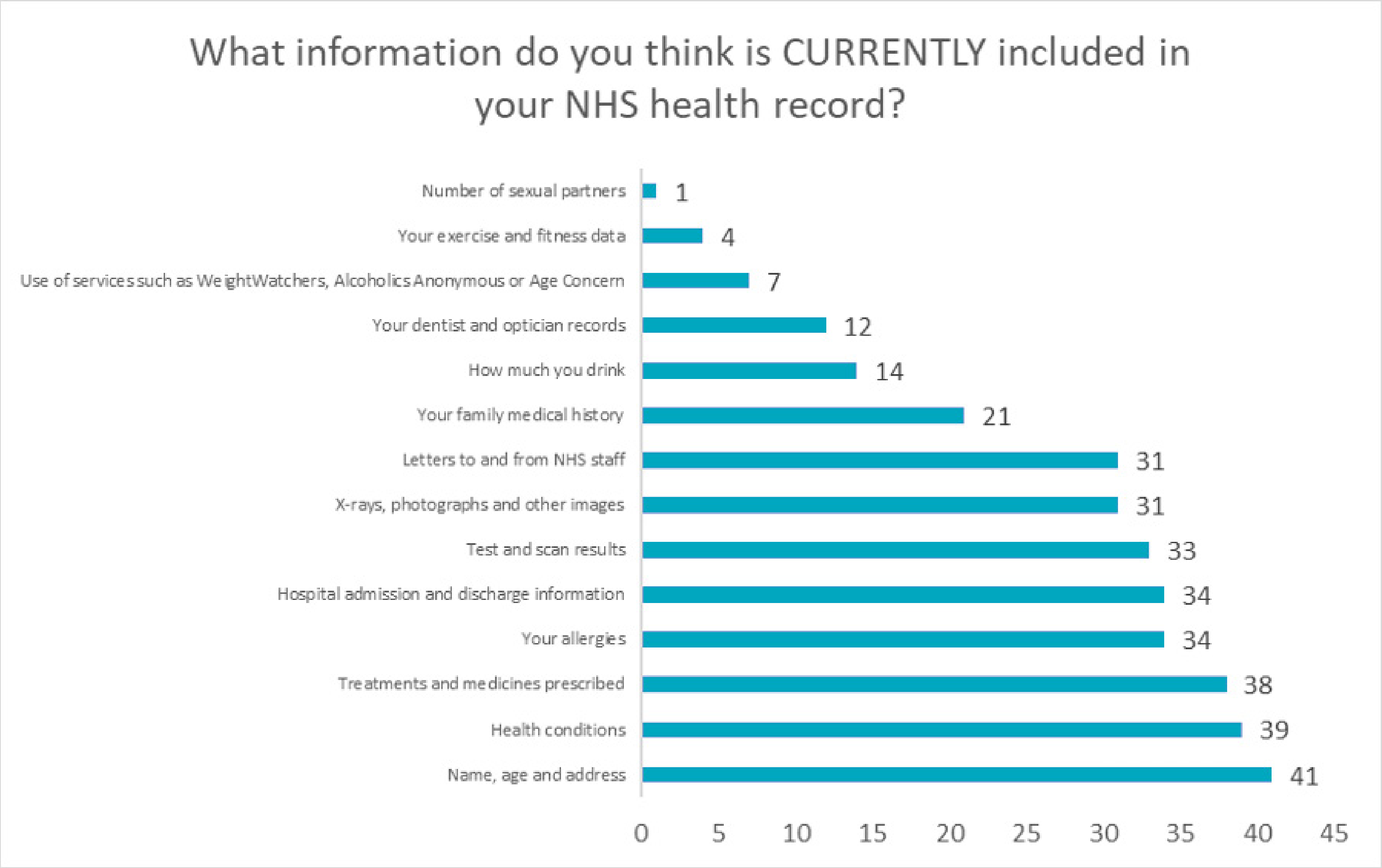
Personal exploration

Respondents were invited to take part in a quiz before attending the Data Dialogues session. The results of the quiz are shown below. The base for each question is all respondents to the quiz. Results are shown in numerical form. The sample sizes are too small for meaningful analysis by respondent characteristics.

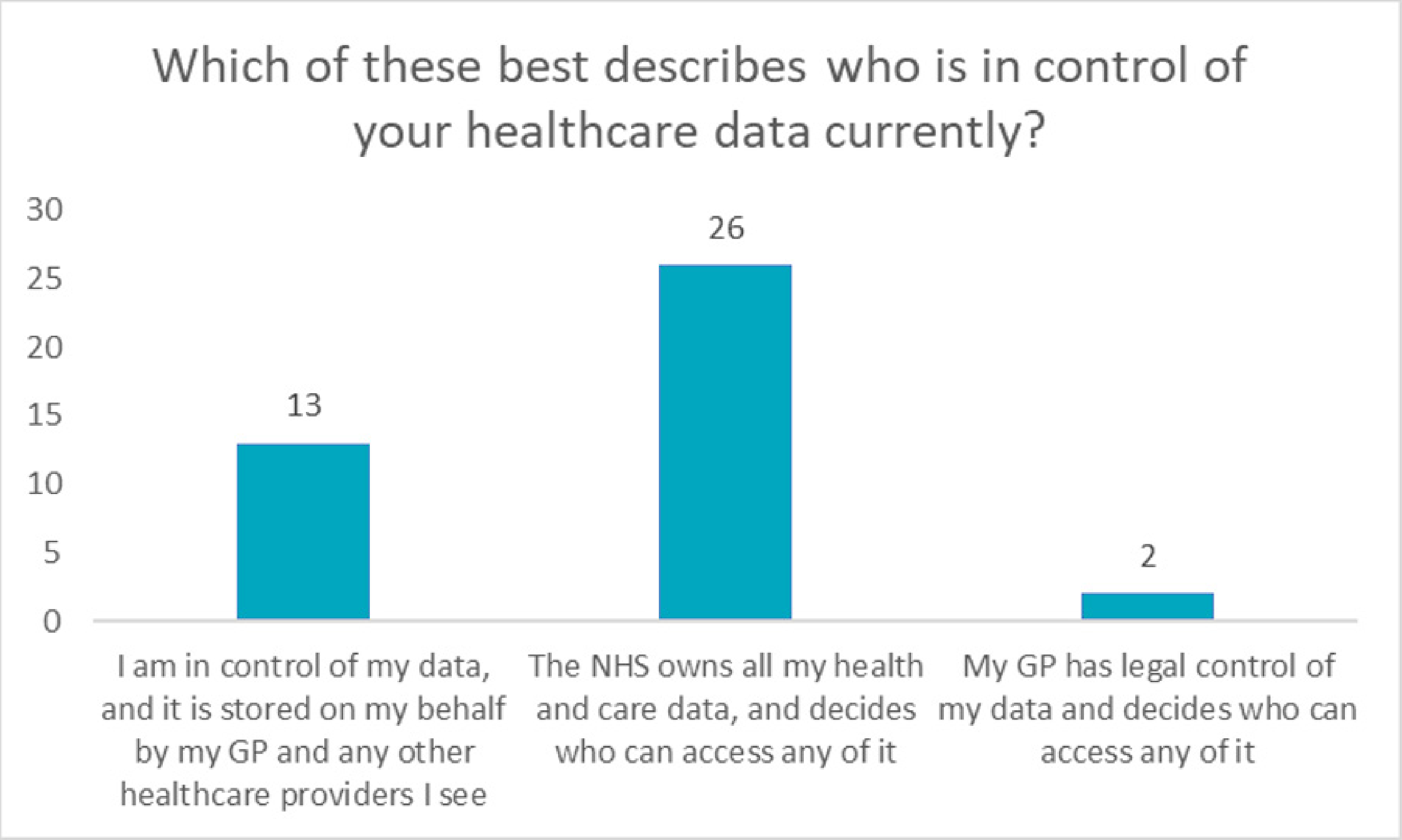
In summary these findings show that most respondents believed that health care data is currently being used by Health and Care Professionals to provide joined up care, to help detect patterns of health conditions, and to help plan hospital services and infrastructure.

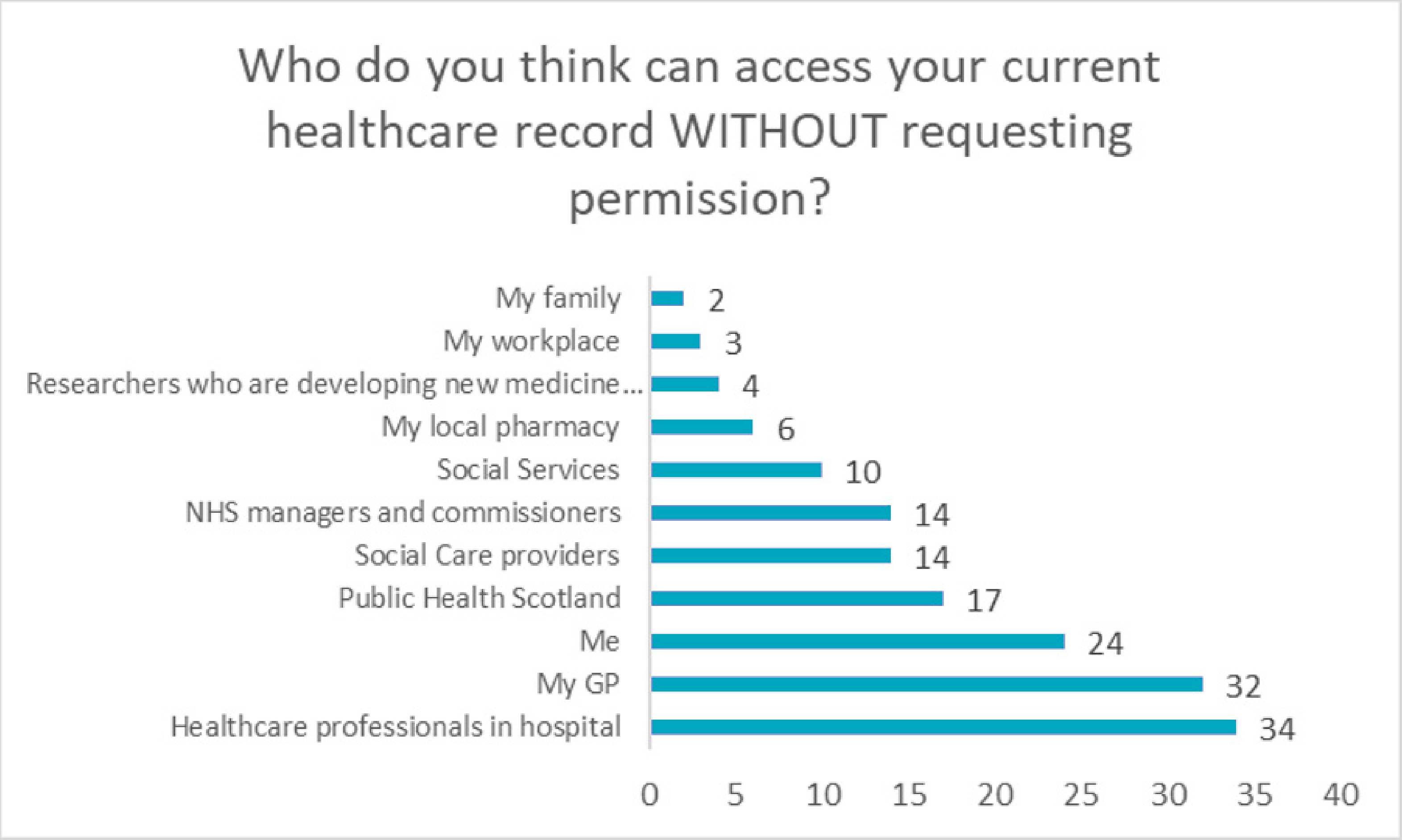


Quiz respondents believed that apart from name, age and address information, health care data revolves primarily around information related to your medical care e.g. health conditions, allergies, medicines, letters to Health and Care Professionals.etc.

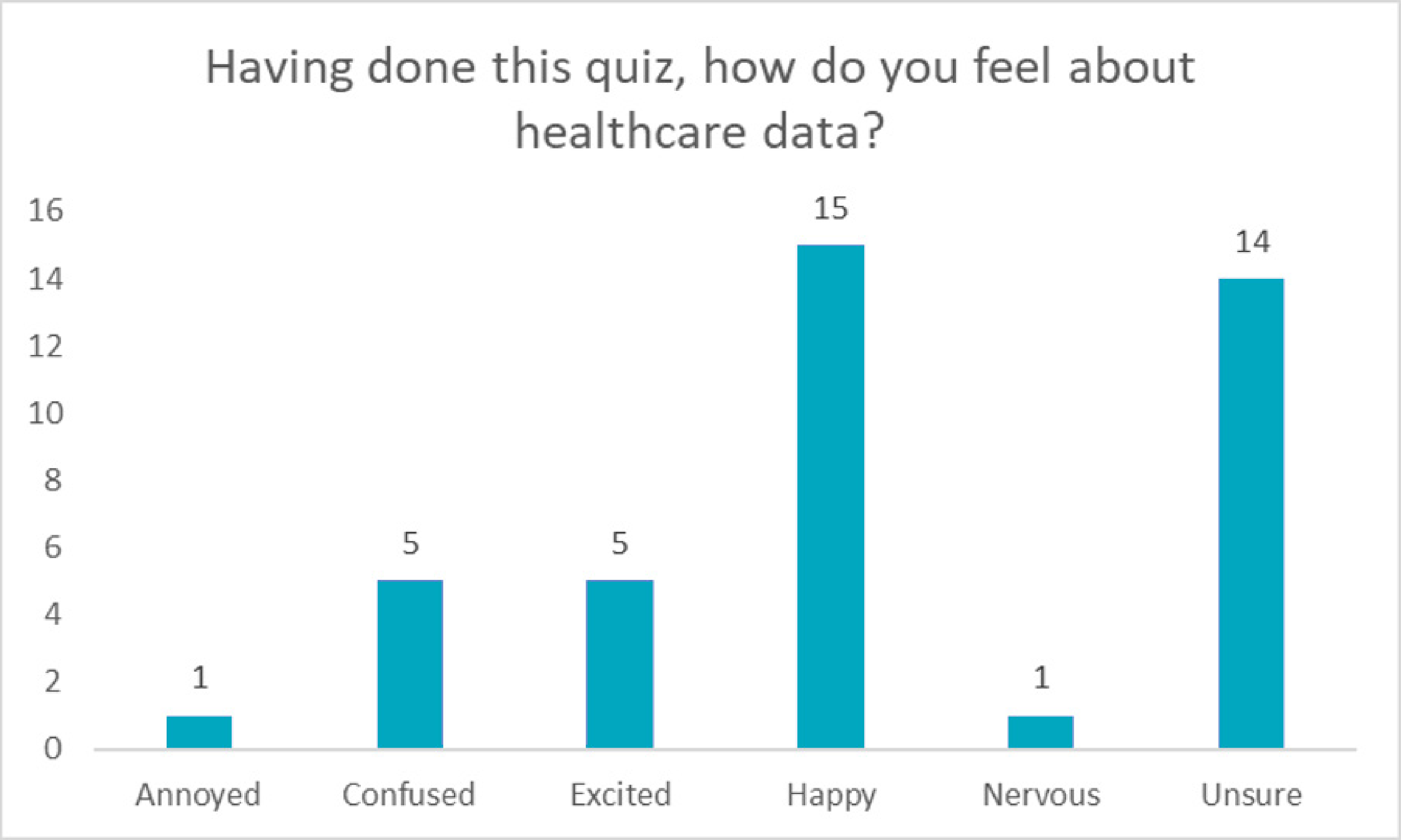


Most respondents thought that the NHS ‘owns’ all their health data and decides who can access it.


Which of these best describes who is in control of your healthcare data currently?
30
25
20
15
10
5
0
13
26
2
I am in control of my data, and it is stored on my behalf by my GP and any other healthcare providers I see
The NHS owns all my health and care data, and decides who can access any of it
My GP has legal control of my data and decides who can access any of it



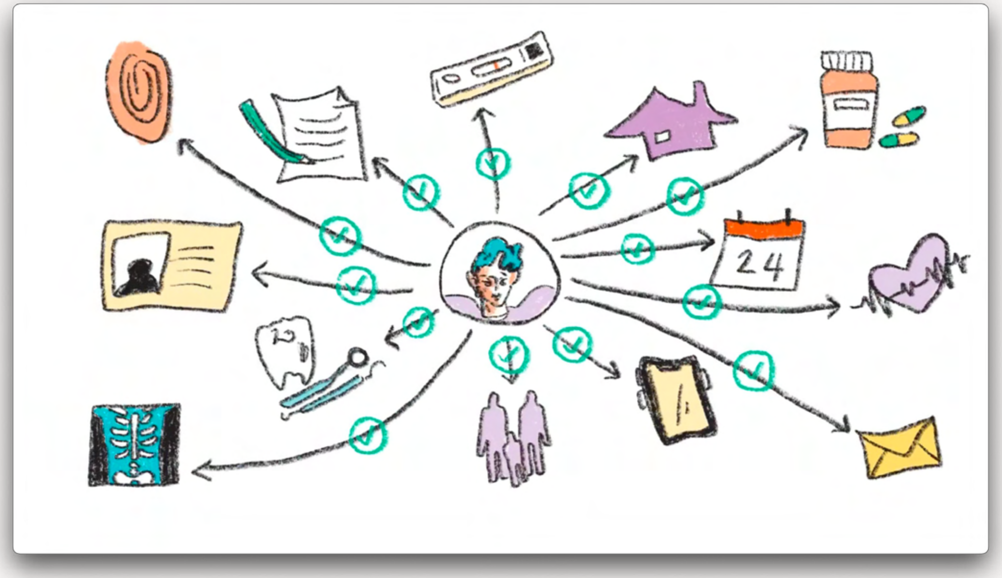
The majority quiz respondents thought that only Health and Care Professionals in hospital and GPs should be able to access health care records. Just over half thought that they should be able to access their own records without permission.



Most respondents were positive about health care data having done this quiz though a significant minority were unsure about how they felt about health care data.

Collaborative Engagement

The Data Dialogues sessions ran for 60 minutes and were divided into four sections:



1. Introductions

Participants and facilitators introduced themselves, facilitators set the context and overview for the workshop

2. Data Ownership and Control

Participants watched a 3 minute video about data ownership and control, followed by an open conversation prompted by questions by the facilitator.

Questions included:

- How comfortable do you feel about sharing your health and care data overall?
- Who are you comfortable about sharing your data with? Why is this? For what purposes would you be happy to share your data?

- What do you think are the benefits of being in control of your data vs getting someone else to manage and control it?
- Do you think the default setting is that people are in control and then they can opt out if it is too much for them? Or should the default be a managed process and then you choose if you want to be in control?
- How active or passive would you want to be in sharing your data?
- Would you want your consent to be asked every time your data was used?
- Who would you trust to be in overall charge of your health and care data?
- What checks and balances need to be put in place to ensure that data sharing is ethical?
- What does 'ethical data collection' look like to you? What do you think should be allowed and what not allowed?

3. Ethical Data Collection:

Facilitators opened their pharmacy box on screen and began conversations about the fictional products, with an open conversation prompted with questions.
Questions included:

- Thinking about these scenarios, where would you trust your data to be used in health and care?
- How personal should your healthcare get?
- When should your personal data be shared and used to keep you well?

- Would you track and share data in order to spot opportunities to improve your health?
- What might be some barriers or blockers for you sharing certain information?
- How widely should your data be shared within healthcare?
- How do you feel about local data being used to reduce health risks in your area?
- All of these items have been created by, linked to or optimised by different types of health and care data. When you think about 'ethical data collection and use' in the future what might this mean? What feels ok?
- How do you feel about private sector organisations sharing / using your data on behalf of the public sector?

4. Reflections

Participants were asked to comment or reflect on anything else that has come up from the session not already said. Prompts for this included:

- What do you think is most important with health and care data for people in the NHS Scotland to consider?
- What is your biggest concern about health and care data?
- What is your hope for the future of health and care data?

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