



Data Futures explored through a Fictional Pharmacy

Data Dialogues report, May 2021

The Liminal Space

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...and receive personalised care plans and product recommendations to keep your mental wellbeing optimised.



When should our personal data be shared and used to keep you well?



Introduction

Pharmacy Stamp	Age
	~~~~~
	D.o.B
	~~~~~

Please don't stamp over age box

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

- Endorsements
- Hearthelopril tablets
ONE to be taken TWICE
Quant: 30 tablets
 - Alzhitamine Tablets 500mg
ONE to be taken FOUR TIMES
Quant: 28 tablets
 - SleepWell tablets 250mg
ONE to be taken before bedtime
Quant: 20 tablets
 - Melanoma Prevention
Use daily as directed
 - Air Pollution Support
Use as needed



Background

This project was commissioned in 2019 as part of the Data Dialogues programme run by Nesta in partnership with the Scottish Government, that aimed to better understand the views, opinions and ideas of Scottish citizens around the use and sharing of health and social care data now and in the future.

As one of five funded concepts, we 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, enable discussion around benefits and trade-offs of data sharing, and hear their individual hopes, concerns and thoughts around possible futures.

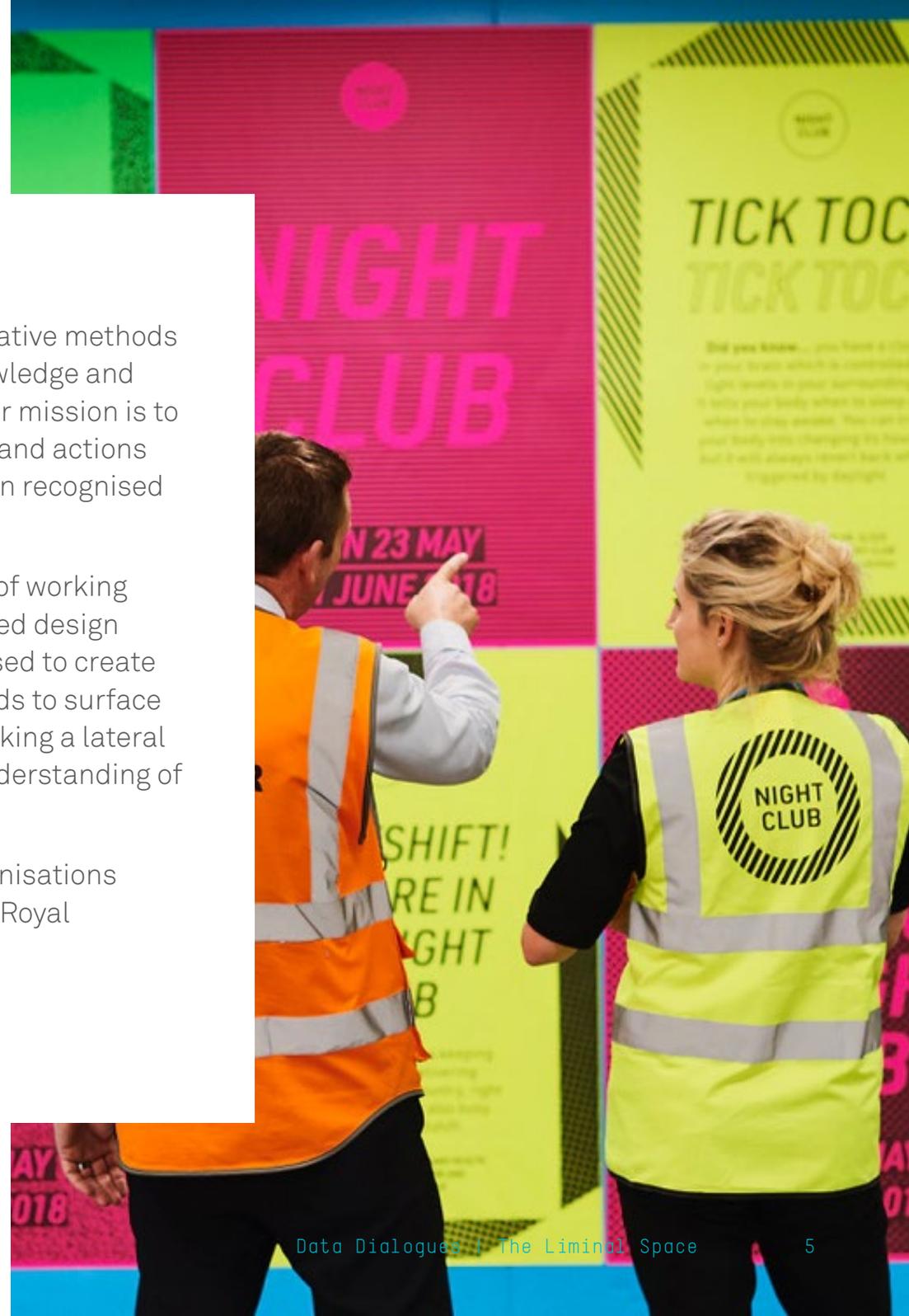


The Liminal Space

The Liminal Space uses people-centred design and novel creative methods to engage and empower people through deepening their knowledge and inspiring them to use this understanding to effect 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 which 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.



Method



This experience involved three parts: personal exploration, collaborative engagement, and self-reflection.

1. Personal exploration

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.

2. Collaborative engagement

Participants were then invited to a choreographed hour-long online session where in groups of 5–6 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. To support these exercises participants were sent a fictional pharmacy pack in the post that included a mixture of unique 2D and 3D elements.

3. Self-reflection

Once the session had finished participants were asked to individually call a specific number and record a short voicemail audio clip responding to one or two questions posed to them. (More detail on the experience process can be found in Appendix B).



METHOD

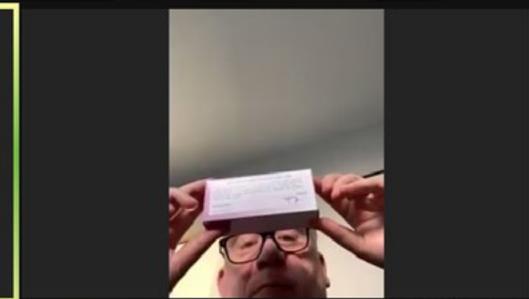
Participants were recruited through two different ways:

The first 50 participants were a representative sample of citizens across Scotland. We recruited at least 10 from each of the age brackets (18–29 / 30–49 / 50–65 / 65+) and from a wide geographic split (min. 5 from each of Glasgow / Edinburgh, Aberdeen, Lanarkshire, Fife and the Highlands & Islands).

For the second group we specifically recruited 10 people who each agreed to recruit 5 members of their family and / or friends. These 10 were also split geographically.

Recruitment was specifically targeted at well people – we screened out those with long-term conditions that necessitated considerable interaction with the healthcare system. Participants were each paid £50 for completing all three tasks.

In total 110 people were recruited, 106 people completed the quiz, 103 people joined an online session and 93 people left voicemail reflections. The Liminal Space team ran 21 online sessions over the week commencing 3rd May 2021, each of which had 5 or 6 participants.



group?

(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 medi
health tracker.

SCOTTISH HEALTH CONNECT

KEEP OUT OF REACH & TIGHT OF CHILDREN

Reflections on the process

Pharmacy Stamp: []
Title, Forename, Surname & Address: []

Please don't

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

with you whenever you go out to help us track
the problem areas and keep vulnerable people
in your community safe.

SCOTTISH HEALTH CONNECT

03-MAY-2021

Disp by: [Signature] Check by: [Signature]

The final method used in this engagement was some distance from the original proposal – pre-Covid our hope had been to run a public engagement exercise in a public space in Scotland.

The plan was to set up a fictional pharmacy intervention in a high footfall location that would have engaged passers-by in the issue of data sharing.

As a result of the pandemic we had to move online – key differences from our original method were that we spent a much longer time with participants who were recruited to reflect a cross-section of Scottish people who were not currently heavy users of health services. All of these participants were paid to take part in the three-stage process. In our original method we would have had all types of people engaging, including those who are heavy users, and none of these people would have been paid for their time – the original aim was to have set up a reciprocal intervention that would have made them feel they had been given something in return for taking part (in terms of knowledge, interesting time and so on).

The online method brought a number of benefits including delivering much more detailed insight than would have been possible from the information collected during the shorter time we would have spent with people in high footfall areas.

It also allowed us to take the participants on a journey – from most knowing very little about the issue of data sharing and not having thought about the impacts for people like them, through the quiz, online session and reflection process – until by the end they had all had an opportunity to think deeply about the issue and share their views.

Looking at the difference in responses collected in the quiz at the start and the telephone voicemail reflections at the end, indicates that as a result of taking part in the whole process participants had an increased vocabulary and knowledge of the issues around data sharing, and an increase in positivity about data sharing. For example:

- In the quiz at the start, one in five say they feel negative about health care data, a third are unsure and about half are positive (See Appendix A for all of the quiz results)
- In the reflections at the end, none of the participants say they would not be prepared to share their data at all – they are open to sharing with a range of controls and caveats (See Appendix C for a summary of the reflections)

REFLECTIONS ON THE PROCESS

Further, the participants were positive about the process – there was no negative feedback in the reflections, and in the workshops themselves the vast majority of participants appeared engaged and gave thoughtful and considered feedback.

Potential negatives to the final method include the exclusion of those who are heavy users of health services - this needs to be taken into account when looking at these findings. Unknowns arising from this exclusion include whether or not heavy users come from a different starting point to lighter health care users – would data and data sharing have more salience in their lives? Also would heavy users have different views about the use of their data based on their greater knowledge of existing systems? Further research is needed to answer these questions.

Another potential negative is the fact that participants were paid to take part in this engagement exercise – ethically we felt that it was right to pay participants as we were asking them to complete a number of tasks over an extended period of time. This entailed a much longer time commitment than we would (or could) have asked for from passers-by engaging in the physical intervention, and therefore it was appropriate to pay a sum that corresponds to the value of their input. The unknown in this case is whether or not this skewed responses – did participants feel they had to answer in a specific way because they were being paid?

Contrarily, did they not engage at all because they were just there to get the money? The experience of the sessions and the positive reactions from participants to the process leads us to believe that the process itself (which was creative and innovative) minimised these outcomes but with no comparable data this remains uncertain.

Overall, we believe this method resulted in participants sharing their true feelings about data and data sharing. The method itself engendered thoughtful reflections from a broad spectrum of people, about an issue that the vast majority of respondents had not thought deeply about before taking part.

.....
“Before doing this workshop, I would have said no or felt uncomfortable about these uses [presented by the loyalty card] of my data. Now I know a bit more about it, I can see the benefit, I feel a bit more confident, and so yeah, I would give my permission. How would my friends and family want to know more? Any advertising would help, like on TV and in the doctors”
.....

thelopril

fe A.R.K

50mg

Key findings

Melanoma Cream

How p
want to be in tracking and
seeing your health data?

DICAL

25ml

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.

SCOTTISH HEALTH CONNECT

03-MAY-2021

Disp by: Check by:

Advanced Eye Drops

LONG LASTING RELIEF
FOR DRY EYES

10ml

Data Dialogues | The Liminal Space

Protect - Hydrate - Lubricate
Preservative Free

Would you share your
data to help you avoid
trip to the GP surgeon?

From interrogating our findings from across the quiz, the workshops and the final reflections, we have highlighted key insights and recommendations that will enable the Scottish Government to build upon some of the conversations and learnings surfaced.

We present the insights under three headings as follows:

1. Typologies & Personas
2. The Trust Spectrum
3. What is data?

Before we detail these insights, there is an important overarching insight that came out from the whole process, namely that data and data sharing is not a current issue of concern among this group of participants.

In other words:

This is not something that the vast majority of participants had thought about prior to this process.

They had not talked about this with their relations / friends, and they did not appear to have been guided in their thinking by opinion formers or influencers – participants felt able to express their own views and feelings when presented with the materials, based for the most part on their overall world view and their tech ‘knowledge’.

Participants understood views on data and data sharing to be a personal issue – it is up to an individual to decide whether or not to participate / share.

As a result it is not currently a divisive issue – participants were not antagonised if another presented a different point of view.

This current lack of salience is important – as a result of this, the Scottish Government has the opportunity to shape the conversation about data and data sharing for the majority of people in Scotland for the greater good. We believe that the Scottish Government needs to take this opportunity now, without delay, before other voices come in and potentially negative views take hold.

.....
“I watched my mother have lots and lots of different medications and the majority of them she had reactions and side effects to, and if data could have been used then that would have saved a lot of time”
.....

.....
“I use a Samsung watch. I don’t always track my sleep on it to be honest, I often take it off, but even for your activity levels and your heart rate I think it’s a good thing. Again it’s down to choice whether you want to share that information and whether you think it would be of any help. I think the more information that you can get the better, so if that means having that information stored somewhere that your GP’s maybe got access to then I think it’s a good idea, I’d be happy with that.”
.....

.....
“Medical research, I’ve done that for the cold. We were given three boxes to try, we didn’t know what it was we were getting, some people were getting dummy boxes, some people were getting the actual drug, and we went into Glasgow to the clinic and were tested every six weeks, I think it was. And I was pretty happy to do that because I thought we’ve never got on top of the cold and we’ve had it for years and years. I was quite happy to get involved in that. And I think it’s a good thing”
.....

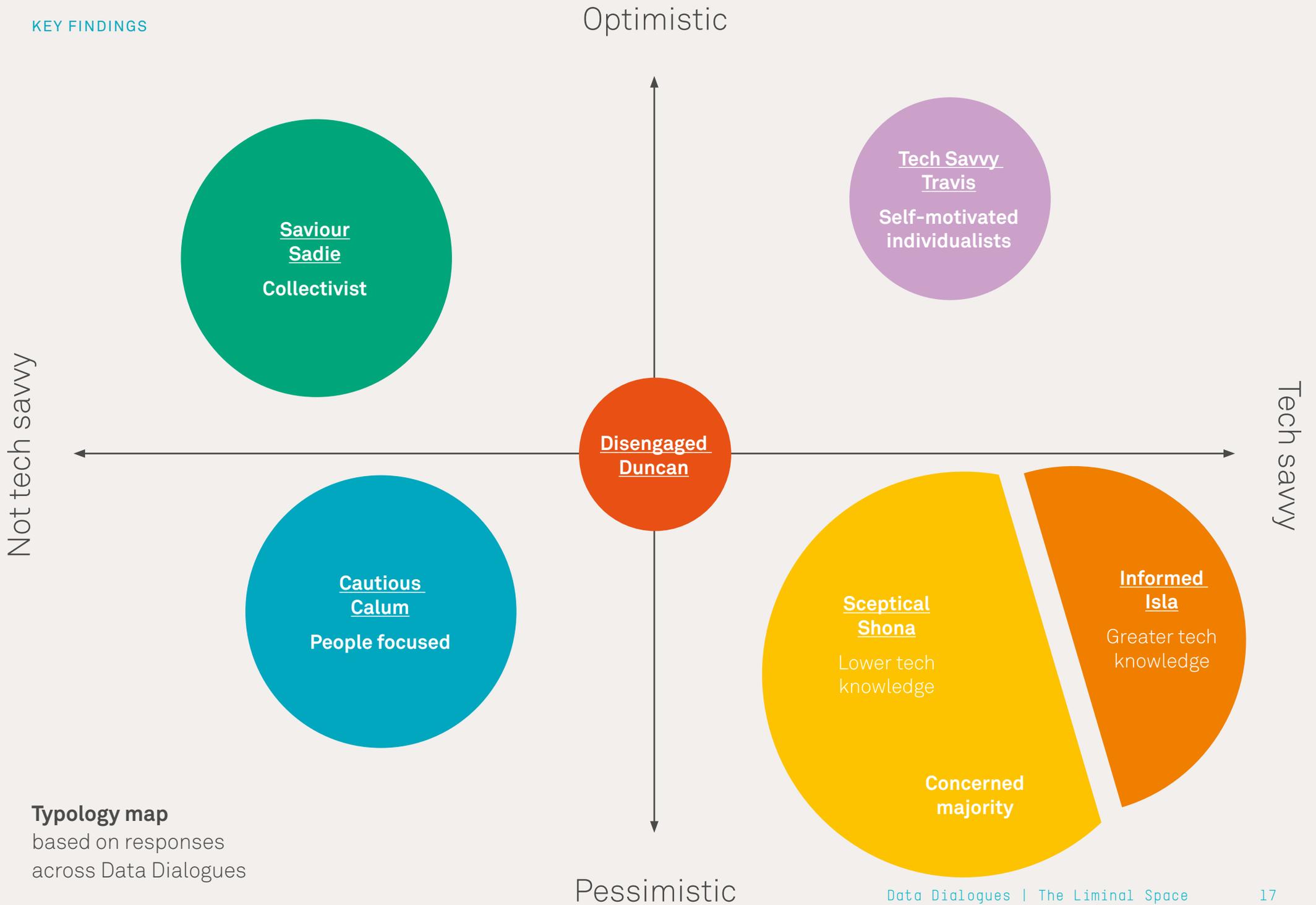
WHAT WE HEARD IN THE ONLINE SESSIONS:

Typologies & Personas

Our analysis has resulted in five distinct typologies (and one sub-typology) that can be mapped onto the following matrix based on how tech-savvy participants are (how much they know about tech, data, AI and so on) and also their overall world view (how optimistic or pessimistic they are about the future).

The personas are composites based on the responses across the sample and do not describe any individual participant.





Typology map
based on responses
across Data Dialogues

1. Concerned Majority typology

The largest group among our participants – this group can be sub-divided into two personas (Sceptical Shona and Informed Isla) with the primary difference being their level of tech knowledge. There were fewer Informed Islas than Sceptical Shonas across our sample. Overall this group were willing to share but only if the right checks and balances are in place.

.....
"Hello Mr Hacker come and take my data"
.....

Sceptical Shona persona

In her 20s, tech savvy,
with no health problems
currently

- Overall data and data sharing is not on her radar as she cannot see the personal benefits.
- However she can see benefits for others – e.g. her Gran might benefit from the care at home package, she thinks it could be good for people who have health care problems currently.
- She is wary of tracking, monitoring data in particular as she doesn't want to be a victim of lifestyle marketing for her health – she already ends up buying loads of stuff on Amazon that she doesn't feel she actually needs because of lifestyle targeting, and she doesn't want to have another area in her life where she can be marketed at – she feels like she knows what she needs to do for her health and doesn't need to be told.
- She also feels that her data on things like weight and sexual health is too personal to share.
- She is worried about the waste caused by excessive targeting of healthcare products and services – e.g. products given to those who don't actually need them, or raising fears unnecessarily among well people.
- She is also worried about potential security issues and scams.
- She is OK for her health data to be shared anonymously to find cures, innovation and research as long as she can opt in and has control.
- But she doesn't want to get involved in trials or anything that might be a hassle.

.....
"I know I'm overweight,
I don't need an app
to tell me"
.....

Informed Isla persona

In her 50s – very tech savvy / understands data

.....
“I would take part but only with my consent - if I found that I had been included in something I hadn't agreed to, there would be hell to pay”
.....

- She can see benefits of data and data sharing but is very cautious – she would want to see more details before she gives informed consent for her data to be shared.
- She can see the long-term benefits for the NHS in terms of efficiency and providing better care.
- She also understands that there is a need for big data in pharma to develop new drugs and so she is not anti per se.
- However she doesn't believe that systems are in place yet for all of the benefits of data sharing to be realised in a safe and robust way.
- She also believes that AI and tech is not as advanced as some people think.
- She worries that investment in these new systems might be at the expense of traditional health care – would the NHS have the back-up delivery in place to support these services –e.g. if there were mental health monitoring, would there be therapists etc. available to support those when they need it. Also she is concerned that the increased weight on preventative care could increase pressures on the NHS as there would be increased contact from well people.
- She is also worried about potential safeguarding issues.
- Overall she thinks there is a need for strict guidelines and checks and balances to ensure the data systems work for everyone.

2.

People Focused typology

The second largest group among our participants are described in the Cautious Callum persona. They do not understand the benefits of data and data sharing and think that investment in this will lead to a reduction in HCPs providing health care. They do not trust data or AI and would always prefer a real person to provide their diagnosis.

.....
“Why should that company benefit from my data and not another?
What have they done to deserve it?”
.....

Cautious Callum persona

Older, has a traditional mind set, is not tech savvy

- He is very anti corporates making money out of health care.
- He is concerned that a move to using more data will mean reduction in HCPs across the NHS.
- He would rather have his GP prescribe him drugs and diagnose what’s wrong with him and not some faceless robot!
- He doesn’t understand difference between lifestyle and medical data – and is not sure about benefits of AI.
- He is very wary of the nanny state telling people what to do.
- And he doesn’t want to be spied on by Big Brother.

.....
“I don’t want my mother being looked after by a robot instead of a carer”
.....

3.

Collectivist typology

Our third typology is described in the Saviour Sadie persona. Of similar size in terms of numbers in our sample as the People Focused typology, the Collectivist typology want to feel that they are supporting future innovation for the greater good in Scotland. Their world view is optimistic and they regard data, data sharing and AI as both inevitable and also a good thing as it will improve systems and healthcare for all.



“I don't mind the pharmacist seeing my data, but not the Saturday girl ...I know her family... Boots would be OK”



Saviour Sadie persona

In her 60s and has a tendency to look at the world through rose-tinted spectacles

- She is happy to share her data as long as it is for the greater good – though she does not have much understanding of data and data sharing or AI.
- She relates all of her thoughts on this issue to her personal experience, for example:
 - Her mother suffers from memory loss and so she can see benefits of an early warning of Alzheimers.
 - She knows lots of people personally with high blood pressure or who have suffered from strokes and heart problems and so she wants to do the right thing and help reduce levels in Scotland as a whole.
 - Her sister works in the NHS and is aware of difficulties in finding free beds and funding and so she thinks whatever she can do to help is a great idea.
- Her only caution is around wasting money – e.g. setting up auto renewal for prescriptions and people end up with more drugs than they need/want – when her aunt died they had to throw away huge amounts of unused drugs.
- And she is slightly nervous about sharing with her local pharmacy...

4.

Self-motivated individualist typology

Our fourth persona is described in the Tech-savvy Tavis persona – smaller than the three preceding personas, this typology are more relaxed about sharing their data (as long as they have some control) but unlike the collectivists are mainly focussed on the personal benefits as opposed to the greater good.

Tech-savvy Tavis persona

In his early 30s. A keen tri-athlete, he uses tracking devices to monitor his performance and to get kudos

- He can see real personal benefits of being able to link his performance tracking data with his health data.
- He is very keen to shape the future of data and data sharing for his own personal benefit.
- He wants to ensure he has full control.
- He is fine about sharing his data with the relevant corporates for his own benefit – as long as he gets to choose which ones.
- And he is happy to share his health data anonymously for the wider good – quite relaxed about permissions if anonymous.

.....
"Anything that can help me improve my performance is good"
.....

5.

The disengaged typology

The final typology is the smallest group among our participants – like Sceptical Shona, Disengaged Duncan does not see the relevance of data and data sharing to his life, but unlike Shona – he is not concerned about the issue.

The individuals in this typology show little interest in exploring the nuances of this topic.

Disengaged Duncan persona

Duncan has no health issues and just doesn't see the relevance of all this to his life.

- He is not really interested and appears to lack the empathy to be concerned about the issues on behalf of others.
- He is open to everything suggested but without questioning/ fatalistic.
- It doesn't feel like real buy-in at this point.

.....

"It wouldnae bother me"

.....

"It's the future, there is nothing we can do about it"

.....

The Trust Spectrum

Levels of trust varied across our sample – from those who trusted all of their data to be shared with all organisations, to those who only trusted their data to be held by their GP and shared in a limited way with health care professionals (HCPs).



There was a general lack of understanding about the structure of the NHS and who had control of their data currently.

The NHS was most commonly perceived as a single entity where data was held centrally and accessed by all HCPs to help with diagnosis and treatment of an individual – it was not generally understood that their data was held by individual GP surgeries.

There was a significant degree of trust in the NHS as a whole, and particularly in GPs who were seen as the access point / gate keeper to health care for all participants.

Other HCPs across the NHS were also trusted, though a few participants were nervous about trusting the NHS system with their data – they perceived the NHS as a whole as too complex, too big, with high potential for data errors, or high potential for data loss / security issues.

.....
'I trust the NHS as they have a lot of my data already, if my data was to go to any other companies, I would lose trust significantly'
.....

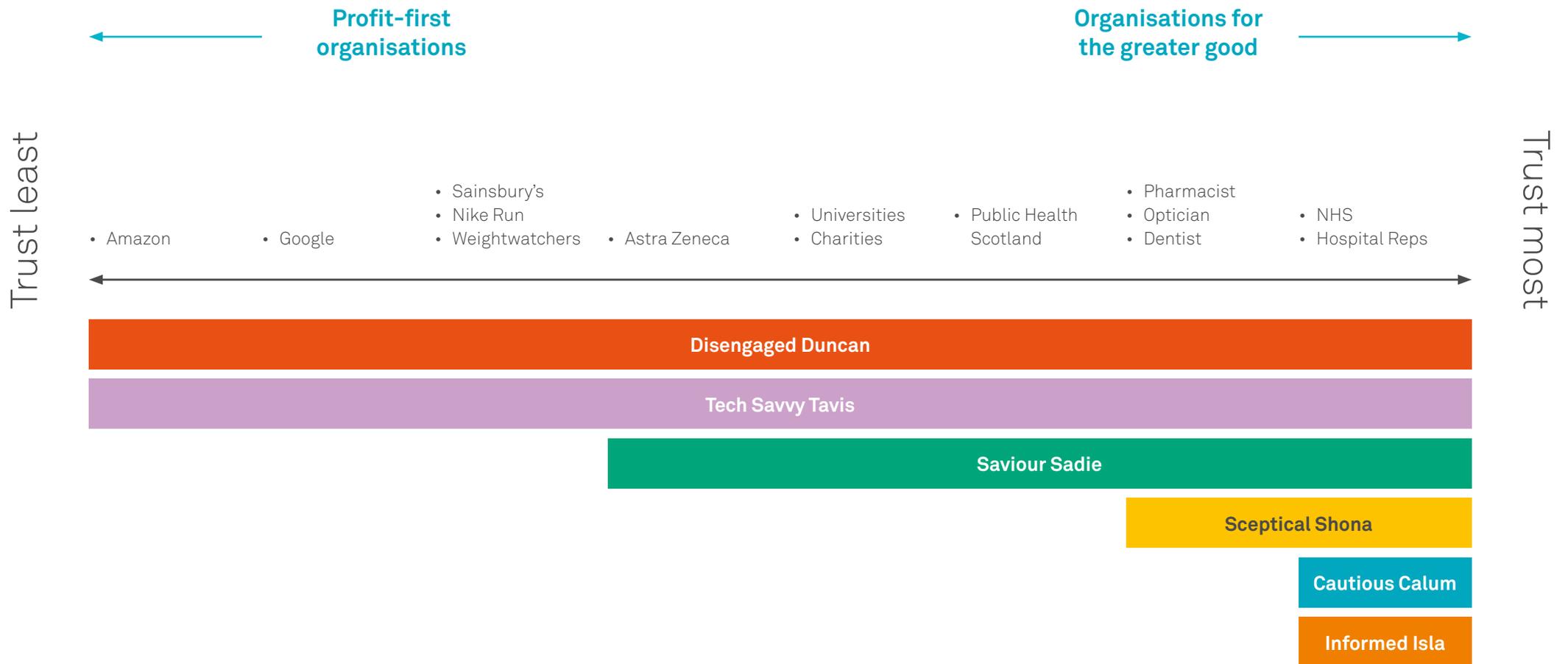
At the other end of the trust spectrum were profit making corporates, and in particular Amazon, which was the least trusted organisation across the whole sample.

The majority perception was that Amazon would only want health data to make more money for themselves, and sharing health data with them would result in unnecessary lifestyle marketing/ targeting of health care products and services.

.....
'These companies only want to make money from us'
.....

KEY FINDINGS

The diagram shows the trust spectrum across the whole sample, and the likely extent of the trust spectrum for each of the six personas.



Disengaged Duncan

Duncan says he is happy to share his data with all organisations indicating potentially high levels of trust but this does not feel like a considered response. Could he flip and say the opposite in a different situation? His trust is not to be counted on.

Tech-savvy Tavis

Tavis is happy to share his data with any organisation that will give him personal benefit for sharing – he trusts the organisations he already deals with to look after his data and handle it responsibly. He believes that regulations like GDPR and bank rules and so on, will stop his data being abused. He is not nervous about scams and data breaches – if he thinks about them at all, he thinks the personal benefits outweigh the potential disadvantages.

Saviour Sadie

Sadie is very trusting with her data and will widely share it as long as there is a public benefit in sharing. She is happy to share her data with an organisation like AstraZeneca as she sees that this will result in new innovations like the Covid vaccine. She is happy to share her data with universities and charities for research purposes too. She is less trusting of profit making corporates like Weightwatchers, Google and Amazon – who she sees as only wanting the data for corporate gain.

Sceptical Shona

Shona uses apps including banking apps and shops online widely – her data is widely shared and she is conscious of scams and data breaches and worries about them. Because of this fear, she is nervous about sharing her health data beyond the NHS except to other health care providers like opticians and pharmacists where it is relevant to her own health management.

Cautious Callum

Callum does not trust anyone with his health data beyond his GP and specific HCPs when it is relevant to his care. He does not understand the broader benefits of sharing health data and does not trust anyone outside these few individuals to look after his data. He is vehemently anti sharing his data with profit making corporates.

Informed Isla

Isla is aware of the benefits of sharing health data but very wary about the potential for data breaches and scams. She always reads the small print and takes considered decisions about whether or not to sign up to programmes – she is nervous about large system failures and thinks the NHS is some way off being in a position to promise data security. She doesn't really trust anyone!

What is Data?

Through our experience the participants covered a range of aspects of health care data – from data about an individual’s itchy eyes to impersonal data monitoring pollution levels; and from simple predictions based on a single characteristic such as age, to complex diagnostic information based on big data using AI.



KEY FINDINGS

The table below shows the different categories of data discussed in the sessions.

Relatable

Circumstantial data

e.g. address

Personal data

e.g. weight

Diagnostic information

e.g. test results

Genetic data

e.g. inherited diseases

Lifestyle / monitoring data

e.g. from wearables

System data

e.g. number of visits to GP

Anonymous data set

e.g. number of people with diabetes in Scotland

Impersonal

Big data

Predictive tools

Data targeting

Use of AI

Reactions to these different types of data varied considerably across our sample but overall there was a clear distinction between reactions to simple and complex data usage.

Put simply, most people were happy to think and talk about the traditional data that in the past would have been stored on paper in the filing cabinets of their GP, and is now stored in databases. They could easily understand that it might benefit their own individual health care if their personal data, their circumstantial data, their own diagnostic information, their genetic information, and even in some cases lifestyle monitoring data – could be shared more widely across the individual HCPs providing their health care – in fact many assumed that there was already a single joined up database that all HCPs across the NHS could access as applicable, to provide the best health care possible to patients.

The majority also understood that the joining together of all of this data at an anonymous level could help academics and researchers in pharmaceutical companies for example, come up with new medicines and so on.

They understood too that sharing of system data would support managers in the NHS to drive efficiencies and better health care plans.

The tipping point, where the vast majority of participants revealed a lack of any real understanding was when talking about the uses of big data such as predictive tools, data targeting and AI. It felt as though once the method became less easily relatable and more impersonal, participants were generally more nervous, and in some cases more critical, about the uses.

Typical words used to describe these methods include – nanny state, creepy, spying, robots, Big Brother.

.....
'It feels like Big Brother
is watching you'
.....

Again we have captured this range of views using our personas, and in many cases this raises unknowns.

Disengaged Duncan

Duncan says he is unconcerned about the use of his data but does not appear to appreciate the nuance of different data types. Will he change his views if he gains a deeper understanding?

Tech-savvy Tavis

Tavis is aware that AI and big data is in the background behind all the apps he uses – he is not concerned as long as he enjoys the personal benefits.

Saviour Sadie

Sadie relates to everything in personal terms – she has no understanding of AI and big data currently – if she did, would this change her attitudes to data sharing – would she become more cautious?

Sceptical Shona

Shona is aware of AI and big data but is relatively uninformed despite her high use of tech in her day-to-day life. The unrelatability of these methods makes her nervous and less positive about the benefits.

Cautious Callum

Callum believes that the GP is central to all of his healthcare and wants nothing to do with any impersonal, unrelatable tech solutions. At the moment he is blinkered to the potential benefits. Is it possible to take Callum on a journey to understanding or are his views too entrenched?

Informed Isla

Isla is the most familiar with the potential for big data and new technology to revolutionise health care. Her issue is not to do with the technology per se (though she does feel it is still some years away from reaching its potential), but with the system, including policy makers, managers and procurement teams, who have previous history in buying the wrong, expensive solutions.

ANECDOTES FROM THE ONLINE SESSIONS:

.....

“As a middle aged bloke, I used to buy my Aunt her Tena Lady, and would use my nectar card. Then I started getting all of these vouchers for feminine products - that’s an example of where data gets it wrong, so I don’t think we should connect this stuff up”

.....

“I can see why other people find Sainsbury’s using your data worrying. But for me, as a diabetic who struggles to monitor my sugar levels, if I could get some recommendations about where I’m going wrong in what I’m eating, and have them say “hey next time try this” then I think that would be great”

.....

“I had a situation a few months ago where I went to get my eyes tested and they said I had dry eye so I should use some drops and I had to go and see my doctor. So they said they would send the result to my doctor. Well I waited a couple of days, made an appointment and got a telephone consultation, and he said we don’t know what the test was so we don’t know what it is we’ve got to give you, we haven’t received any information from them. Well I thought the two of them were gonna tie up and I was gonna go and pick up a prescription. Why couldn’t you do that? So I had to go back to the guys I got my eyes tested from and ask them what I was supposed to do from there.”

ANECDOTES CONT.

.....

“I think on a diagnosed condition it could be quite good. Like, for example, the Sainsbury’s one, my mom was on dialysis and things like that. And I think if she could have access to an app that would recommend foods for her condition and things like that so she can take responsibility for herself, I think that would be a good thing. And then she could opt in or out of sharing that information with the doctor.

I think these things that are a wealth of knowledge in their own right, it would be your choice, at points of diagnosis or after you’ve been diagnosed, to share that information with your doctor so you can monitor how your health is being maintained with the with the illness as a care package. But I think it should be optional so that you can take extra responsibility for yourself.”

.....

...and receive personalised care plans and product recommendations to keep your mental wellbeing optimised.

When should our personal data be shared and used to keep you well?

Conclusions & recommendations

Pharmacy Stamp

Age



D.o.B



Please don't stamp over age box

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

Endorsements

Hearthelopril tablets
ONE to be taken TWICE
Quant: 30 tablets

Alzhitamine Tablets 500mg
ONE to be taken FOUR TIMES
Quant: 28 tablets

SleepWell tablets 250mg
ONE to be taken before bedtime
Quant: 20 tablets

Melanoma Prevention
Use daily as directed

Air Pollution Support
Use as needed

SleepWell

S
S H C
C

The process we have undertaken has provided insights into how our participants feel about data and data sharing. We have taken them on a journey from the majority knowing little and caring less, to a position where they can provide more nuanced, considered responses to the issues involved.

That said, this is a very complex issue and we were only able to skim the surface in the time available.

Our analysis has shown the wide range of views held about data and data sharing – we have described this breadth in the key finding section above.

Despite this breadth, there are a number of key themes coming out of the analysis including:

Positive views of data and data sharing – the vast majority of participants felt that it was appropriate to use data for the following reasons:

Using anonymous big data sets for research to understand disease and find cures for illnesses

Saving time and money for the NHS

As long as this doesn't mean replacing people with robots!

Ensuring that an individual's healthcare is joined up and holistic

Negative views of data and data sharing – the majority of participants felt that it was not appropriate to use or share data for the following reasons:

Use of AI to predict disease and help with prevention

This area was believed to lead to waste (over-prescription of medicines), would raise fears in the worried well, and increase the burden on the NHS as more people need health care services.

Personalised support

The majority did not understand how data and tech solutions would allow this to happen – in fact they felt that literally the opposite would occur as HCPs are replaced by robots.

Self-maintenance and management

The majority felt that this was encroaching on their personal freedom – Big Brother!

Sharing data with profit making corporates

Unless there are very good reasons e.g. strong personal benefits (Nike Run personal training plan) or for the greater good (AstraZeneca Covid vaccine development). There is little understanding that innovation and development of new medicines needs multiple partners including corporate partners.

Other generalised themes included:

A desire for convenience, hassle free solutions

All participants who had experience of repeat prescriptions or a long-term illness were keen to see simple processes to ease the hassle of accessing health care. Note that the majority still wanted to have direct, face to face access to HCPs even once these processes were in place. Most of those who were happy to share their data for research purposes wanted it done on an anonymous basis and did not want to be asked to take part in trials or anything else that might take up their time.

Data control

At the same time, the vast majority of participants when prompted said that they wanted to take active control of their data and provide consent/ opt in to data sharing, on a case-by-case basis.

Access to their own data

The majority of participants also liked the idea of having access to their own individual data as and when they wanted and being in control of it. The fictional idea of a loyalty card that held their data (and which could be used to give different organisations access) was positively regarded by many, though there were issues around the potential for scams and data breaches.

Positive views about the NHS

There were very positive views about the NHS across the sample – it is highly trusted and seen to act in the best interests of Scottish people. There appeared to be a widespread lack of understanding about how the NHS is actually structured – the vast majority of participants thought of it as one joined-up organisation, as opposed to the reality which is much more fragmented. GPs were seen as the access point to the NHS – and were the most trusted of all – but there was little understanding about their role in data and data sharing.

Based on all of the analysis, we recommend the following actions for the Scottish Government to take forward:

Take action now

The Scottish Government has the opportunity to shape the conversation about data and data sharing for the majority of people in Scotland for the greater good.

Provide education about the benefits of data sharing including across multiple partners (private, public and third sector)

Assume talking to the lowest common denominator, make the explanation relatable and set realistic time-lines.

Provide education about controls and regulations

At the same time as explaining the benefits make sure people understand what checks and balances are being put in place to ensure that people feel secure about their data

Show appreciation when people share

Ensure people feel valued when they do share data – don't take their sharing for granted. For example, consent processes should be simple and transparent, people's time has a value and use of it should be rewarded – this not need to be financial, it could be a reward in terms of feeling that you have helped society, learning something new and so on.

Don't take trust in the NHS for granted

Trust in the NHS runs deep. It is seen as something that both benefits individuals but is also for the greater good in Scotland. This trust is fundamental to the future of data usage in Scottish health care – it is the bedrock on which future data sharing and AI usage rests. The Scottish Government need to understand how they can maintain this level of trust in a less relatable world.



Arnoproxacin
100mg capsules

28 CAPSULES

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Prescription Only

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ADVANCED MEDICAL
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Dermatologically
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Appendix



Appendix A: Quiz Results

All participants were invited to take part in a quiz prior to the workshop session. The quiz was designed to find out how much participants know about data and data sharing, and also to provide information about key issues.

The final sample was 106.

The full wording of the questions and answers to the quiz are shown in the following pages plus the results and a summary of the findings to each question.

Overall summary of findings from quiz

- The responses showed that there was no definitive view of what people understand by the term health and care data.
- There was a widespread lack of knowledge around what is currently included in a healthcare record.
- There was a widespread lack of knowledge around who is in control of health data and who can access it without permission.
- The vast majority (87%) mistakenly think their health and care data is already used to provide 'joined up care by linking GP, hospital and social care data'.
- One in five respondents say they feel negative about health care data – around half feel positive and a third are unsure.

Q.

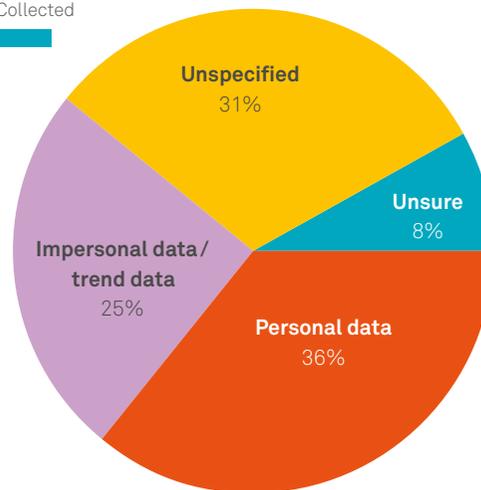
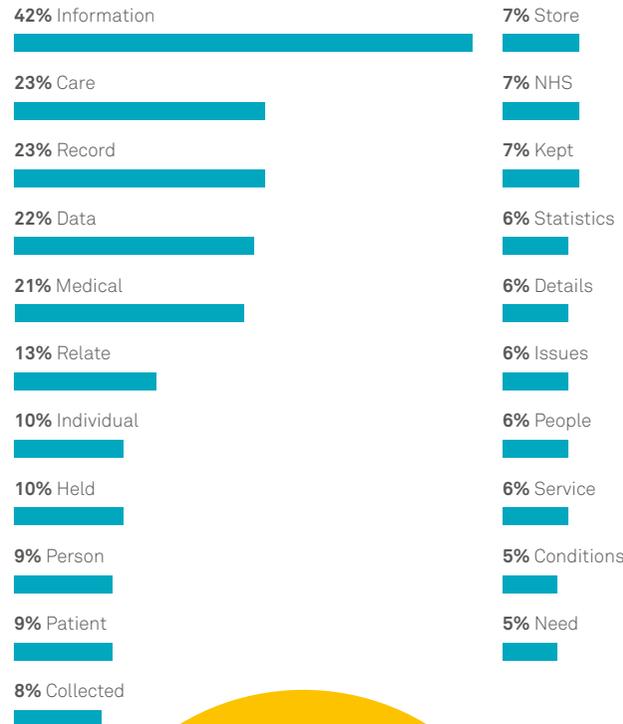
First of all, tell us in a couple of words what you understand by the term ‘health and care data’?

Base: 106 (all respondents)

Overall there were varied responses to this question – there is no definitive view of what people understand by the term ‘health and care data’.

- Around one third (36%) described it in personal terms e.g. data held by my doctor or hospital about me.
- One quarter (25%) described it as being impersonal, relating to efficiency of the NHS or the monitoring of the health of Scotland as a whole.
- Nearly a third (31%) described this data in more general terms e.g. information collected about health; information collected by the NHS.
- Less than one in ten of this sample (8%) were unsure or gave a vague response e.g. technology, records and so on.

% of respondents mentioning item



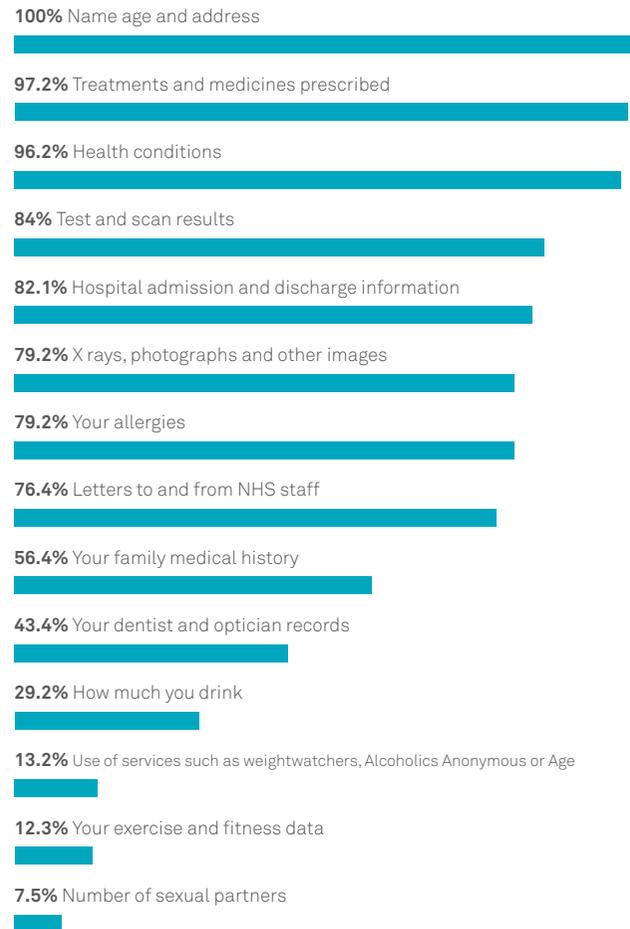
Quiz response:

Whenever we use the NHS or social care service, information is collected about us and our medical history. A patient’s health and care data includes any health-related information that is collected, created or used as part of their NHS care.

Q.
What information do you think is currently included in your NHS health record?

Base: 106 (all respondents)

- While only one respondent picked only the right categories – a quarter of respondents 26% picked all of the correct categories.
- The most common category included in error was family history (57% picked this).
- And the most common category excluded was how much alcohol you drink (71% did not pick this).



The answer is:

Legally, health professionals have to maintain records about you, your health and any treatment or care that you have received. Other specialists, such as dentists, physiotherapists and psychologists, will also create records that include data relating to your physical or mental health, social care needs and services, and any counselling or assistance you have been given.

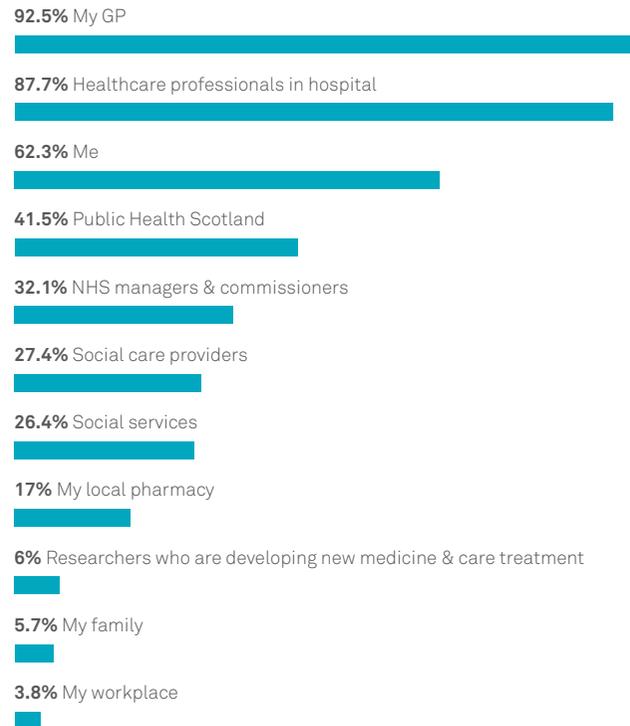
- ✓ Name, age and address
- ✓ Health conditions
- ✓ Treatments and medicines prescribed
- ✓ Your allergies
- ✓ X-rays, photographs and other images
- ✓ How much alcohol you drink
- ✓ Hospital admission and discharge information
- ✓ Letters to and from NHS staff
- ✓ Test and scan results

Q.

Who can access your current healthcare record without requesting your permission?

Base: 106 (all respondents)

- Only two respondents picked only the right categories – and only one in ten respondents (11%) picked all of the correct categories.
- The most common category included in error was ‘me’ (62% picked this).
- And the most common category excluded was social services (74% did not pick this).



The answer is:

Only healthcare professionals who are directly involved in your care will be able to access your full patient record. However, some of the information from your record may also be shared for specific purposes beyond your individual care, such as to improve health, care and services across the NHS.

- ✓ Your GP
- ✓ Some healthcare professionals in hospital
- ✓ Some social care providers
- ✓ NHS managers and commissioners
- ✓ Public Health Scotland
- ✓ Social services

Q.

Which of these best describes who is in control of your health care data currently?

Base: 106 (all respondents)

- Nearly two thirds (60%) thought that the NHS owns health and care data and controls who can access it – and a further 18% thought their GP had legal control over their healthcare data.
- One in five (22%) thought they had control of their data.

Note:

It was not possible to give a blank response to this question.

60.4% The NHS owns all my care data, and decides who can access any of it

21.7% I am in control of my data and it is stored on my behalf by my GP and other healthcare providers I see

17.9% My GP has legal control of my data and decides who can access any of it

The answer is:

There is currently no one place where all of your data is stored together. GP surgeries, NHS Trusts, disease registries and charities that work with patients all collect and hold data separately. They must follow the law and manage patient data responsibly, but can make their own agreements with other organisations, including researchers and companies.

Q.

Health and care data can be used to improve medical treatments, services and programmes, can you think of an example of something that has been developed or improved using this type of data?

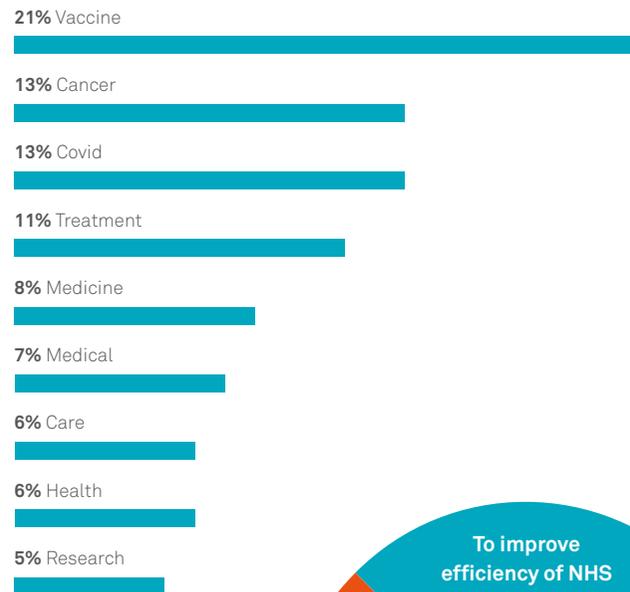
Base: 106 (all respondents)

All respondents answered this question.

Responses to this question fell into two main categories:

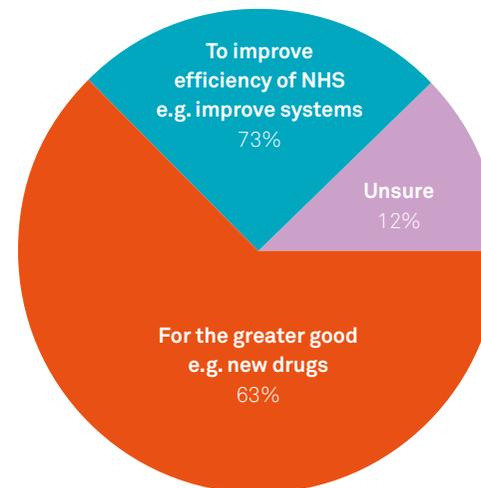
- Around two thirds (63%) described the benefits in terms of using health and care data for the greater good e.g. treatment for hereditary conditions and cancer, and in particular the development of COVID vaccines.
- One quarter (25%) described the benefits in terms of helping the NHS improve efficiency e.g. reduce waiting times for hospitals, support training of doctors and nurses, help prioritise funding.
- And around one in ten of this sample (12%) were unsure.

% of respondents mentioning item



Quiz response:

Did you know: Health records are vital for your individual care, but if small amounts of data from many patients are combined, doctors and researchers can look for patterns that may help them improve disease diagnosis and prevention, develop new treatments and medicines, increase patient safety and plan services across the NHS.



Note: Only one respondent answered 'nothing'

Q.

Which of these do you think your healthcare data is currently being used for?

Base: 106 (all respondents)

- Only one respondent picked only the right categories – one in five respondents (23%) picked all of the correct categories.
- The most common category included in error was ‘joined up care by linking GP, hospital and social care data (87% picked this).
- And the most common category excluded was planning hospital services infrastructure, such as the number of beds, doctors/nurses required at different times (60% did not pick this).

86.8% To provide joined-up care by linking GP, hospital and social care data



74.5% To help detect patterns of health conditions across the population



55.7% To develop new treatments and vaccines



45.3% To tailor treatments, practices or products to small groups of patients based on genetic, environmental and lifestyle factors



44.3% To allow pharmacists to access information when checking prescriptions or offering enhanced services



42.5% To predict healthcare conditions by linking your medical data with family medical history



39.6% To plan hospital services infrastructure, such as number of beds, doctors/nurses required at different times



32.1% To connect your health records with your own health or lifestyle monitoring data



24.5% To send real-time alerts from wearable devices that collect health data continuously



22.6% To identify undiagnosed disease by using machine learning programmes to analyse patient records



19.8% To offer personalised therapies and customised treatments using your DNA data



8.5% To predict health outcomes using data from social media accounts



The answer is:

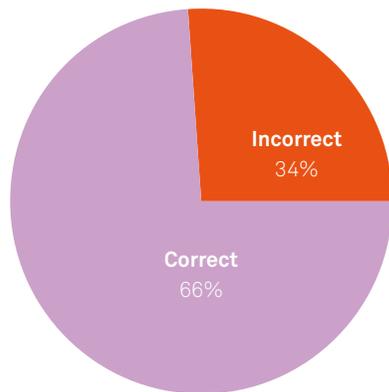
Healthcare data is currently only used for a few of the options listed in the question, but all of the others are potential future uses.

- ✓ To help detect patterns of health conditions across the population
- ✓ To tailor treatments, practices or products to small groups of patients based on genetic, environmental and lifestyle factors
- ✓ To develop new treatments and vaccines
- ✓ To plan hospital services infrastructure, such as the number of beds, doctors/nurses required at different times

Q.
True or false – you can opt out of any data sharing

Base: 106 (all respondents)

- All respondents answered this question.
- Two thirds of respondents (66%) got this question right.



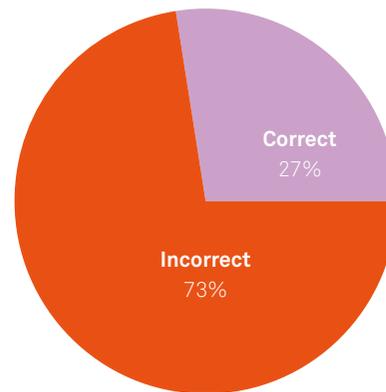
The correct answer is **true**

If you are not happy for NHS Scotland to use information from your GP patient records for planning health and care services and for research then you can opt-out via your GP.

Q.
True or false – you can easily access your own health records

Base: 106 (all respondents)

- All respondents answered this question.
- Three quarter of respondents (73%) got this question wrong.



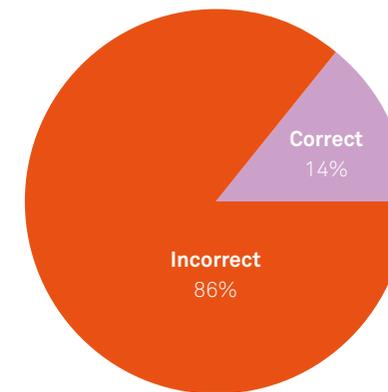
The correct answer is **false**

You have a right to see or get a copy of your health records, however you will have to apply in writing to the organisation that is responsible for them, for example, your GP practice manager, your dental surgery manager or the records manager at your hospital, and it can take 30 days to receive your records.

Q.
True or false – the NHS will store your data for the whole of your life

Base: 106 (all respondents)

- All respondents answered this question.
- The vast majority of respondents (86%) got this question wrong.



The correct answer is **false**

Whilst GP records are kept until 3 years after a patient's death, all adult hospital records (apart from maternity records) are only kept for 6 years after last entry or 3 years after death if earlier.

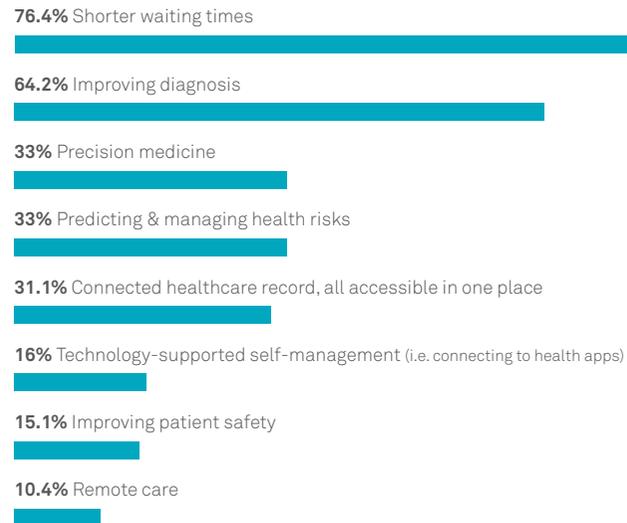
Q.

Which of these do you think the NHS should prioritise that would improve your health and social care experience?

Base: 106 (all respondents)

All respondents answered this question.

- Most popular responses related to easily understood concepts.
- Shorter waiting times (76%) this is something reported on frequently in the media and commonly understood as a measure for how well the NHS is/ or isn't working.
- Improving diagnosis – again this is easily relatable – everyone wants their illness to be diagnosed as quickly as possible.
- Less frequently chosen were harder to understand items such as precision medicines, predicting health risks and connected health care – each were chosen by around a third of respondents.
- Least often chosen were items including technology supported self-management, patient safety and remote care – each was chosen by one in six or less.



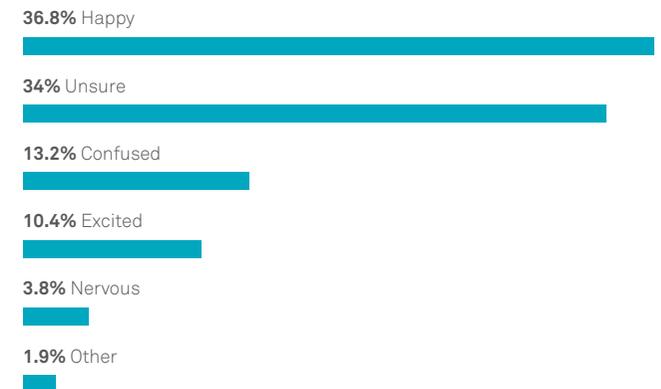
Q.

Having done this quiz, how do you feel about healthcare data?

Base: 106 (all respondents)

Overall, people split into three categories in terms of how they feel about health care data after doing this quiz.

- Overall nearly 50% are positive about health care data - just over a third (37%) say they are happy about their healthcare data and 10% are excited about health care data as a result of having done this quiz.
- A further third are unsure (34%).
- Less than one in five (19%) feel negative about health care data at this point.



Appendix B: **Online engagement**



The online sessions had four sections:

1. Introductory video

An introduction video that explained the background to the project, shared some of the quiz answers and explained the process for the following hour:



“The session you are about to take part in is based around a fictional pharmacy we have created called Scottish Health Connect. This fictional pharmacy is like one you might find on your local high street – it offers products over the counter, it fills prescriptions, and it offers some healthcare services. Just like the pharmacy you might go to, it does not currently have access to any health or care data to support you, but what if it did? What if health and care data was shared across the services you used? How widely should it be shared? What do you think it should be used for?”

Themes across the products included:

- Using big data sets to understand and predict disease.
- Optimising the service / support received.
- Finding cures for known illnesses – innovation and research.
- NHS Efficiency – saving money / time.
- Preventative support (screenings / behaviour suggestions).
- Personalised support / Personalised medicine.
- Self-maintenance and management.

Prompt questions included:

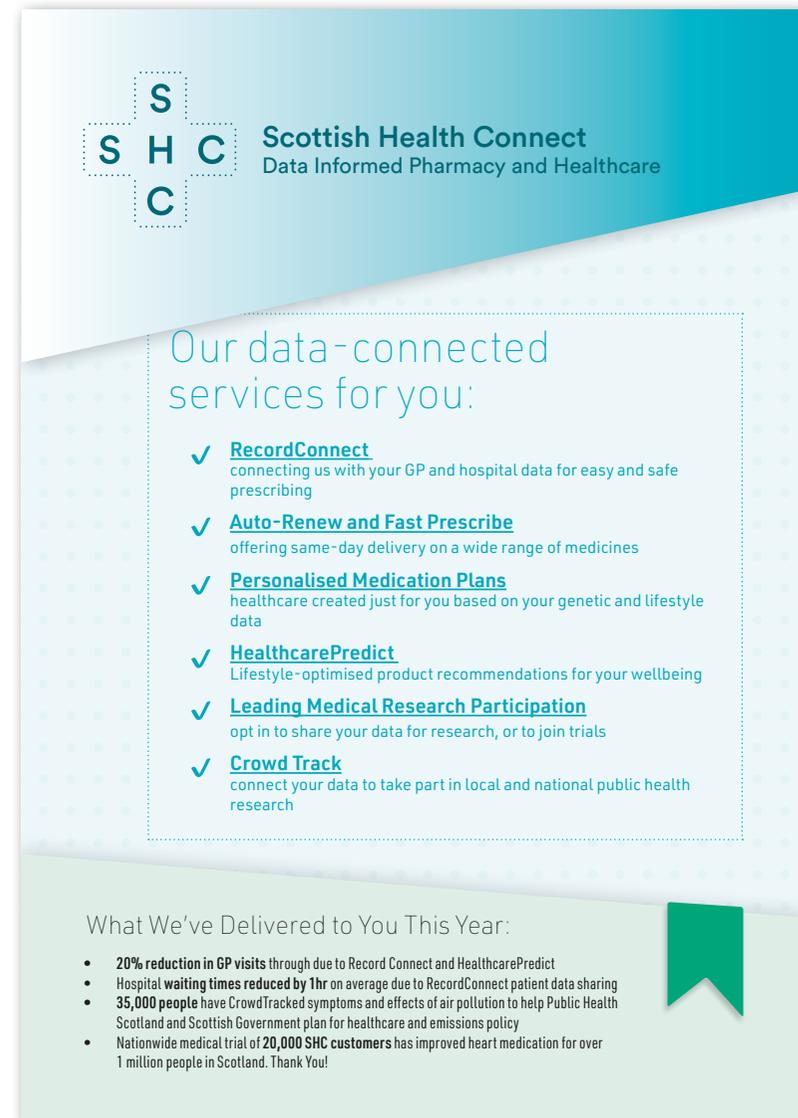
- Would you share your data to help you avoid a trip to the GP surgery?
- Would you want data to be used to help take pressure off the healthcare system?
- When should your personal data be shared and used to keep you well?
- Would you track and share data in order to spot opportunities to improve your health?
- How widely should your data be shared within healthcare?
- How can your data save lives?
- How do you feel about local data being used to reduce health risks in your area?
- How personal should your healthcare get?
- How proactive would you want to be in tracking and seeing your health data?

3. Scottish Health Connect brochure

A quick response activity designed to gauge what makes participants excited or concerned. In particular bringing in conversations about care data.

Participants were invited to read through the brochure, and conversation prompts included:

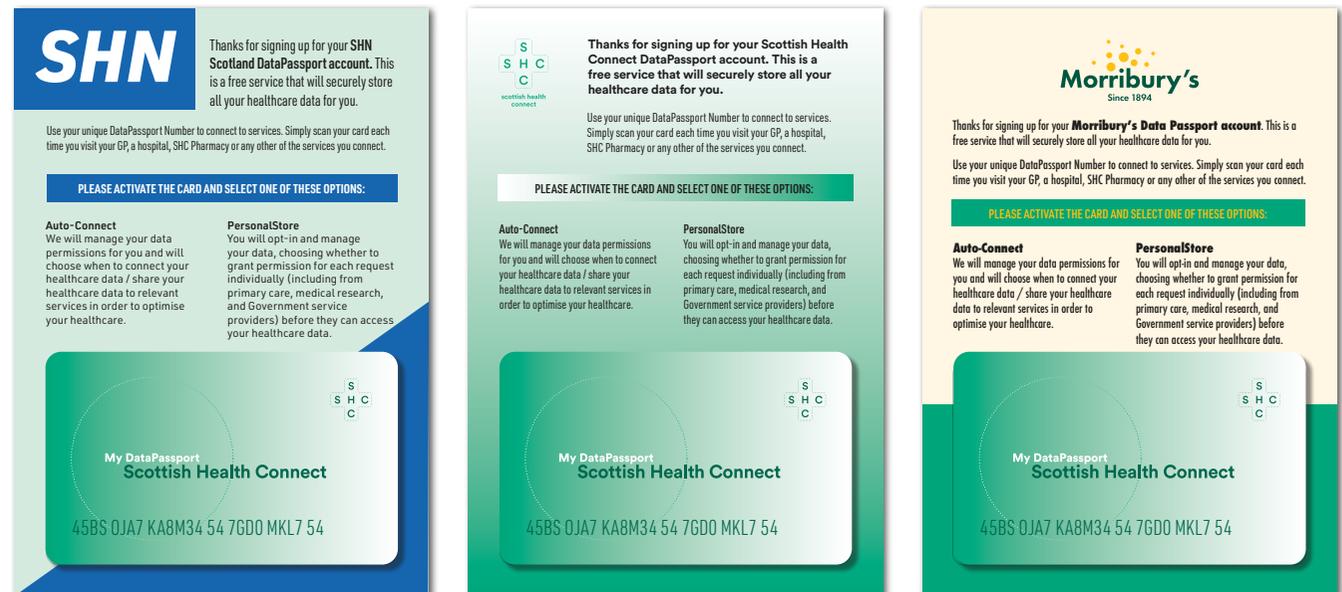
- Which of these product ranges or services are the most exciting / most concerning? Why?
- Which haven't you thought about before? Are there any you have wanted?
- Which product ranges / services interest you the most / feel most relevant to your life?



4. Loyalty card

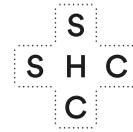
The final section was designed to encourage discussions of trust, value and ownership.

Three different versions of a loyalty card were designed: one from the fictional Scottish Health Connect, one from a fictional version of the NHS, and one from a fictional supermarket: Morribury's. The front of the card packaging asked how active or passive people would want to be in sharing data, whilst the back had 2 lists with choices for participants: one asking what they would connect with for personal benefit and the other asking who they would share their data with for wider public benefit.



Prompt questions included:

- How comfortable do you feel about sharing your data?
- Who would you choose to share it with?
- Would you want to opt in or opt out?
- How active or passive would you want to be in sharing your data?
- Automated or consented each time? Who should be in charge of the data?
- Do you understand the range of people that could have access to your data?
- How does this make you think about other parts of data sharing in your life?
- What of your data would you freely donate? (access to old records vs. new / what is too private to share?) Would you want to choose what it's used for?
- What would make you confident that your data was secure?



THANK YOU

for taking part today and helping the Scottish Government understand what matters to you. All your thoughts, opinions and ideas will be shared back anonymously to help the Scottish Government as they build new systems that support how health and care is delivered, managed and experienced in Scotland.

To complete your experience please call the number below and leave us a voicemail message with your answer to at least 2 of the questions below. Please be completely honest, there is no wrong answer and everything you share is very helpful.

What do you think should happen in the future with health and care data - please leave us a message with an answer to at least 2 of these questions:

- **What do you think** should happen with your personal health and care data?
- **How do you feel** about sharing this data?
- **How do you think** data and technology will change your healthcare experience?
- **Anything else** you want to tell us that you didn't share in the group?

Call +44 (0) 330 043 4893

to leave your message

Remember to say your first name so we know you have completed all the research tasks.



At the end at the session participants were prompted to find their receipt which directed them to the final activity – as detailed in Appendix C

Appendix C: Personal Reflections

At the end of the Data Dialogues process participants were asked to phone a telephone number and share their reflections on the process and answer at least 2 of the following questions:

- What do you think should happen with your personal health and care data?
- How do you feel about sharing this data?
- How do you think data and technology will change your healthcare experience?
- Anything else you want to tell us that you didn't share in the group.

93 people shared their reflections.

1. Controlled sharing and less open to corporates

Around half of all responses (47%) were more open to sharing their data than group 1, but only if there were control around who it could be shared with, particularly around sharing data with corporates/profit making organisations. This group would like to be able to control what is shared and who with.

.....
"I would be happy to share data as long as it was in safe hands and I was able to be in control of what data was being shared"
.....

.....
"I think certain stuff should be shared if it is relevant but only if it's not for profit and it's for the greater good"
.....

.....
"I think regards to the sharing of your personal health data that it should remain in the hands of your GP or NHS Scotland but no further and if they want to share they have to ask for your personal consent"
.....

2. Only if it brings immediate personal benefits

Around one in five (22%) want to keep their data private within NHS or related professionals e.g. pharmacy, optician, dentist, and for it to be used for their healthcare only or to streamline their healthcare.

.....

“I think my data should be kept as confidential as possible and only shared with the NHS my GP, my optician and my dentist maybe as well.”

.....

3. Open to sharing

The remaining 30% were overall positive about the benefits of sharing (particularly throughout NHS, for benefit of NHS, for greater good) – they did not raise negative points.

.....

“I’m ok with my data being shared for ultimately anything as long as it’s bringing something to future generations”

.....

“I think a card to allow you access your own personal data is a great idea.”

.....



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The Liminal Space



Scottish Government
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gov.scot