

Themes, Sub-themes, Codes and Raw data (quotes)

| Themes                                       | Sub-themes  | Codes                                      | Raw data (quotes)   |
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| Benefits of sharing data                     | Advancement in healthcare                                       | Develop new medications and treatment      | <i>“develop new medications and treatment, because it's not just improve, it's develop new as well”</i> (Female Participant; Workshop 1)  |
|  |   | Improve health practice and treatment      | <i>“I know of several instances where I've shared data and other people have too and it's led to increased knowledge in the medical profession, so now they don't do those things (for which there is no evidence) with other patients coming through”</i> (Male Participant; Workshop 1)   |
|  |   | Inform funding                             | <i>“I think it'll get out there into the media and they'll be saying, “Because of the research into,” we'll use mental health, “into mental health, we now are able to supply better funding. We can train more doctors because we know that the information is out there, that more people have mental health issues”</i> (Female Participant; Workshop 2)   |
|  | Altruism  | Helping family – genetic research          | <i>“research on genetic data is going to help immediate family and future families by increasing the knowledge and information... people with particular genetic disorders can help for mapping that, which can help for mapping future people, which can help prevent issues”</i> (Female Participant; Workshop 1)   |
|  |   | Helping others                             | <i>“I do it for the reason it increases the general knowledge in the health sphere, and it might help some other person”</i> (Male Participant; Workshop 1)   |
|  | Self-interest   | Knowledge is power                         | <i>“If you're well-informed (about research) you know, you've got the knowledge. You're better empowered too – yeah, I think that's really important”</i> (Female Participant; Workshop 1)  |
|  |   | Better care for oneself in the long term   | <i>“I would like the person who looks after me to do a good job. It's in my interest to give health data”</i> (Female Participant; Workshop 2)  |
|  | Uncertainty about research findings                             | Uncertainty about research findings        | <i>So, you could say, oh, I fit into this group, this category. But you can only do that if the population you're looking at is representative of the general population. Is it? I don't know”</i> (Male Participant; Workshop 2)   |
| Uncertainty around data collection processes | Lack of understanding of how and why data is collected and used | Cultural, religious, and language barriers | <i>“A lot of people don't understand how the data is collected and managed. Privacy, culture, language, religion - these things come into it... I think we need to start thinking about data gathering, how do we need to change our messaging from a cultural point of view. That's really for me the key message here”</i> (Female Participant; Workshop 1) |

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|  | How and why data is collected                          | <i>The other thing, this part here about knowing how it's used, why it's being collected. People don't know. So, I think that having a professional, having somebody with easy English writing skills in your team will help with that</i> ” (Female Participant; Workshop 2)  |
| Accuracy of data collected (omission of data)          | Not sharing because of feeling patronised by age       | <i>“Straight away you're over 65 and you got into a slot in their mind and the white hair doesn't help and you become 'dear' and it's dismissive... you can be worried about that”</i> (Female Participant; Workshop 2)  |
|  | Too embarrassed to share                               | <i>“Embarrassed about the condition which it could be any problem. Men with their prostate, all sorts of things, going in with a UTI or something like that”</i> (Male Participant; Workshop 2)  |
|  | Is data correct  | <i>It's counterproductive. If people are strange, I might shut up because you're not being nice to me, and so I won't tell you about something that's going to help me and help you. Is it [the data] correct?”</i> (Male Participant; Workshop 2)   |
| Insidiousness nature of data collection within society | Insidiousness nature of data collection within society | <i>“I think it's clear these days that we're all impacted by the insidiousness of large corporations, and small, who gather our data using artificial intelligence online. Every time you spend your credit card, somewhere its data being fed somewhere else”</i> (Female Participant; Workshop 1)  |
| Data sharing fears                                     | Indifference   | <i>“The information goes between here, there and everywhere. It doesn't worry me”</i> (Male Participant; Workshop 2)   |
|  | Threats/fears shaping concerns                         | <i>“It's also the issue of cybersecurity, because a lot of people are worried that their data is going to be hacked”</i> (Male Participant; Workshop 2)  |
|  | Big Pharma – bad reputation                            | <i>“There's a general fear of sharing information, I'm certain, with Big Pharma, pharmaceutical companies. They have such a bad reputation”</i> (Male Participant; Workshop 1)   |
|  | Human error  | <i>“Yeah, that button wasn't clicked, name (wasn't) removed. Yes, that's human error. Biggest fear of the lot”</i> (Male Participant; Workshop 1)  |
| Negative perceptions of data leaks                     | Don't want family to know your health information      | <i>“If [it was your hospital] and the health data [got] shared, I suppose you don't want your family to know”</i> (Female Participant; Workshop 2)   |
|  | Financial consequences                                 | <i>“I don't want someone else to know about it because it may affect my work or my job applications and things like that”</i> (Male Participant; Workshop 1)   |
| Data sharing can be a double-edged sword               | Data sharing can be a double-edged sword               | <i>“There's a general fear of sharing information, I'm certain, with Big Pharma, pharmaceutical companies. They have such a bad reputation, but we rely on them. Without big pharmaceutical companies, we won't be getting out tablets that, well, keep us alive - well, cure diseases. So, it's a double-edged sword... But Big Pharma is a big scare for most of us, but it's an essential at this point. So, yeah, they need access to our data”</i> (Male Participant; Workshop 1) |

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| Distrusting data security processes     | Concern around confidentiality          | <i>“I can understand with mental health. They guarantee us don’t they, that this stuff is not going through, so do you believe them, or don’t you – this is the thing isn’t it?”</i> (Male Participant; Workshop 2)   |
|   | Deidentification – is my name withheld? | <i>“Is my name withheld? That would be the question. Is it really? Is it really withheld? You’re telling me it is, but do I believe you? And I think that’s a lot of the fear”</i> (Female Participant; Workshop 1)   |
| Develop trust in data sharing processes | Control over our data                   | <i>“At an individual level, I’d want to know that I can challenge and/or change information, and every now and then find out what it is that you’ve got, because otherwise I’m not even going to know what you’re keeping”</i> (Male Participant; Workshop 2)                                   |
|   | Publicise data security measures        | <i>“I’m quite happy as a consumer to say this is my history, you can do what you like with it, but I don’t want the company down the road to find out that it was me. I think you have to publicise how secure your information technology systems are...”</i> (Female Participant; Workshop 1) |
|   | Accountability                          | <i>Once we have this system going there has to be accountability, especially if our human rights and our privacy is being taken. It’s all good putting all this together, but if they do use it incorrectly, they must be punished”</i> (Female Participant; Workshop 2)                        |