

Table 1: Demographic profile of study participants.

Participant Demographics	
FG Age-groups	No.
18–25	12
26–35	13
36–50	16
51–65	11
65+	15
Gender	
F	44
M	21
GD	1
DNS	1
Self-identified ethnicity	
NZ European	47
Māori	4
Chinese	2
Indian	2
American Caucasian	1
Asian Filipino	1
Australian	1
Cook Island Māori	1
Dutch	1
English	1
Lithuanian	1
Fijian Indian	1
Irish	1
Fijian	1
Sri Lankan	1
DNS	1

FG: Focus group; No.: Number of persons; F: Female; M: Male; GD: Gender diverse; DNS: Did not say

Table 2: Participant quotes from focus groups.

Theme	Topic	Participant quote
Importance of the topic	National importance	“I think it’s really important... So, it needs to be at the forefront of people’s mind about what is actually going to happen to this information when you do pass. And with research and development being so important, especially for our country, it is very crucial that we do actually have some parameters around the laws for how people are going to use this information. So, definitely a worthwhile topic to be discussing.”
	Respect	“It’s also about having respect for posthumous data, like it someone died it would be having respect to that person by using that data appropriately.”
	Cultural importance	“I think it’s important. I’m Māori and I, death is very important in our culture. And lots of mahi in your body, and you’re not meant to be burned and things like that. So, I’m very interested in this [subject], personally.”
Utilisation	Insurance companies	“I can see a scenario where an insurance company might just grab hold of it and then use it to basically tighten up, make things restrictive for people who had certain conditions and would create societal inequities.”
	Insurance companies	“I think they’re all evil, very evil. There is potential for discrimination.”
	Royalties	“I wouldn’t mind if my children profited off it, yeah. I would trust that they would use their best judgement to use it wisely.”
	Royalties	“I don’t really like the idea of my family profiting off my illness, not at all.”
	Commercialisation	“Commercialising the data itself makes me feel a bit unhappy, not very, but commercialising the results from that data might be something more practical and more useful anyway.”
	Commercialisation	“I think that maybe commercial use would be okay on the big scale if it was a New Zealand company.”
	Commercialisation	“I see no problem with people making money out of it if it is for the betterment of the health of future generations.”
Māori perspectives	Sovereignty	“Most iwi’s now have doctors and barristers, graduates. You know, the younger generations. And I think that possibly I know Tainui have stuff in place. You know, it varies from iwi to iwi but I think that perhaps iwi’s should appoint kaitiaki’s [custodians] you know, for the information.”
	Sovereignty	“Yeah. I don’t think that, I don’t want you to take offense to this, but I don’t think Pākehā have much right to govern such...records”.
	Storage	“I don’t feel like my wairua would be able to move on and be happy walking with my tūpuna knowing that there’s still a bit of information about me sitting somewhere.”

Table 2 (continued): Participant quotes from focus groups.

Theme	Topic	Participant quote
Consent	Information	“You’ve got to make sure though that people are informed about it, coz a lot of people probably would never think about what’s happening to their healthcare data after they die.”
	Ownership	“I see it as, it’s like a chattel that I have, that after I die, I make provision before I die for what’s gonna happen to my chattels when I do die.”
	Opt-in	“Well, the [organ] donor programme is a, is a classic example of the opt in not working. I prefer to opt in, to be honesty with you. I can see the point in having a much larger dataset, and I can see the importance of that. But it feels like it’s just another breach of interpersonal trust for me.”
	Opt-out	“And in the interest of collecting as much as possible but still giving people choice, I feel like an opt-out system would be more beneficial than an opt-in where you’re just not going to get enough people.”
	Opt-in or opt-out	“If personal data, for me, isn’t going to be used in a way that’s equitable and accessible to all, then I think we should have the ability to opt-in or opt-out.”
Family interest	Intermediary	“Because it’s almost like someone has to be there to advocate for the dead.”
	Anonymity	“At a personal level, I wouldn’t mind, but I can see the situations when it would be a problem for a lot of people.”
	Access	“Yeah some of your family will wanna know and some won’t, you know, and then do the ones that know, how do they share with the ones that don’t, you know?”
Infrastructure	Storage	“I don’t care [where data is stored], as long as it’s not accessible by Donald Trump.”
	Storage	“I would be happy for my records, personally, to be held in perpetuity.”
	Storage	“If the data’s going to be accessible and pieces of information are going to be comparable across a large section of the population, which is potentially where it becomes valuable I think, then it has to be catalogued and stored and accessible in a uniform way and not through however different agencies just happen to have stored it.”
	Who stores data	“I think it needs to be a government. I don’t think it can be ay health or university because it’s going to cost money to set it up and run it and that means it’s money that one of those agencies can no longer spend on bandages and suture which isn’t going toe acceptable to them. But I think it should be a taxpayer government initiative that holds the database in the same way that they have a database of car registration information or whatever.”
Governance	Anonymity	“I think the more that you use software and the internet, stuff like that, the more probably sophisticated you’ve become in terms of understanding that there really is no anonymity. There’s no privacy.”
	Anonymity	“For me they [posthumous healthcare data] absolutely need to be anonymous”
	Custodian	“The aspect of control is so vital to this whole thing working or not. Who controls the data, and how’s it shifted around, how’s it accessed, free or otherwise.”
	Custodian	“I mean that’s my biggest concern, if this goes forward who’s the guardian, who’s the gatekeeper?”
	Cultural perspectives	“I think we need to be aware of the fact that we are asking a number of different cultures to accept this.”