

An exploration of Aotearoa New Zealanders' attitudes and perceptions on the use of posthumous healthcare data

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ABSTRACT

AIM: Posthumous electronic healthcare data (PHCD) are ubiquitous and increasing in volume. Despite their potential utility and value, no empirically-derived, publicly-generated information exists to guide what uses society may view as acceptable. This study explores the attitude and perceptions of Aotearoa New Zealanders to PHCD utilisation.

METHODS: Focus groups explored topics focused around PHCD utilisation, including family access, consent models, infrastructure, anonymity, governance, and commercialisation. Data were transcribed and general thematic analysis utilised to explore themes and topics.

RESULTS: Sixty-seven people participated across 12 focus groups (mean=50 minutes). Participants indicated conditional support for a centralised, Government-managed PHCD repository allowing controlled, no-cost access for healthcare and research purposes. Public benefit from data was important. Participants prioritised any benefits being preferentially directed to family, then Aotearoa New Zealanders, then others. Commercialisation from data use was viewed as likely and acceptable. Māori PHCD was considered preferably managed by Māori. Participants struggled to define appropriate levels of family access, anonymity, and consent models.

CONCLUSIONS: This study delivers the first empirical evidence of social license for PHCD utilisation, providing guidance for establishing trustworthy data governance. Further exploration of the subject is warranted to guide development of frameworks to utilise PHCD in Aotearoa New Zealand.

Large sets of digitised healthcare records are widely used to increase healthcare efficiency and effectiveness,^{1,2} examine patient and disease profiles,³ and explore epidemiological trends. Such digital files can exist for a potentially infinite period, ushering in an era of digital “e-mortality” (electronic immortality) where healthcare records will far outlive the persons whose data is held within them.

Digitised posthumous healthcare records, referred to here as posthumous healthcare data (PHCD), are the digitised healthcare records of those persons who have died, and they constitute an ever-growing collection whose potential use and utility are little explored.⁴ If these data are not erased or destroyed, they will become the largest repository of digitised healthcare information. Due to their ever-expanding volume, PHCD will become increasingly valuable for inter- and intra-generational analysis of health datasets, including genomic analyses, or to allow comparison with other non-healthcare datasets (eg other government information).⁵

While large healthcare datasets can provide benefit, there are risks and harms associated with their use, including erosion of trust between the public and healthcare professionals which may affect how healthcare users access services.⁶ In addition, within Aotearoa New Zealand there exist different cultural perspectives on healthcare data use, with frameworks around Māori data sovereignty⁷ highlighting the necessity to include different perspectives around the future use of healthcare data in this country to guide socially and ethically appropriate utilisation of such a resource.

At present, there are no publicly informed guidelines or data to assist the future utilisation of PHCD in Aotearoa New Zealand. Neither are there any contemporary empirical data, from any country, that exist to guide a conversation around public expectations and social license on this subject.⁸ This study explores the public's views on the use of PHCD in Aotearoa New Zealand, in order to provide information that can guide responsible management or utilisation of this precious resource.

Methods

Focus groups were used to gather information from a cross-section of the Dunedin community. Potential study participants over 18 years of age self-selected by responding to advertisements placed on several local public notice boards, in local newspapers, a local general practice with established links to the local Māori community (Te Kaika, Caversham, Dunedin) and via social media. Respondents were sent information, and registrants allocated to focus groups by age groups including years of age 18–25, 26–35, 36–50, 51–65, and 65+, with participant numbers across groups guided by recent NZ Census data.⁹ Registered participants were allocated to focus groups to balance gender representation. Ethical approval was received from the University of Otago Human Ethics Committee (18/090), and the Ngāi Tahu Research Consultation Committee (2018). Participants provided informed consent and were gifted \$35 koha for their participation.

Focus group format and questions

Focus groups were delivered in a face-to-face setting (authors JC, KM) using a semi-structured format with open-ended, investigator-driven questions on a range of topics that aimed to elicit discussion around PHCD, focusing on how participants viewed aspects surrounding the use of their own healthcare data in a posthumous scenario. Topics included discussion around general access, family access, anonymity, commercialisation of data, consent processes, data governance, and scope of data use. Focus groups were audio recorded.

Data analysis

Audio recordings were transcribed, then checked for accuracy by investigators (KM, JC). Transcriptions were then entered into the software analysis programme ATLAS.ti (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany). A generic inductive thematic analysis was conducted, through an iterative process that examined transcript themes, compared differences between datasets, and explored responses from different individuals.¹⁰ Descriptive codes were established and organised into higher order thematic categories. The plausibility and explanatory value of the categories were independently assessed by two researchers (KM, JC). Where differences arose, discussion of data helped to reconcile where content should be most appropriately allocated.

Results

Demographic and general data

Twelve focus groups were held, with a total of 67 participants (Table 1). Forty-seven persons self-identified as NZ European, four as Māori, and 16 as other ethnicities with one non-responder (Table 1). There were 598 total minutes of data from 12 focus groups (average focus group 50 minutes). The mode for focus group participation was six persons.

The importance of the topic

Participants were generally unaware of the topic of PHCD; however, there was general agreement that management of PHCD was an important social issue, stating a necessity to explore issues and provide clarity on future options (Table 2). Overall, there were strong themes of altruism, usefulness, community, beneficence, and respect conveyed by participants. Specific posthumous interests were acknowledged, focusing on both a person's own and familial interest in being well remembered after death, and in being respectful towards someone after they have died. Participants linked the idea of posthumous interests with the concept of respecting the data itself as having come from a living person.

Utilisation

Participants broadly agreed if data were useful, they should be used to benefit others, with the importance and difficulties of controlling data use specifically highlighted. This use was interpreted as a hierarchy with family benefiting preferentially, then Aotearoa New Zealanders, then other persons. Participants raised concerns over personal exploitation, whereby data use was for purposes they did not agree with. Commercialisation of data, and also data use by insurance companies, were identified as two major potential sources of exploitation, with participants suggesting discrimination “would create social inequities”. However, there was general agreement that commercial use and/or profit was acceptable if it provided benefit to the community, though some participants expressed a general unease over money being made from PHCD. The prospect of using data to generate profit for Aotearoa New Zealand was acceptable and spread evenly across age groups, while some participants were in favour of commercial profits being returned to communities. Family profiting or receiving honoraria from data was discussed, and was acceptable

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.”

in some instances, particularly if data use brought substantial commercial benefit—although a few found the idea of family profiting from data unacceptable. Participants were clear that PHCD itself should not be sold.

Māori perspectives

Māori participants viewed healthcare data as taonga (treasure), saying these data held special value and required specific protocols for guardianship. Furthermore, they indicated Māori governance of such data are essential. Some Māori participants said Māori may not wish to have data stored due to beliefs surrounding death and spirit, with the wairua (spirit) being intimately linked with existing data, suggesting that ongoing data storage meant the wairua of the deceased remained tied to its existence on earth, and that permanent retention of PHCD was therefore not acceptable.

Informed consent

The notion of acquiring informed consent prior to death was considered important by the majority of participants, with discussion focused on two main themes: public education and the importance of personal choice. Opinions around the need for informed consent largely focused on public education or autonomy, and informed consent was discussed more frequently among older age groups, with concern over health literacy regarding informed consent more commonly discussed in the 26–50 age groups.

Participants discussed “opt-in” or “opt-out” systems for individuals to give consent for their records to be included in a national database. Those in favour of opt-out outweighed those in favour of opt-in by a large margin. The two main reasons for this support were that more people would be part of the dataset, and that if people felt strongly about it, they could opt-out. Those in favour of an opt-in system of consent did value PHCD, but wished to make a choice to enter the system themselves.

Family interest

Participants considered some family situations would provide complexity to data collection, storage, and use. Scenarios included the implications of identifying non-biological relatives and issues regarding inheritance of genomic material, the possibility of incidental findings, and the idea of finding out a family secret—such as an abortion. The stigma associated with some health issues, such as sexually transmitted infections, was also raised, as was the possibility of different cultures

having different values. The appointment of an external decision-maker/guardian alleviated concerns around respecting the wishes of the dead, given this identity should advocate for the interests of the dead.

Infrastructure

A majority felt PHCD should be stored in Aotearoa New Zealand, expressing concern over storing data overseas, based on differing laws and values in other countries. However, a few participants stated that they did not have a preference where data was stored. The main issues were concerns over hacking, the need for one system to create a streamlined framework for data, and breaches of privacy and trust.

The majority of participants supported keeping data indefinitely. Several participants specifically wanted their data kept indefinitely, citing mainly the usefulness of it, and not caring because they will “not be here”. This position was especially marked in older age groups. A small number of participants did not want their data being kept indefinitely; two of these were Māori who cited spiritual reasons.

Governance

The advantages and disadvantages of a centralised system were discussed across age groups. A majority thought that posthumous data should be controlled by the Government. Of these, some thought the Ministry of Health or the National Archives should be responsible for data storage, with medical personnel involved in managing decisions around data use. Responses highlighted the need for posthumous data to have robust infrastructure, noting government departments likely have existing frameworks that may be fit for purpose. Non-governmental control over the data was explored widely but rejected due to lack of consistency in data management versus the extant stability of government systems.

Participants discussed data use and anonymity, with some not caring about being anonymous, while others insisted anonymity was important. Views included there being “no privacy” with electronic data, while others suggested added value or benefit would be seen without anonymity.

Discussion

Globally, awareness about posthumous digital data use is increasing,¹¹ including discussion around PHCD.^{1,12} Findings suggest Aotearoa New

Zealanders provide conditional support for PHCD use, having PHCD stored indefinitely, and used in an ongoing manner. However, there are multiple factors to clarify further including appropriate infrastructure and governance, different consent models, and how Māori or different ethnic and cultural data should be managed.^{13,14}

Utilisation

Within Aotearoa New Zealand, the Integrated Data Infrastructure (IDI) research database exists to allow access to a limited range of non-identifiable health information,¹⁵ while similar international databases also exist for this purpose.¹⁶ However, the amount of healthcare data available within these databases is both non-identifiable and limited to specific healthcare data (eg cancer registrations, mortality data). The storage of all posthumous health records in their entirety, potentially being identifiable to facilitate more precise health analyses, could therefore extend the utility of Aotearoa New Zealand's IDI system. Study findings also guide future uses to prevent erosion of trust between the public and data custodians,^{17,18} with strong social license⁸ for PHCD utilisation, and almost universal support for the information being used to benefit the future generations and global citizens. Participants suggested it is logical for PHCD to be used for research, with general agreement commercial use is acceptable *if* there is benefit, and agreement some commercialisation is necessary to benefit society. The most prominent concern was exploitation of a person's data, which is a common fear around healthcare data use^{2,6} including within Aotearoa New Zealand.¹⁹ Clear also was that PHCD should not be for sale, and that it should be a free resource to be used for benefiting others.

Insurance companies were almost exclusively viewed negatively, with a strong indication across all age groups that access to PHCD should not be allowed in this commercial area because of the potential for discrimination, especially for those persons with inheritable diseases. Some participants felt that allowing insurance company access to PHCD was an argument for retaining anonymity of data, so that individuals and families could not be specifically identified.

Māori and Other cultural perspectives

Perspectives indicated recognition and respect around Aotearoa New Zealand's multicultural society and the necessity to acknowledge that different groups may wish to govern their own data.²⁰ From the small number of Māori partici-

pants this view was also clear, with comments generally congruous with the framework of Te Mana Raraunga (Māori Data Sovereignty Network) recognising Māori data should be subject to Māori governance.⁷ Broadly, study findings align with the concept of autonomous data rights, and data sovereignty for individuals and communities where control and decisions about the data are overseen by the communities themselves.²¹ Local exploration in this space is continuing with the recently funded Genomics Aotearoa Rakeiora programme²² and the framework of Whakamaau: Māori Health Action Plan 2020–2025.²³

Consent

Participants considered informed consent important because of the notion of personal agency, though this was also viewed as potentially problematic with people not understanding what they are consenting to. Discussions around consent were driven by participants' wish to have control over the destiny of their "own" data before they died, with this attitude congruent with global trends around perspectives of data "ownership": participants wanted to be able to guide who could access it, and for what purpose. This is in line with global data trends around data control, such as the General Data Protection Regulation in Europe²⁴ that gives control of personal data to the person who generated it. However, there are suggestions that "co-constructors" of such data are "custodians", and the view of "ownership" of one's own health data need further exploration.²⁵ Comments around consent align with the strongly upheld value of informed consent within health services in Aotearoa New Zealand,²⁶ a value that is codified in law with the Code of Health and Disability Services Consumers' Rights (1996)²⁷ and the Health Information Privacy Code (2020).²⁸

While an opt-out system would likely provide a more extensive and useful database, ensuring this has satisfactory social license would be required to ensure the public were sufficiently educated about uses and potential risks. Globally, opt-in systems of "data donation" are being highlighted as a way to increase the size and utility of healthcare datasets.^{1,12,29} Yet while this mode of consent presents a greater amount of personal autonomy to potential donors, the likelihood is that data donations will almost certainly be a very small portion of those which an opt-out system would acquire, similar to those issues identified around opt-in systems of organ donation,³⁰ rendering poorer utility than a larger dataset that opt-out would facilitate.

Family interest

Family interest in PHCD is controversial globally,³¹ and there are distinct differences between Māori and European cultures in Aotearoa New Zealand.²⁶ Family interests are difficult to manage around PHCD interests,^{32,33} with discussion regarding the complexities of family indicating there are things that people want to keep private during *and* after their lifetime, and that this is a reasonable expectation which should be upheld. Despite this, there was overwhelming support for allowing families access to PHCD when necessary, but this was not a universally appropriate guideline. This means any system would require clear guidance around health information privacy,^{32,33,34} data sharing and use in respect to family access, including discussions about information sharing with subsequent generations of descendants.

Infrastructure and governance

Many responses supported a centralised, secure system of data storage, with PHCD having most utility if they existed in perpetuity. This is problematic in Aotearoa New Zealand, as healthcare records, in general, are legally able to be destroyed ten years after a person's death.^{4,34} However, there is provision for PHCD to be lawfully used beyond that point,²⁸ despite existing law being designed in an era where PHCD were not ubiquitous. If a system of centralised records were established, it would require a law change to assist holding health records in perpetuity to prevent them being destroyed or erased. In addition, further clarity is required about using these data and the level of anonymity that could or should be applied (eg identifiable vs non-identifiable information) as this affects potential uses and impacts descendant healthcare. While some participants did not care about anonymity, some expressly did, and cited data security as a concern, tying the subject in to an issue around trust and potential misuse of data.⁶

While "ownership" of data was not specifically discussed, conversations hinted at data governance being of a custodianship or guardianship role, with persons continually referring to "my" data with the implication that "my data is to be overseen and used by someone else". Many responses favoured this type of data governance being overseen by some type of ethics committee review for access to PHCD, which is congruent with calls within Aotearoa New Zealand to explore how oversight of healthcare data are managed.³⁵ Most participants thought that the data should be

controlled by the Government, mainly the Ministry of Health or National Archives, and include some medical personnel, which highlights the trust in the medical profession that already exists within the community. The main reason for this was preference for a robust infrastructure, and using an existing, stable and enduring administration made the most sense. National storage and governance was suggested, necessitating appropriate data storage and transfer legislation to ensure transparency around data custodianship. Responses by and around Māori interests favoured independent governance of Māori data, discussed earlier.

Aotearoa New Zealand's future posthumous healthcare data utilisation and implications

Findings suggest many Aotearoa New Zealanders conditionally support a centralised system of governed PHCD that was overseen by a government agency, and that included oversight from medical professionals, with data being available for healthcare and research purposes. It was suggested that data should be held in Aotearoa New Zealand, with benefits being foremost for family, then Aotearoa New Zealand citizens, then global benefit. This altruistic perspective also supported the necessity of commercialisation being an obvious downstream effect of data utilisation to extract reasonable benefits; however, selling of the data itself was not supported. A complex array of suggestions around consent concluded with a majority supporting an opt-out system, and Māori data were identified as requiring Māori governance. Implementation of such a system would require alterations to current health data legislation to ensure data are held in perpetuity, a review of how privacy laws (eg the Health Information Privacy Code) may affect inter and intra-generational data sharing,³⁶ further exploration around how "identified" or "non-identified" data should be defined, and continuing efforts to address ethics frameworks around the utilisation of such data.^{7,35} Public consultation to acquire social licence for such changes would be essential to support its development and implementation.⁸

The suggested system is congruous with several positive ideological principles including beneficence, altruism and usefulness; however, there are potential harms associated with the proposed framework should data be misused or outside what is socially or culturally acceptable. These include an erosion of trust in the health-

care system that could lead to possible compromises in healthcare from patients failing to seek treatment or choosing to withhold information,^{2,6} and the risk of discrimination and potential for group-based harm.^{17,37} This is particularly relevant when research that includes genomic information potentially affects generations, cohorts or communities of individuals and their families,^{31,33} while a lack of consensus around consent—both for the individual and future generations—means further investigation is required to identify acceptable solutions. Public consultation and future implementation will need to be transparent about systems, governance, and utilisation in order to establish and maintain public trust while balancing the risks and benefits of data sharing.^{2,6}

Limitations

The information may not be representative of Aotearoa New Zealanders in general as the sample size is modest and restricted to one geographic location, which has the potential to affect the generalisability of the findings to other regions of Aotearoa New Zealand. There is also the potential influence of participant selection bias, given participants self-selected for this study, and this may affect the work in regard to the identification of personal attributes, such as altruism or usefulness, or indeed participant attitudes towards PHCD use. Further, there was also a lack of diversity amongst the participant population, with specifically few Māori, Pasifika, Chinese, Indian or other ethnic backgrounds, and their views in ongoing work are important in order to more accurately represent the diverse nature of Aotearoa New Zealand's population. Importantly,

Māori participant numbers were low, and while the information provided provides vital insight around how some Māori may wish to manage PHCD, the numbers are not large enough to allow confidence that these views are representative of all Māori.

Conclusions

This study provides the first empirical data on the topic of PHCD utilisation, providing contemporary information around Aotearoa New Zealanders attitudes and perceptions regarding the use of PHCD. It finds conditional support for a centralised database of PHCD, a repository that should be primarily held and managed by the government of Aotearoa New Zealand, for the benefit of family and Aotearoa New Zealanders, and subsequently for global benefit. Given this study establishes the platform for a social license to explore PHCD collection and use, perhaps a logical sequelae is not “Where are the data?” but “How can we utilise the data in a culturally, ethically, and socially responsible and acceptable way?”. Further exploration of this topic is required to add perspective on the nuances associated with utilising these precious data in Aotearoa New Zealand, including elements around consent models, data anonymity, and family access. More substantive consultation across a variety of Aotearoa New Zealand locations and ethnicities, in particular Māori and Pasifika, is also necessary to elaborate on these findings, and to consolidate an understanding of what is required to appropriately manage PHCD in this country.

COMPETING INTERESTS

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