

Exploring older peoples' attitudes and preferences around the use of their healthcare information

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ABSTRACT

AIMS: Routinely collected health data can provide rich information for research and epidemiological monitoring of different diseases, but using the data presents many challenges. This study aims to explore the attitudes and preferences of people aged 55 and over regarding the use of their de-identified health data, and their concerns and comfort in different scenarios.

METHODS: An anonymous online survey was conducted with people aged 55 and over currently engaged with health services in a New Zealand health district during June–October 2022. The survey could be completed online or by telephone and was available in eight languages.

RESULTS: Seventy-nine percent of respondents knew that their health information was currently being used in the ways described in the scenarios, and between 80–87% felt comfortable or very comfortable with their data being used as described in the scenarios. In contrast, 4% (n=9) felt “uncomfortable” or “very uncomfortable” across all of the scenarios. Participants expressed concerns about data accuracy, privacy and confidentiality, security, transparency of use, consent, feedback and the risk of data being sold to commercial companies. Some participants identified situations where permission should be required to link data, including being used by people other than health professionals, containing sensitive health issues, or being used for commercial purposes.

CONCLUSION: This study finds general support from patients for the use of their routinely collected data for secondary purposes as long as its use will benefit the population from which the data are taken. It also highlights the necessity of including the perspectives of different cultures in the collection, storage, use and analysis of health information, particularly concerning Māori cultural considerations.

With new technologies for storage, control and analysis, routinely collected health information has become a valuable tool for researching and developing health services. Utilisation of routinely collected data presents many different challenges, such as the quality of the information, proper management of privacy, ethical use of the information in contexts such as research and development, culturally appropriate use of health data and, in the context of New Zealand, the sovereignty of Māori health data.^{1–4}

The use of routinely collected data has facilitated the monitoring of specific health conditions for epidemiological monitoring and improvement of health systems.⁵ In New Zealand, analysis of routinely collected national data has been used to develop a clinical risk tool for cardiovascular disease⁶ and a virtual diabetes register.⁷ In the field of dementia, routinely collected health data have been used to estimate the prevalence of dementia using national datasets; the findings suggested that the prevalence of dementia in Māori

and Pacific Island communities is higher than in other ethnic groups.⁸ However, community-based dementia prevalence data in New Zealand to test the accuracy of these routinely collected health datasets are scarce.⁹ At a more local level, studies using routine health data allow statistical adjustment for potential confounding factors such as comorbidity. These studies suggest there are differences in outcomes for Māori and Pacific Islanders living with dementia (for example, utilisation of dementia services and mortality).^{10–13}

Although routinely collected de-identified data can provide valuable knowledge about the epidemiological characteristics of common chronic diseases in New Zealand, these data have tended to be used without individual consent. To date, there has been little research into peoples' opinions about the use and treatment of their health information. In Canada, McCormick et al. (2019) conducted an online survey to compare the opinions of people about the use of routinely collected data for health research and reported

that close to 80% of the surveyed people felt positive about the use of that information for research.¹⁴ Similarly, Colombo et al. (2019) conducted a survey to understand the opinions and attitudes of people about using their data in clinical studies in Italy. Thirty-nine percent of the participants approved access to health data to researchers and professionals, and identified important topics, such as data de-identification, secure archives and access agreements, as essential aspects of the sharing models.¹⁵

In New Zealand, an online survey (Dobson et al., 2021) conducted at Waitematā District Health Board (DHB) investigated patient perspectives, preferences and comfort levels regarding the use of their health data.¹⁶ In the population of inpatients and outpatients they found that more than 80% of participants (aged 16 to 95 years) were comfortable with how de-identified health information was used across various scenarios. However, many stated that they would require the information collected to be accurate and stored securely within the health system, that privacy was maintained, and the data were only used for the public good. They also expressed a preference for improved communication and transparency around how their data were used.

Our research group is interested in exploring whether routinely collected data can be used to predict future decline in brain health and/or dementia and what might be done to promote resilience of brain health. The Lancet Commission for Dementia^{17,18} described 12 modifiable risk factors for dementia—in early life (education), in middle age (hearing loss, TBI, hypertension, alcohol and obesity) and in later life (smoking, depression, social isolation, physical inactivity, air pollution, diabetes). Some of these risk factors could be identified using routine health data and would allow the identification of groups of people at higher risk at a population level, which might inform population-level interventions targeted at reducing risk of disease. The prevalence of dementia is rising rapidly due to global demographic ageing and is expected to triple between 2015 and 2050.¹⁹ To date, there is no cure for dementia, so researchers worldwide are attempting to find clinical biomarkers that might provide early identification of people at high risk and hopefully intervene before the onset of irreversible dementia. This is a rapidly developing field, particularly with the growing development of artificial intelligence and machine learning methods for diagnosing and detecting risk factors

for various diseases, including dementia, which could be utilised with routinely collected health data.^{20–21}

The early identification of decline in brain health is a controversial area, as dementia is still a highly stigmatised disease,²² and people may not feel comfortable about their health data being used for this purpose, particularly if they fear being identified as being at risk. For that reason, our research group felt that we could not assume that the findings of Dobson et al.¹⁶ (2021) would apply in the specific area of cognitive decline and dementia; thus, we decided to repeat the survey with a focus on brain health.

Our research aimed to explore the attitudes and preferences of people aged 55+ regarding the acceptable use of their de-identified health data and understanding their concerns and comfort in different scenarios related to identification of factors related to cognitive decline and dementia. This would allow New Zealand health institutions and researchers to gain a clearer picture of patients' attitudes and preferences around the use of their de-identified health data in brain health research.

Methods

Participants

People aged 55 and over currently engaged with health services in Te Whatu Ora Counties Manukau were invited to participate in the survey. We chose the cut-off at age 55 because, compared to NZ Europeans, the average age of the onset (or recognition) of dementia is younger for Māori or Pacific peoples living in New Zealand.¹⁰ We included people living with dementia who were known to the Te Whatu Ora Counties Manukau Memory Team and their caregivers. This was done to ensure we had a good representation of people who had lived experience of dementia (either personal or as a caregiver).

The survey sought to gain an understanding of the opinions of older people about the management of their health information, with the following inclusion criteria:

- Currently resident in New Zealand
- Aged 55 years or older
- Currently using health services in Te Whatu Ora Counties Manukau

These criteria were waived for caregivers of a person living with dementia to ensure their inclusion and representation.

Survey design

Our survey was based on the survey constructed by Dobson et al. (2021).¹⁶ A study advisory group with broad representation—including Māori health expertise—drafted questions for Dobson’s survey. The research group, advised by Dobson, adapted the original questionnaire for our target population, referencing brain health. We also asked people if they were willing to be individually interviewed (Q13 in the survey) so that we could go into more depth regarding specific issues for Māori and Pacific Islanders.

The survey included a total of 13 questions, assessing:

- Perceptions about the current use of health information by the health service (Te Whatu Ora Counties Manukau) across six different scenarios (mandatory question).
- Perceived comfort with the use of health information on a Likert scale from 1 (very uncomfortable) to 5 (very comfortable) across the same six scenarios, plus one extra (mandatory question).
- Free-text comments about their level of comfort with the use of health information.
- Free-text comments about situations where permission should be sought before their health information was combined with other peoples’ to better understand the health of the local population.
- Final comments on the use of health information by Te Whatu Ora Counties Manukau.
- Socio-demographic variables, including year of birth and ethnicity.

All participants received the exact same survey without any randomised items, and adaptive questioning was employed when necessary to minimise the burden on respondents and simplify the complexity of the questions. Also, they could review their answers using the “back button” available in the online questionnaire. The complete survey is available in Appendix 1.

A preliminary survey pilot was conducted to evaluate response times, the relevance of the questions, and the design of the data capture and collection instrument. The final survey was administered in Qualtrics and distributed via an anonymised email link.

In the introduction to the survey, we offered the option of conducting the survey by telephone for those who wished to do so, either in English

or in another language: Te Reo Māori, Samoan, Tongan, Mandarin, Cantonese, Hindi or Fijian Hindi.

Ethical approval

This research was approved for three years by Auckland Health Research Ethics Committee AH22266 on 18 October 2021.

Procedures

A link to the online survey was sent by email to outpatients aged 55+ whose email addresses were verified in the Te Whatu Ora Counties Manukau Patient Information Management System (PIMS). The emails were sent to attendees of the Health of Older People outpatient services between 3 January 2019–31 December 2021, including people referred to the memory team, irrespective of the diagnosis made. We invited both patients and their whānau members to be involved in the survey (see survey: Appendix 1). We also specifically invited caregivers of people living with dementia who were current service users of Te Whatu Ora Counties Manukau Memory Team to ensure that their views were included.

Patients (or caregivers of people living with dementia) who wanted to participate but did not wish to complete an online survey were offered the option of an adapted telephone interview. The research assistant conducting the telephone interviews entered the participants’ responses into the online survey in real-time, so that responses remained anonymised, and the information was stored in one database. Participation in the study was entirely voluntary, and no rewards or incentives were offered for taking part. Prior to being granted access to complete the survey, participants were requested to provide their consent.

Statistical analysis

The analysis of the survey data was descriptive, using frequency tables and graphs. Due to the potential risk of identifying participants based on the ethnicity question, certain categories were combined using the ethnicity prioritisation method as outlined by Statistics NZ and further elucidated by Yao et al. (2022).²³ This approach was implemented to ensure the protection of participant privacy and confidentiality. The free-text responses were coded using a simple inductive approach identifying common categories and meanings from the data. The analyses were performed in the statistical software R, version 4.2.1.²⁴

Results

The survey is reported based on the CHERRIES checklist (Appendix 2).

A total of 326 responses (out of 1,314 emails sent; response rate = 24.8%) were received between 7 June 2022 and 5 October 2022, including 15 from the telephone survey (of which four were completed in Fiji Hindi). Of the responses received, 226/326 (69.3%) were rated as “valid,” as they included complete responses to the two mandatory survey questions. No duplicates were identified.

Socio-demographic characteristics

The socio-demographic characteristics of the sample are presented in Table 1. Respondents were mostly NZ European (64.9%), Māori (11.9%) and Asian (10.9%), and their average age was 74.2 (10.6) years. Forty-two percent of the sample knew of a family/whānau member or friend who had been diagnosed with mild cognitive impairment (MCI) or dementia. With respect to caregivers, it is important to note that the responses provided in the data are anonymised, thus precluding the identification of specific individuals in caregiving roles. At least 15 people were caregivers of people living with dementia who were contacted through the Te Whatu Ora Counties Manukau Memory Team. However, 42% of respondents (n=85) reported having a family member or friend living with dementia, so it is reasonable to assume that at least some of these were also caregivers.

Current use of health data

Most participants (179/226, 79.2%) believed that Te Whatu Ora Counties Manukau used their health information in the ways described in all of the six different scenarios (see Figure 1 and Table 2), but up to 15% were unaware that health information from the whole population was combined to look at trends and improve services (scenarios E and F). When we separate this information by whether respondents know a family member/friend living with dementia, the trend does not change. The perception of participants regarding the utilisation of their health data across all proposed scenarios remains independent of having a family member or friend who is living with dementia (See Appendix 3, Table 1).

Level of comfort with use of health information

Figure 2 and Table 3 show that between 79.2

and 86.8% of participants were either comfortable or very comfortable in each of the scenarios proposed (A: 80.2% [n=182], B: 81.9% [n=186], C: 86.8% [n=197], D: 86.3% [n=196], E: 80.1% [n=181], F: 83.2% [n=188] and G: 79.2% [n=179]) and 63.3% [n=143] felt “comfortable” or “very comfortable” across all seven scenarios. In contrast, less than 10% of the respondents felt uncomfortable or very uncomfortable in each of the scenarios presented (A: 7.1% [n=16], B: 8.0% [n=18], C: 5.3% [n=12], D: 5.8% [n=13], E: 8.0% [n=18], F: 7.0% [n=14] and G: 8.4% [n=19]). Four percent (n=9) felt “uncomfortable” or “very uncomfortable” across all of the scenarios. None of the scenarios drew a markedly different response compared to others. Despite the generally high levels of comfort observed (indicated by scores 4 and 5), individuals who have personal knowledge of someone living with dementia exhibit a slight decrease in the frequency of assigning a score of 5 compared to those without such personal connections (see Appendix 3, Table 2).

Free-text comments

Free-text comments about level of comfort and concerns regarding use of personal health data

A total of 54/226 (23.9%) participants commented on their comfort with the use of their health information in the different scenarios. Of those who commented, 57.4% (31/54) felt comfortable with the use of the data in any scenario, although some stated specific conditions for use. Nine respondents (16.7%) were not comfortable, and 14 did not have any relevant comments.

Most expressed the opinion that they were comfortable, provided that health information should be used to improve health services for the local population.

“The wonderful care I have received has been informed, and developed, over time, so am happy that anything learnt about me can be used to help others into the future. Win win!” (Female, 65–74 years, “other” ethnicity)

“As long as it improves the time it takes to get healthcare” (Female, 75–84, NZ European)

Participants were also asked if they had any

concerns about how Te Whatu Ora Counties Manukau uses their data, and 141/226 (61.9%) free-text responses were obtained. These overlapped with the level of comfort comments and were analysed together. Most people (102/141, 72.3%) stated that they had no concerns, but 27.7% mentioned scenarios in which they would have concerns. These themes are presented in Box 1.

Free-text responses regarding permission to combine data

Sixty-four percent of respondents (144/226) commented on situations where permission would be required before combining health data with other data to better understand the entire population's health. Of the 144, 45.8% (n=66) said that obtaining permission to combine health data was not required in any situation, and 18.8% (n=27) specified it would not be necessary to obtain permission if data were de-identified, stored securely, not shared publicly and handled only by health professionals/researchers. Nineteen respondents (13.2%) said that permission should *always* be obtained to combine the data for any situation, and two respondents (1.4%) commented that, although *a priori* consent was not required, they would like to be informed if their data were used. Nineteen respondents (13.2%) responded that they did not know, or their responses did not correspond to the question asked.

Eleven of the 144 respondents (7.6%) specified other situations where permission should be obtained, for example, if the health information:

- is to be used by people other than health professionals/researchers (n=2)
- contains sensitive health issues or identifiable information (n=5)
- is combined with data from an organisation not related to health (n=1)
- is discussed outside the specific health service that collected it (n=1)
- is used for commercial purposes (n=2)

Discussion

This study found that 79% of the people surveyed knew that Te Whatu Ora Counties Manukau currently used their routinely collected health information in the ways described in the scenarios, and 63% were comfortable or very comfortable with their data being used as described. Approximately 10% were not comfortable with

their data being used in the ways described. Participants expressed concerns about the accuracy of data, privacy and confidentiality, security, transparency of use, consent, feedback and the risk of data being sold to commercial companies.

Although the majority of respondents commented that it was not necessary to obtain specific permission for data linkage, there were a range of conditions mentioned that underpinned peoples' comfort with their health information being combined with the health information of others for secondary purposes: data must be anonymous, not shared outside the health service with the public or sold to private companies such as insurers or pharmaceutical companies, and that patients should be informed beforehand about how data will be used.

Our results align with those presented by Dobson et al.,¹⁶ which suggests that older people living in New Zealand have opinions about managing their health data that are similar to that of the wider population. Regarding the current use of health data across the scenarios presented in both Dobson's study and ours, more than 80% of the participants were comfortable or very comfortable with how their data were being used, and less than 10% were uncomfortable or very uncomfortable. Given that the studies had different populations—Dobson's study encompassed a wide age range spanning from 16 to 95 years—while the present study specifically focussed on the opinions and preferences of older individuals with a mean age of 74 years. Additionally, Dobson's study was conducted in Te Whatu Ora Waitematā, whereas the current study took place in Te Whatu Ora Counties Manukau—the finding supports that most people agree with their de-identified data being used for the greater good, as long as key conditions are met around the protection, storage and care of the data. Our findings also coincide with those of Rezaei et al. (2021), who surveyed a sample of healthcare professionals regarding ethical challenges in using health data.²⁵ The main issues were privacy, autonomy and security. Papoutsi et al. (2015) surveyed patients from primary and secondary care settings in West London (United Kingdom)²⁶ and found similar concerns about data inaccuracies, prejudice “about sexual or mental health and being labelled as ‘hypochondriac’ or as having social problems,” and potential security and privacy threats; however, the majority of participants were in favour of using data for personal healthcare provision

Table 1: Socio-demographic characteristics of respondents.






		%
Ethnicity (n=202)*	Asian	11
	Māori	12
	NZ European	65
	Pacific	6
	Other	6
Age (n=201)*	<55	4
	55–64	14
	65–74	22
	75–84	47
	>=85	13
Gender (n=202)*	Female	56
	Male	44
Know a family member/friend with dementia or mild cognitive impairment (n=202)*	Yes	42
	No	49
	Don't know	9

*Completed responses

Table 2: Current use of health information.

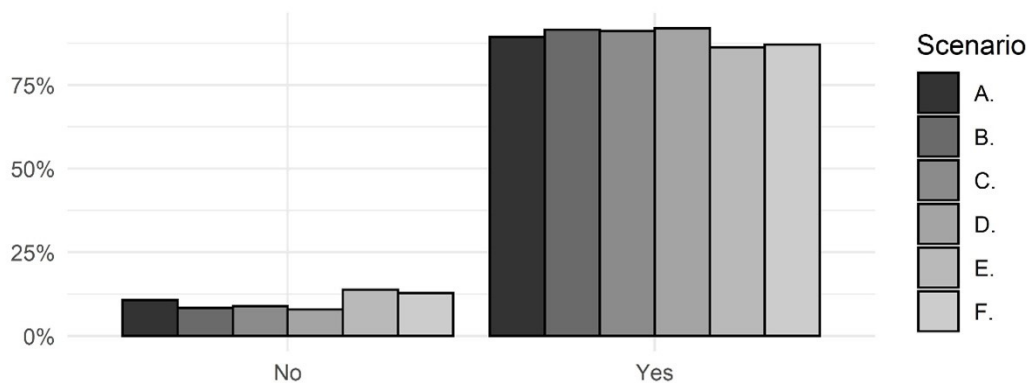
Scenario	Yes	No	Total
A. To make decisions about your healthcare now.	202	24	226
B. To make decisions about your healthcare in the future.	207	19	226
C. To share with other health professionals involved in your care in this organisation.	206	20	226
D. To share with other health professionals involved in your care in other organisations (e.g., your GP, a private hospital, a hospital in another city).	208	18	226
E. To make decisions about improving Counties Manukau services (e.g., combining health information from lots of people to inform and improve the care for other patients using these services in the future).	195	31	226
F. To investigate how to better understand our population and their needs by combining information on our whole population to look at trends (e.g., to investigate how some health conditions could be linked to decline in brain health as we get older and to see how we can help people to keep their brains healthy as they age).	197	29	226

Table 3: Level of comfort for use of health information.

Scenario	Level of comfort*					Total
	1 	2 	3 	4 	5 	
To make decisions about your healthcare now.	15	1	28	50	132	226
To make decisions about your healthcare in the future.	11	7	22	57	129	226
To share with other health professionals involved in your care in this organisation.	9	3	17	58	139	226
To share with other health professionals involved in your care in other organisations (e.g., your GP, a private hospital, a hospital in another city).	10	3	17	61	135	226
To make decisions about improving Counties Manukau health services (e.g., combining health information from lots of people to inform and improve the care for other patients using these services in the future).	10	8	27	56	125	226
To investigate how to better understand our population and their needs by combining information on our whole population to look at trends (e.g., to investigate how some health conditions could be linked to decline in brain health as we get older and to see how we can help people to keep their brains healthy as they age).	10	4	24	63	125	226
To continue to help others even once you have died, or have moved out of our district, where your information continues to be useful and contributes to the full picture for two statements above. This is because removing health information of people can give us an incorrect or incomplete picture of what happened.	14	5	28	57	122	226

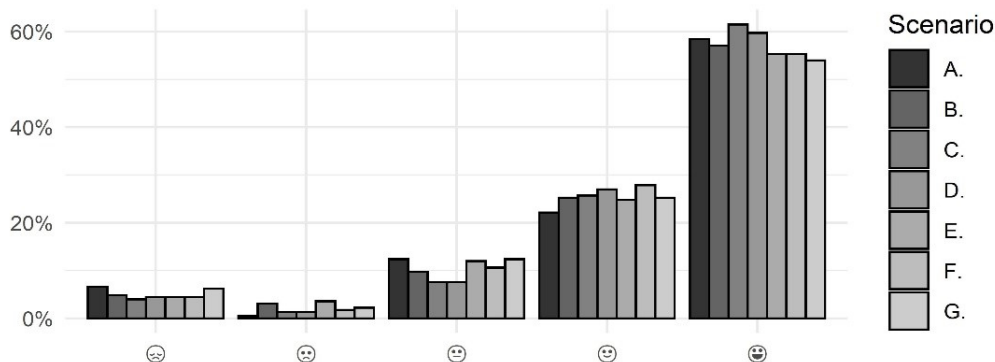
*Scale: 1 (very uncomfortable) through to 5 (very comfortable) with how health information is used now.

Figure 1: How people think Te Whatu Ora Counties Manukau currently use their health data.



- A. To make decisions about your health care now.
- B. To make decisions about your health care in the future.
- C. To share with other health professionals involved in your care in this organisation.
- D. To share with other health professionals involved in your care in other organisations.
- E. To make decisions about improving Counties Manukau services.
- F. To investigate how to better understand our population and their needs by combining information on our whole population to look at trends.

Figure 2: Comfort level with how Te Whatu Ora Counties Manukau used their health data.



- A. To make decisions about your health care now.
- B. To make decisions about your health care in the future.
- C. To share with other health professionals involved in your care in this organisation.
- D. To share with other health professionals involved in your care in other organisations.
- E. To make decisions about improving Counties Manukau services.
- F. To investigate how to better understand our population and their needs by combining information on our whole population to look at trends
- G. To continue to help others even once you have died or have moved out of our district where your information continues to be useful and contributes to the full picture for two statements above.

Box 1: Areas of concern regarding the use of routinely collected health data.

<p>Accuracy of data</p> <p><i>“My concern would be, how often is your information up to date and current? How transparent is your procedure in how you gather the information, and are your procedures authentic and culturally responsive to elderlies from all ethnicities?”</i> (Female, 75–84, Pacific)</p> <p><i>“Data can be incorrectly put into a computer ... imperfect humans can have their own agenda.”</i> (Female, 75–84, NZ European)</p>
<p>Privacy and confidentiality</p> <p><i>“Security of my name etc. being linked to my health conditions, as I regard this as a priority and only to be shared with the health officials. I assume that there is adequate protection/process to ensure patient details are totally kept confidential. I have nothing to hide but it is information about myself which I would only want used in the healthcare environment.”</i> (Male, 55–64, NZ European)</p>
<p>How the data are used</p> <p><i>“I don’t believe basing your decisions about my healthcare now or in the future should solely be based on what you have on the data base you hold.”</i> (Female, 75–84, Pacific)</p> <p><i>“In my experience, unless you speak to people concerned directly, too much information is taken out of context distorting facts. Medical records are exceptionally bad for this.”</i> (Female, 55–64, NZ European)</p> <p><i>“Grouping people for statistics and planning is one thing, but for actual delivery of medicine the individual must always be front and centre. As with any group of people, older people can be stereotyped, and this does not necessarily lead to the best individual health outcomes.”</i> (Female, 65–74, NZ European)</p>
<p>Consent to use data and feedback on how health information has been used</p> <p><i>“I would like them to ring me up first before using/sharing my data.”</i> (Female, 65–74, Māori)</p> <p><i>“It would be nice to get feedback on how my information has helped collaboratively to create/determine/understand health of, specifically, my population.”</i> (Female, 65–74, Māori)</p>
<p>Use of data from deceased patients</p> <p><i>“Once I am passed my specific information dies with me.”</i> (Male, 55–64, Māori)</p> <p><i>“Not to use my personal health information after I am gone, only for my immediate family.”</i> (Female, 55–64, Māori)</p>
<p>Data being sold to private companies</p> <p><i>“As long as there is no sell out—you know how modern technology can sometimes do weird things and make mistakes. Whether it’s a machine/human error, as long as it’s been protected.”</i> (Female, 75–84, Pacific)</p> <p><i>“(Not) In situations where it will be used for marketing purposes.”</i> (Female, >85, Asian)</p>

(89.7%), for health services policy and planning (79.5%), or for research (81.4%). The authors concluded that public participation and transparency are the pillars to establish the limits of the information to be shared and how researchers and medical personnel should access the data.²⁶

A limitation of our study is the generalisability of the results. According to the 2018 population census,²⁷ the distribution of ethnicity in the Counties Manukau population aged 65+ was 7% Māori, 12% Pacific Islanders, 20% Asian and 60% NZ European. The ethnic breakdown of our sample was partially representative of the local population (12% Māori, 6% Pacific Islanders, 11% Asian and 65% NZ European), but the small sample size did not allow us to fully explore inter-ethnic differences in responses. In addition, about 25% of patients in the Te Whatu Ora Counties Manukau Memory Team have verified email addresses, contributing to the under-representation of different ethnicities in the responses. To address this issue, alternative sampling techniques should be implemented to ensure a more comprehensive representation of all ethnicities.

For Māori people, data should be considered as taonga, which relates to the idea that data are owned collectively by one or more whānau and are covered by rights, with obligations for active protection of that power by the Crown.²⁸ Further work is required to delve deeper into the use of healthcare information and the implications for Māori Data Sovereignty, the inherent rights and interests that Māori have in relation to the collection, ownership and application of Māori data.²⁹ It was notable that several Māori respondents did not agree to their data being used after their death, because one tikanga perspective is that the deceased are tapu and items belonging to the deceased are to be destroyed.³⁰ More work needs to be done to address Māori data concerns, particularly post-mortem data, which are important predictors of mortality and need to be analysed in research. Such concerns might indicate that IT-system design needs to be considered

to reflect a culturally responsive system that aligns with the use of routinely collected health data relevant to examination of *mate wareware* (dementia) from a Māori perspective.³¹ Current health IT systems are not designed to give patient control over the use of their data (for example, to opt out of research that is deemed not culturally appropriate). Adequately addressing cultural considerations with respect to data use may place demands on IT systems for greater patient control over their data and effective consent mechanisms for the use of their data.

The results of our study suggest that health services need to reflect on how best to use and protect peoples' health data—a rich resource—while also respecting peoples' rights to say how their data are used. Our findings are a first step towards describing older peoples' opinions about how to use their health data for health research around brain health. The next phase of the study will focus on conducting more in-depth individual interviews to gain a deeper understanding of peoples' opinions in different scenarios regarding the use of their health data. This could be particularly relevant for Māori, Pacific Island and Asian communities, who may possess distinct perspectives that differ from the majority of the survey sample, which predominantly was NZ European (65%).

Conclusion

Our findings indicate that these respondents are supportive of their health information being used for secondary purposes to benefit others, but there are conditions/limitations to this comfort that researchers need to consider, ensuring they use health information in a patient-informed way. It also highlights the necessity of including the perspectives of different cultures in the collection, storage, use and analysis of health information, particularly with respect to Māori cultural considerations.

COMPETING INTERESTS

Nil.

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Appendices

Appendix 1: Counties Manukau DHB* survey on use of your health information.

We warmly invite patients and their whānau members aged 55 and over using the Counties Manukau DHB Memory Service or other older peoples' health services to take a short survey on how their health information is used by the DHB.

The following information will help you decide whether you would like to take part.

What is the aim:

The aim of this survey is to improve our understanding of how people want Counties Manukau to use their health information and their concerns about how it is used. We would like to check what you think about how we currently use your health information, and what we should and should not do with it in the future.

We have a particular interest in using health information to explore whether some health conditions might contribute to a decline in brain health as we get older. So, we are asking people who have recently been seen by the Memory Service and/or other older peoples' health services in Counties Manukau, and their whānau/family members.

Who has authorised this study and who is undertaking it:

This research was approved for three years by Auckland Health Research Ethics Committee AH22266 on 18/10/21. The study is being undertaken by researchers at the University of Auckland and Counties Manukau Health. The study is funded by the New Zealand Health Research Council.

Researchers:

Assoc Prof Sarah Cullum, The University of Auckland & CMDHB Memory Service
Dr Yu-Min Lin, Consultant Geriatrician, Middlemore Hospital, CMDHB
Dr Daniel Wilson (Ngāpuhi, Ngāti Pīkiao), School of Computer Science, The University of Auckland
Prof Gill Dobbie, School of Computer Science, The University of Auckland

What are you being asked to do?

- Your participation in this survey is totally your choice and voluntary.
- When you click on the link below you are indicating your consent to take part in this study.
- The survey is anonymous so once you have finished and clicked on the submit button you cannot withdraw your information from the study.
- By taking part in this survey you are indicating that you:
 - have read this information
 - live in New Zealand
 - are 55 years of age or more
 - are currently using an older peoples' health service at CMDHB and/or you are a whānau member of someone using the service
- If you do agree to take part, you may stop answering questions at any time.
- Whether or not you participate in this survey, and your response if you do, will not in any way impact on the care you are receiving from your healthcare team.
- The survey should take you about 10 minutes to complete.

What will be done with the information from this survey?

The survey information will be stored securely at The University of Auckland for 10 years and then destroyed according to The University of Auckland research code of conduct guidelines.

Your name will not be recorded on the survey. No information that could personally identify you will be used in any report from this survey. We will combine the anonymous responses from all participants for analysis.

The results will be presented at conferences and published in a research journal. The findings of the survey will be shared with the funders of this study and also with the staff at Counties Manukau.

Appendix 1 (continued): Counties Manukau DHB* survey on use of your health information.

Telephone survey option

If you would prefer to take this anonymous survey by telephone either in English or in another language (eg., Te Reo Māori, Samoan, Tongan, Mandarin, Cantonese, Hindi, or Fijian Hindi) we may be able to help you. Whichever way you choose it will be confidential—your answers will be entered on to the anonymous survey but not your name.

Thank you for taking time to read about this study. Thank you in advance for taking part and helping to increase our understanding of how our patients want us to use their health information.






By clicking on the next button to begin the survey you are indicating that you consent to take part in this study.

* Counties Manukau DHB is the previous name for the health service, now renamed Te Whatu Ora Counties Manukau, which is how it is referred to in the article

START SURVEY				
<p>Health information is any information that we collect about you during your visit. This information is used to guide your treatment and may be shared with your GP (general practitioner) for your ongoing care.</p> <p>We would like to check what you think about how we currently use your health information, and what we should and should not do with it in the future.</p> <p>There are a number of terms used in this survey, this is what they mean:</p> <p>Healthcare = any services provided to you by health professionals (in hospitals, clinics, primary care, community centres, at home)</p> <p>Older peoples' health services = any health services provided for older people</p> <p>Health information = is any information regarding your health, or any health or disability services provided to you. This could include information such as appointment times, health conditions/illnesses, demographic information (e.g., age, gender, ethnicity), and test information (e.g., blood results, brain scans).</p> <p>Health professional = Any person that is involved in providing you with healthcare services e.g., doctor, nurse, physiotherapist, radiographer.</p>				
Q1	Considering the health information (e.g., information about your age, gender, ethnicity, diagnosis, tests, treatments) that Counties Manukau collects about you, do you think that we are using this health information:*			
			Yes	No
	a	To make decisions about your healthcare now.	<input type="radio"/>	<input type="radio"/>
	b	To make decisions about your healthcare in the future.	<input type="radio"/>	<input type="radio"/>
	c	To share with other health professionals involved in your care in this organisation.	<input type="radio"/>	<input type="radio"/>
	d	To share with other health professionals involved in your care in other organisations (e.g., your GP, a private hospital, a hospital in another city).	<input type="radio"/>	<input type="radio"/>
e	To make decisions about improving Counties Manukau services (e.g., combining health information from lots of people to inform and improve the care for other patients using these services in the future).	<input type="radio"/>	<input type="radio"/>	

Appendix 1 (continued): Counties Manukau DHB* survey on use of your health information.

f	To investigate how to better understand our population and their needs by combining information on our whole population to look at trends (e.g., to investigate how some health conditions could be linked to brain health as we get older and to see how we can help people to keep their brains healthy as they age).	<input type="radio"/>	<input type="radio"/>
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Q2	How comfortable do you feel with your health information being used in the following ways on a scale from 1 to 5 where 1 is “ very uncomfortable ” and 5 is “ very comfortable ”:*						
			1	2	3	4	5
							
	a	To make decisions about your healthcare now.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	b	To make decisions about your healthcare in the future.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	c	To share with other health professionals involved in your care in this organisation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	d	To share with other health professionals involved in your care in other organisations (e.g., your GP, a private hospital, a hospital in another city).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	e	To make decisions about improving CM-DHB health services (e.g., combining health information from lots of people to inform and improve the care for other patients using these services in the future).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	f	To investigate how to better understand our population and their needs by combining information on our whole population to look at trends (e.g., to investigate how some health conditions could be linked to brain health as we get older and to see how we can help people to keep their brains healthy as they age).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g	To continue to help others even once you have died or have moved out of our district where your information continues to be useful and contributes to the full picture for (e) and (f) above. This is because removing health information of people can give us an incorrect or incomplete picture of what happened.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

Appendix 1 (continued): Counties Manukau DHB* survey on use of your health information.

Q3	You can make any comments on your level of comfort on any of the above uses of health information here:
Q4	In which situations would you want us to get your permission before we combine your data with other peoples' to better understand the health of our population?
Q5	Do you have any further concerns about how we (Counties Manukau) look after or use your health information?
<p>The following questions are about you so we can look at patterns in responses to this survey and to make sure a range of people have completed the survey:</p> <p>(The following questions are optional)</p>	
Q6	Which year were you born? (e.g., 1954) Year:
Q7	What is your gender? <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Another gender
Q8	Which suburb do you normally live in? (e.g., Māngere, Papakura, Howick)
Q9	Which ethnic group do you belong to? Mark the box or boxes which apply to you. <input type="checkbox"/> NZ European <input type="checkbox"/> Māori <input type="checkbox"/> Samoan <input type="checkbox"/> Cook Island Māori <input type="checkbox"/> Tongan <input type="checkbox"/> Niuean <input type="checkbox"/> Chinese <input type="checkbox"/> Indian <input type="checkbox"/> Other such as Dutch, Japanese, Tokelauan. Please state:

Appendix 1 (continued): Counties Manukau DHB* survey on use of your health information.

Q10	Are you descended from a Māori (that is, did you have a Māori birth parent, grandparent, or great-grandparent, etc)? <input type="checkbox"/> Yes <input type="checkbox"/> Don't know <input type="checkbox"/> No				
	<table border="1" style="width: 100%;"> <tr> <td style="width: 10%;">Q10a</td> <td>Do you know the name(s) of your iwi (tribe or tribes)? <input type="checkbox"/> Yes <input type="checkbox"/> No</td> </tr> <tr> <td>Q10b</td> <td>Give the name(s) and region(s) of your iwi (tribe or tribes): Iwi: Region: Iwi: Region: Iwi: Region: Iwi: Region:</td> </tr> </table>	Q10a	Do you know the name(s) of your iwi (tribe or tribes)? <input type="checkbox"/> Yes <input type="checkbox"/> No	Q10b	Give the name(s) and region(s) of your iwi (tribe or tribes): Iwi: Region: Iwi: Region: Iwi: Region: Iwi: Region:
Q10a	Do you know the name(s) of your iwi (tribe or tribes)? <input type="checkbox"/> Yes <input type="checkbox"/> No				
Q10b	Give the name(s) and region(s) of your iwi (tribe or tribes): Iwi: Region: Iwi: Region: Iwi: Region: Iwi: Region:				
Q11	If you live in New Zealand but were not born here, answer this question. Which year did you first arrive to live in New Zealand? (e.g., 1974) Year:				
Q12	Do you have a family/whānau member or friend who has been diagnosed with mild cognitive impairment (MCI) or dementia? (yes/no) <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I don't know				
Q13	We are hoping to talk to some people about the issues in this survey in more detail, either face-to-face or online, using Zoom. If you click on the “yes” button, you will be directed to a separate database which is not connected to this survey—your answers to the survey will still remain anonymous. We will contact you in a few months to see if you are still interested. There is no obligation to participate, and you are free to change your mind. Are you interested in participating in the next phase of the study? If you click on the yes button, you will be redirected to a separate database after you click on the submit button below. <input type="checkbox"/> Yes <input type="checkbox"/> No				
Thank you for taking the time to complete this survey.					

Appendix 2: Checklist for reporting results of internet e-surveys (CHERRIES).

Item category	Checklist item	Explanation
Design	Describe survey design	A consecutive sample of people who are aged 55 and over, currently resident in New Zealand, engaged with health services in Te Whatu Ora Counties Manukau, and have a verified email address. We included people living with dementia who were known to the Te Whatu Ora Counties Manukau Memory Team and their caregivers.
Institutional Review Board (IRB) approval and informed consent process	IRB approval	This research was approved for three years by Auckland Health Research Ethics Committee AH22266 on 18 October 2021.
	Informed consent	Participant information was presented in the first part of the survey document. After they read the information, we presented a button: “by clicking on the next button to begin the survey, you are indicating that you consent to take part in this study.”
	Data protection	The survey did not ask for personal information. Every answer was completely anonymous.
Development and pre-testing	Development and pre-testing	The survey was adapted from Dobson et al. (2021). The changes were discussed with the research team and Advisory Group. The survey was carried out on Qualtrics, and we conducted two pilot studies: the first one within the research team and the second with volunteers from a population similar to the target population.
Recruitment process and description of the sample having access to the questionnaire	Open survey versus closed survey	This was a closed survey. We sent the link to the questionnaire via email to people who met the inclusion criteria.
	Contact mode	The initial contact with the potential participants was through verified email addresses held on file by Te Whatu Ora Counties Manukau.
	Advertising the survey	We did not advertise the survey.
Survey administration	Web/email	The link to the survey was sent out through email. The link was generated from Qualtrics, and the responses were stored in the Qualtrics database.
	Context	NA—a website was not used for our survey
	Mandatory/voluntary	This was a voluntary survey. We sent out the link to the list of email addresses, and they answered voluntarily.
	Incentives	No incentives.
	Time/date	7 June 2022–5 October 2022

Appendix 2 (continued): Checklist for reporting results of internet e-surveys (CHERRIES).

Item category	Checklist item	Explanation
Survey administration	Randomisation of items or questionnaires	We did not randomise the items.
	Adaptive questioning	Yes, conditional to Q10: are you descended from a Māori (that is, did you have a Māori birth parent, grandparent, or great-grandparent, etc.)? We displayed Q10a: do you know the name(s) of your iwi (tribe or tribes)? if they selected “yes”. Likewise, we displayed Q10b: give the name(s) and region(s) of your iwi (tribe or tribes) if they selected “yes” in Q10a.
	Number of items	Page 1: presentation of the survey. Page 2: one question (Q1). Page 3: two questions (Q2, Q3). Page 4: two questions (Q4, Q5). Page 5: seven questions (Q6–Q12). Page 6: one question (Q13).
	Number of screens (pages)	Six.
	Completeness check	Q1 and Q2 were mandatory. They were highlighted as mandatory, and the respondent could not continue the survey without first answering those two questions. The others were non-mandatory. For Q10: are you descended from a Māori (that is, did you have a Māori birth parent, grandparent, or great-grandparent, etc.)? and Q12: do you have a family/whānau member or friend who has been diagnosed with mild cognitive impairment (MCI) or dementia? we offered the option “I don’t know.”
	Review step	Respondent could review their answers using the back button in the questionnaire.
Response rates	Unique site visitor	Qualtrics associated every response with an IP address. We used the IP address to identify if the respondent was unique. We did not have duplicates.
	View rate (ratio of unique survey visitors/unique site visitors)	NA
	Participation rate (ratio of unique visitors who agreed to participate/ unique first survey page visitors)	326/326

Appendix 2 (continued): Checklist for reporting results of internet e-surveys (CHERRIES).

Item category	Checklist item	Explanation
Response rates	Completion rate (ratio of users who finished the survey/users who agreed to participate)	226/326 completed the two mandatory questions and were considered the “valid” sample.
Preventing multiple entries from the same individual	Cookies used	NA
	IP check	Qualtrics associated every response with an IP address. We used the IP address to identify if the respondent was unique. We did not have duplicates.
	Log file analysis	NA
	Registration	Respondents could leave the survey and finish later. We were able to monitor that from the Qualtrics control. When the period of the survey finished, we collected all the incomplete surveys.
Analysis	Handling of incomplete questionnaires	As Q1 and Q2 were the two mandatory survey questions, we only analysed information from those surveys that had completed the two mandatory questions (n=226). The other questions were optional, so we had some missing data. We reported the number of responses and missing data in the paper.
	Questionnaires submitted with an atypical timestamp	We evaluated the time stamps for the 226 “valid” responses and did not find any atypical ones. On average, respondents took 55 minutes to answer the survey, including people that stopped and came back later to finish the survey.
	Statistical correction	We did not apply any statistical correction for non-response.

Appendix 3: Knowledge and comfort level of respondents by whether the respondent has a family member/friend living with dementia.

Appendix 3, Table 1: How people think Te Whatu Ora Counties Manukau currently use their health data by whether the respondent has a family member/friend living with dementia.

Scenario		Knowing family member/friend with dementia		
		Yes (n=85)	No (n=99)	Don't know (n=18)
A. To make decisions about your healthcare now.	Yes	92%	92%	67%
	No	8%	8%	33%
B. To make decisions about your healthcare in the future.	Yes	93%	92%	83%
	No	7%	8%	17%
C. To share with other health professionals involved in your care in this organisation.	Yes	89%	94%	89%
	No	11%	6%	11%
D. To share with other health professionals involved in your care in other organisations (e.g., your GP, a private hospital, a hospital in another city).	Yes	92%	94%	89%
	No	8%	6%	11%
E. To make decisions about improving Counties Manukau services (e.g., combining health information from lots of people to inform and improve the care for other patients using these services in the future).	Yes	84%	90%	83%
	No	16%	10%	17%
F. To investigate how to better understand our population and their needs by combining information on our whole population to look at trends (e.g., to investigate how some health conditions could be linked to decline in brain health as we get older and to see how we can help people to keep their brains healthy as they age).	Yes	86%	88%	83%
	No	14%	12%	17%

Appendix 3, Table 2: Comfort level with how Te Whatu Ora Counties Manukau used their health data by whether the respondent has a family member/friend living with dementia.

Scenario		Knowing family member/friend with dementia		
		Yes (n=85)	No (n=99)	Don't know (n=18)
To make decisions about your healthcare now.	1 😞	8%	6%	0%
	2 😐	1%	0%	0%
	3 😊	13%	6%	22%
	4 😄	22%	19%	17%
	5 😁	55%	69%	61%
To make decisions about your healthcare in the future.	1 😞	6%	5%	0%
	2 😐	4%	4%	0%
	3 😊	14%	5%	17%
	4 😄	25%	20%	17%
	5 😁	52%	66%	67%
To share with other health professionals involved in your care in this organisation.	1 😞	5%	4%	0%
	2 😐	1%	2%	0%
	3 😊	7%	4%	11%
	4 😄	34%	16%	22%
	5 😁	53%	74%	67%
To share with other health professionals involved in your care in other organisations (e.g., your GP, a private hospital, a hospital in another city).	1 😞	5%	5%	0%
	2 😐	2%	1%	0%
	3 😊	6%	6%	17%
	4 😄	31%	22%	11%
	5 😁	56%	66%	72%
To make decisions about improving Counties Manukau health services (e.g., combining health information from lots of people to inform and improve the care for other patients using these services in the future).	1 😞	5%	5%	0%
	2 😐	5%	3%	0%
	3 😊	12%	7%	22%
	4 😄	27%	23%	6%
	5 😁	52%	62%	72%

Appendix 3, Table 2 (continued): Comfort level with how Te Whatu Ora Counties Manukau used their health data by whether the respondent has a family member/friend living with dementia.

Scenario		Knowing family member/friend with dementia		
		Yes (n=85)	No (n=99)	Don't know (n=18)
To investigate how to better understand our population and their needs by combining information on our whole population to look at trends (e.g., to investigate how some health conditions could be linked to decline in brain health as we get older and to see how we can help people to keep their brains healthy as they age).	1 😞	6%	4%	0%
	2 😐	0%	3%	0%
	3 😊	8%	8%	11%
	4 😄	34%	21%	17%
	5 😁	52%	64%	72%
To continue to help others even once you have died or have moved out of our district where your information continues to be useful and contributes to the full picture for two statements above. This is because removing health information of people can give us an incorrect or incomplete picture of what happened.	1 😞	8%	6%	0%
	2 😐	2%	1%	0%
	3 😊	9%	10%	22%
	4 😄	29%	22%	11%
	5 😁	51%	61%	67%