

**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.

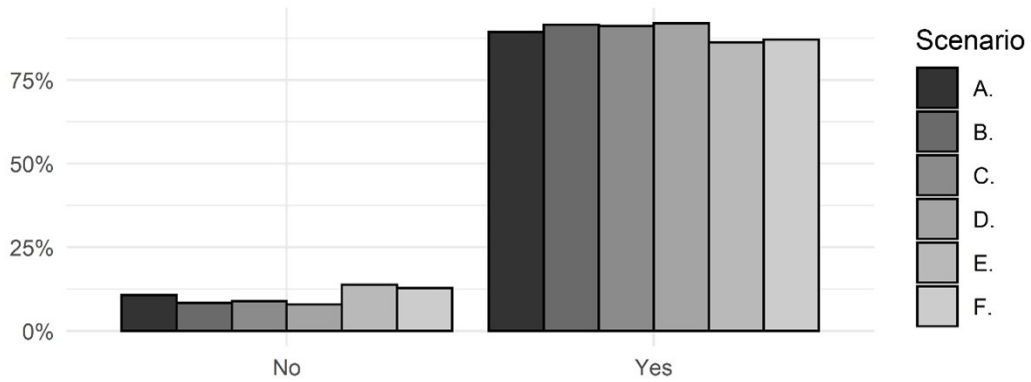
Scenario	Yes	No	Total
A. To make decisions about your healthcare now.	202	24	226
B. To make decisions about your healthcare in the future.	207	19	226
C. To share with other health professionals involved in your care in this organisation.	206	20	226
D. To share with other health professionals involved 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

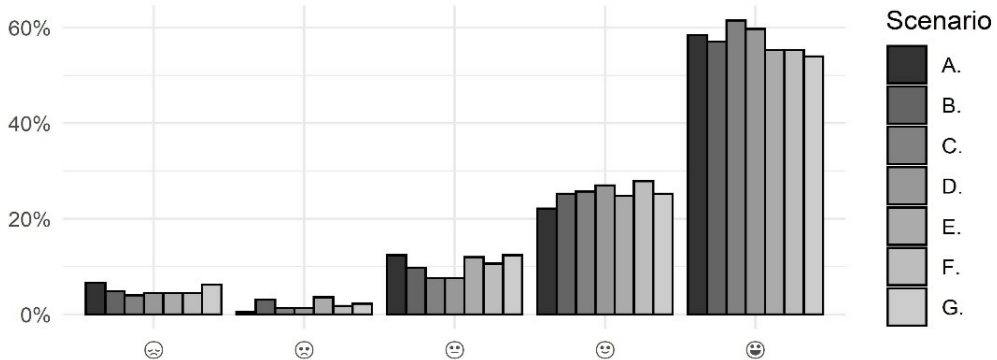
\*Scale: 1 (very uncomfortable) through to 5 (very comfortable) with how health information is used now.

**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><b>Accuracy of data</b></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><b>Privacy and confidentiality</b></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><b>How the data are used</b></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><b>Consent to use data and feedback on how health information has been used</b></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><b>Use of data from deceased patients</b></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><b>Data being sold to private companies</b></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, &gt;85, Asian)</p>