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Aotearoa New Zealand Public Perceptions of the Use of Personal Health Information

18 January 2022

Acknowledgements

Thank you to the New Zealanders who gave their time to participate in this survey.

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Citation: Dobson R, Whittaker R, Garner K, et al. 2022. *Aotearoa New Zealand Public Perceptions of the Use of Personal Health Information*. Wellington: Ministry of Health.

Published in April 2022 by the Ministry of Health
PO Box 5013, Wellington 6140, New Zealand

ISBN 978-1-99-110031-3 (online)



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Executive summary

It is vital that New Zealanders' preferences around the use of their health information are prioritised as the potential uses for health data increase. A cross-sectional survey was conducted to gather the perceptions of the Aotearoa New Zealand public on using their personal health information by health services and organisations. A total of 2,572 previous respondents of the New Zealand Health Survey completed the survey.

Findings indicate that the majority of respondents are comfortable with their health information being used in the scenarios presented with the following conditions:

- The use of their data is for the greater good or to benefit others.
- It is stored securely to prevent breaches.
- Their privacy is prioritised, and only anonymised data is shared beyond their immediate care.
- That data is not shared outside the health system (e.g. insurance or commercial companies) or used for commercial gain.
- There is communication and transparency around its use.
- The information is up-to-date and correct.

At the same time, a small but significant proportion of respondents are uncomfortable with the use of their personal health information because of mistrust in the health systems or health services. Further, some respondents would only be comfortable with the use of their health information if they have provided specific consent, and some would be uncomfortable with any use beyond their immediate care.

It appears that respondents are happy for their health information to be used without specific consent if it is anonymous (i.e. no personal or identifying information is shared), the use of the data is for the right reasons (to benefit others), the security of the data is assured, and the data (or the combined dataset) is not shared outside the health system.

If the health information is to be used in the following situations, then personal consent/permission for its use is needed:

- When personal (identifiable) information is included in the dataset.
- When data is being sent or shared outside the health system or used for commercial purposes.
- When data is sensitive in nature, including DNA/genetic data, mental health, sexual health, rare diseases, specific medical conditions, gynaecology information, terminal illness, or COVID-19 related data.
- When the data is specific to a population group e.g. Māori, minors.

Respondents expressed concerns over security risks, privacy and confidentiality, the use of health information outside the health system, and the lack of transparency and communication. Many of these concerns could be addressed by increased communication and transparency around the use and protection of personal health information.

1 Background

As the digitisation of health records progresses, opportunities for health data use grow. It is vital that New Zealanders' preferences around the use of, and access to, their health information are prioritised to ensure that health services use the data in a patient and whānau-informed manner.

In 2020 a survey was undertaken in Waitematā District Health Board (DHB) by researchers from the University of Auckland to assess patient perspectives, including preferences, needs and concerns, on the use of, and access to, individual healthcare information. The project was overseen by a study advisory group with representation from health service consumers as well as experts from a range of settings including the DHB (clinicians, funding and planning, Māori Health, and innovation), primary care, and the University of Auckland. The development of the questions involved extensive consultation with members of the advisory group as well as pretesting with patients within hospital services. A total of 1,377 patients currently using Waitematā DHB inpatient and outpatient services completed the survey with over 80% of participants reporting that they were comfortable with their health information being used across the scenarios presented (range: 81-89%). Māori were significantly more likely than non-Māori to be comfortable with their health information being combined with the health information of others to better understand population needs ($p=0.006$). The level of comfort with the use of individual health information was related to assurances that its use was for public good, data was stored securely, individual privacy was maintained, the information was accurate, and there was communication on how it was used. These findings showed that most health care consumers are comfortable with the health service using their de-identified health information beyond their care if it benefits others. Further information about his survey can be found in the published paper.¹

Following the completion of the Waitematā DHB survey of healthcare consumers, the Ministry of Health was interested in further exploring the perceptions of the use of their health information from members of the general population. This report presents the findings of the administration of the survey within the general population in late 2021.

2 Methods

A cross-sectional survey was conducted to gather the perceptions of the New Zealand public on the use of their personal health information by health services and organisations. The survey was based on the previous survey administered to Waitematā DHB patients in late 2020.¹ Minor wording changes were made to the survey for the context of a national public survey (e.g. instead of referring to how the DHB uses health information, it was updated to refer to how 'health services and organisations' use health information). The extensive process undertaken to develop and pretest of the survey are described in the published paper.¹

The survey covered the following:

- Introduction and definitions
- Perceptions on how health services currently use health information
- Level of comfort with health information being used in different ways
- Situations where permission is needed before individual health information is combined with others
- Concerns about how health information is used
- Demographics

CBG, an independent provider of public sector research services in New Zealand and who administers the New Zealand Health Survey, sent an invitation to participate in the survey to previous New Zealand Health Survey respondents who had self-identified as willing to participate in future surveys. To participate, respondents needed to meet the following inclusion criteria:

- Have previously completed a New Zealand Health Survey and consented to be contacted regarding future surveys and provided an email address
- Be 16 years or older
- Live in Aotearoa New Zealand

The survey was administered online with the invitation sent via email. Surveys were considered complete when all compulsory questions were answered, and only complete surveys were included in the analysis. Survey data were analysed and summarised using descriptive quantitative analyses. Chi-square tests were used to assess differences between groups. All statistical tests were two sided at a 5% significance level. Qualitative comments were analysed using a simple general inductive thematic approach to identify common themes and meanings from the data.² Ethnicity was coded as per New Zealand Ministry of Health Protocol for the reporting of ethnicity data, with both the total response (overlapping) and prioritised ethnicity output methods reported.³

3 Results

3.1 Sample

CBG sent the survey invitation to 9,215 people from the New Zealand Health Survey mailing list. A total of 3,139 (34.1%) people responded to the survey with 2,575 (27.9%) completing the survey. There were three survey responses that were excluded from the analysis due to the respondents not meeting the inclusion criteria (resided outside New Zealand) therefore the final sample includes 2,572 respondents. The demographic characteristics of survey respondents can be seen in Table 1.

Table 1: Demographic information (n=2,572)

	n	%
Age group		
≤34	395	15.4
35–54	880	34.2
55–74	901	35.0
≥75	178	6.9
Missing	218	8.5
Age (mean (SD), range)	52 (16)	16–100
Gender		
Male	1,042	40.5
Female	1,364	53.0
Another gender	13	0.5
Missing	153	5.9
Ethnicity (non-prioritised)*		
European	1,735	67.5
Māori	385	15.0
Pacific peoples	250	9.7
Asian	361	14.0
MELAA	24	0.9
Other ethnicity	1	0.0
Residual categories	166	6.5
Ethnicity (prioritised, Level 1³)		
Māori	385	15.0
Pacific	227	8.8
Asian	348	13.5
MELAA	23	0.9
Other Ethnicity	0	0.0
European	1,426	55.4
Residual categories	163	6.3
Descended from Māori		
Yes	436	17.0
No	1,882	73.2
Don't know	93	3.6
Missing	161	6.3
New migrant[#]	192	7.5

MELAA: Middle Eastern/Latin American/African; SD: Standard Deviation

* Could select multiple options

[#] Moved to New Zealand less than 10 years ago.

As the respondents were not required to be currently engaged with health services, respondents were asked about how long it had been since they had engaged with different health service types. The results can be seen in Table 2. Although 88% of respondents had engaged with primary care services recently, defined as within the last 2 years, only 41% had engaged with hospital-based services recently (e.g. for surgery or to visit a clinic). The high proportion of respondents who reported recent engagement with laboratory testing facilities likely reflects the recent outbreak of COVID-19 in the community at the time the survey was administered.

Table 2: Time since last encounter with health services (n=2,572)

Health service type	< 6 months		6–24 months		2–10 years		> 10 years		Missing	
	n	%	n	%	n	%	n	%	n	%
Primary care	1,692	65.8	578	22.5	122	4.7	13	0.5	142	5.5
After hours or ED	395	15.4	531	20.6	761	29.6	331	12.9	196	7.6
Hospital	533	20.7	526	20.5	767	29.8	319	12.4	181	7
Screening service	442	17.2	680	26.4	436	17	80	3.1	190	7.4
Laboratory testing	1,137	44.2	772	30.0	350	13.6	55	2.1	167	6.5

ED: Emergency Department

3.2 Current use of health information

Respondents were asked to consider what they thought their personal health information was used for by health services and organisations (Table 3). Although most (81%) thought their health information was being shared with other health professionals involved in their care within the same organisation, lower proportions were seen for the other scenarios (62%–73%). Nearly one-quarter of respondents were not aware if their health information could be used to make decisions about improving the health service.

Table 3: Current use of health information (n=2,572)

Scenarios*	Yes		No		Don't know	
	n	%	n	%	n	%
a To make decisions about your health care now	1,718	66.8	323	12.6	531	20.6
b To make decisions about your health care in the future	1,692	65.8	337	13.1	543	21.1
c To share with other health professionals involved in your care within the same organisation	2,080	80.9	204	7.9	288	11.2
d To share with other health professionals involved in your care in other organisations	1,771	68.9	370	14.4	431	16.8
e To make decisions about improving the health service	1,600	62.2	344	13.4	628	24.4
f To investigate how to better understand the population and their needs by combining information on the whole population	1,865	72.5	253	9.8	454	17.7

* Note, these are not the full scenario descriptions used in the survey questions.

3.3 Comfort with the use of health information

Respondents were asked to rate their level of comfort with the health service and organisations using their health information across seven scenarios on a Likert scale from 1 (very uncomfortable) to 5 (very comfortable). Results can be seen for the whole population (Table 4), Māori versus non-Māori (Table 5), and Pacific versus non-Pacific (Table 6).

Over 70% of respondents were comfortable with their health information being used across the scenarios presented (range: 71–79%) but there were between 7–11% of respondents who were uncomfortable with their health information being used across the scenarios presented. Approximately half of the respondents (55%; $n=1,411$) were comfortable across all items presented, and only 2% ($n=60$) were uncomfortable across all items.

There were significant differences in ratings of comfort seen for some scenarios between the key groups. Māori respondents ($n=385$) were significantly less likely to be comfortable than non-Māori respondents ($n=2,187$) with their health information being shared with other health professionals involved in their care in other organisations ($p=0.009$), with their health information being used to make decisions about improving the health service ($p=0.023$), and with their health information continuing to be used to help others once they had died or moved out of New Zealand ($p=0.026$). Pacific respondents ($n=250$) were significantly less likely to be comfortable with their health information continuing to be used to help others once they have died or moved out of New Zealand ($p=0.035$) than non-Pacific respondents ($n=2,322$).

Table 4: Rating of comfort for use of health information (n=2,572)

Scenarios	Uncomfortable (1 or 2)		Neutral (3)		Comfortable (4 or 5)	
	n	%	n	%	n	%
a To make decisions about your health care now	189	7.3	431	16.8	1,952	75.9
b To make decisions about your health care in the future	212	8.2	423	16.4	1,937	75.3
c To share with other health professionals involved in your care within the same organisation	168	6.5	370	14.4	2,034	79.1
d To share with other health professionals involved in your care in other organisations	230	8.9	448	17.4	1,894	73.6
e To make decisions about improving the health service	198	7.7	458	17.8	1,916	74.5
f To investigate how to better understand the population and their needs by combining information on the whole population	220	8.6	481	18.7	1,871	72.7
g To continue to help others even once you have died or have moved out of New Zealand where your information continues to be useful and contributes to the full picture for points (e) and (f) above	277	10.8	466	18.1	1,829	71.1

Table 5: Rating of comfort for use of health information for Māori (n=385) versus non-Māori respondents (n=2,187)

Scenarios	Uncomfortable (1 or 2)				Neutral (3)				Comfortable (4 or 5)				Significance <i>p</i> value
	Māori		Non-Māori		Māori		Non-Māori		Māori		Non-Māori		
	n	%	n	%	n	%	n	%	n	%	n	%	
a To make decisions about your health care now	28	7.3	161	7.4	80	20.8	351	16	277	71.9	1,675	76.6	0.0705
b To make decisions about your health care in the future	34	8.8	178	8.1	76	19.7	347	15.9	275	71.4	1,662	76	0.1298
c To share with other health professionals involved in your care within the same organisation	31	8.1	137	6.3	65	16.9	305	13.9	289	75.1	1,745	79.8	0.1060
d To share with other health professionals involved in your care in other organisations	33	8.6	197	9	88	22.9	360	16.5	264	68.6	1,630	74.5	0.0094
e To make decisions about improving the health service	42	10.9	156	7.1	73	19	385	17.6	270	70.1	1,646	75.3	0.0228
f To investigate how to better understand the population and their needs by combining information on the whole population	45	11.7	175	8	69	17.9	412	18.8	271	70.4	1,600	73.2	0.0580
g To continue to help others even once you have died or have moved out of New Zealand where your information continues to be useful and contributes to the full picture for points (e) and (f) above	56	14.5	221	10.1	72	18.7	394	18	257	66.8	1,572	71.9	0.0262

Table 6: Rating of comfort for use of health information for Pacific (n=250) versus non-Pacific respondents (n=2,322)

Scenarios	Uncomfortable (1 or 2)				Neutral (3)				Comfortable (4 or 5)				Significance <i>p</i> value
	Pacific		Non-Pacific		Pacific		Non-Pacific		Pacific		Non-Pacific		
	n	%	n	%	n	%	n	%	n	%	n	%	
a To make decisions about your health care now	27	10.8	162	7	44	17.6	387	16.7	179	71.6	1,773	76.4	0.0714
b To make decisions about your health care in the future	27	10.8	185	8	47	18.8	376	16.2	176	70.4	1,761	75.8	0.1342
c To share with other health professionals involved in your care within the same organisation	23	9.2	145	6.2	43	17.2	327	14.1	184	73.6	1,850	79.7	0.0610
d To share with other health professionals involved in your care in other organisations	28	11.2	202	8.7	48	19.2	400	17.2	174	69.6	1,720	74.1	0.2597
e To make decisions about improving the health service	27	10.8	171	7.4	47	18.8	411	17.7	176	70.4	1,740	74.9	0.1202
f To investigate how to better understand the population and their needs by combining information on the whole population	28	11.2	192	8.3	53	21.2	428	18.4	169	67.6	1,702	73.3	0.1225
g To continue to help others even once you have died or have moved out of New Zealand where your information continues to be useful and contributes to the full picture for points (e) and (f) above	30	12	247	10.6	59	23.6	407	17.5	161	64.4	1,668	71.8	0.0345

Comfort with the combining of health information

When focusing only on the items relating to the combining of health information with the health information of others (items e and f), 6% (n=141) of respondents were uncomfortable (ratings=1 or 2). Respondents who identified as Māori were significantly more likely to be uncomfortable with the combining of their health information (8.6%) than non-Māori (4.9%, $p=0.004$). Similarly, respondents who identified as Pacific were significantly more likely to be uncomfortable with the combining of their health information (8.8%) than non-Pacific (5.1%, $p=0.015$). There were 3% (n=67) of respondents who were *very uncomfortable* (ratings=1) with the combining of their health information. Pacific respondents were significantly more likely to be *very uncomfortable* with the combining of their health information (4.8%) than non-Pacific (2.4%, $p=0.022$).

3.4 Comments on level of comfort with the use of health information

Respondents were able to provide comments on their level of comfort with the health information scenarios presented in the previous question of the survey. Of the 2,572 survey respondents, there were a total of 661 (26%) who provided responses to this question. From the responses, six key themes were identified.

Theme 1 – Comfortable with use of health information but with conditions

The most common theme was that respondents were comfortable with the use of their health information in the ways described on the condition that it was used for the right purposes (e.g. to help others), was stored securely, kept confidential, and was correct/accurate.

Many respondents stated that they were happy for their information to be shared if it was used for the good of their own health or for the population's health, if it was to benefit and help others with similar conditions or for the future of New Zealand.

"I'm happy to have my information used to assist on improving health care for our country." [Pacific, Female, 35–54 years]

These respondents raised the point that they were happy for their information to be used as long as it is secure and safe, and that the Ministry of Health needed to have adequate security measures to protect their health data.

“Security is a concern. The data shouldn’t be sitting on an unsecured server, in plain text, waiting for a hacker to steal it.” [Māori, Male, 35–54 years]

“Assuming that health providers have strong cybersecurity practices.” [European, Male, 55-74 years]

“Comfort for use of health data being used for anything beyond affecting personal care depends on it being properly anonymised and securely stored, which I assume it must be.” [NZ European, Male, ≤34 years]

Further, respondents’ level of comfort was based on the assurances that their personal information remains private and confidential and that if health information was shared beyond their immediate care that this was anonymous:

“I assume all my information is subject to privacy and shared only when given permission. Like if referrals are made in regards to my healthcare. However if my information is used to gather data/stats on the overall picture I would think that this would be used in a non identifiable format” [Māori, Male, ≤34 years]

“It is important that personal health information remains confidential” [NZ European, Female, ≥75 years]

“As long as the security around access is water tight to the health system and my personally identifiable information is not passed outside of the health system it should be available to all analysis” [NZ European, Female, 55–74 years]

Finally that their comfort was based on an assumption that the information used was correct and up to date:

“The caveat of course, is that: a) The stored information is correct and up to date. ...” [NZ European, Female, 55–74 years]

“Mostly agree to all the uses suggested except when something goes wrong or is recorded incorrectly and then can’t be untangled...” [NZ European, Female, 55–74 years]

Theme 2 – Uncomfortable with the use of health information due to mistrust

The next theme described being uncomfortable due to mistrust in the Ministry of Health, their healthcare providers, or the government. Although less common, these respondents raised important concerns about the use of their health information because of this mistrust. Many of these comments described mistrust stemming from personal negative experiences, the COVID response, views that the health system was under-funded and under-resourced, or that data sharing was not happening when it should be.

“I would love my health information to be used but don’t believe it will be used correctly, I have quite a health journey with myself, and my daughter and the NZ healthcare has a lot to be accountable for and I do not trust many health professionals because of mis-diagnosis and ignorance from health professionals, we are no longer patients and just numbers” [NZ European, Female, 35–54 years]

“Because of the vaccine mandate, I no longer trust the Ministry of Health with my health information and I do not want them to have access to my health information in the future.” [NZ European, Female, 55–74 years]

“Not very comfortable as I’m not sure anymore about the health system since I had a cardiologist lie to me about the delay in retrieving my test results that I had seven months before my clinic appointment” [Māori, Female, Age not provided]

Theme 3 – Sharing of health information is important and necessary

Some respondents highlighted the importance of data sharing and in some cases, there was a need for more sharing. For example, better and easier sharing between healthcare services across the country when people move or attend a different clinic.

“I wish it had been effectively shared with other relevant people would have made my life much better” [NZ European, Female, 55–74 years]

“In order to make better healthcare decisions for individuals AND the wider population, I EXPECT my healthcare data to be centralised. I find it ridiculous, that in this decade, that my health data is scattered across different healthcare providers... My complete record should be easily available to ANY healthcare provider in NZ (probably providing I give consent). For research purposes (and population-health monitoring, etc.), yes, my data should be available, along with everyone else’s. However, there probably should be a degree of individual anonymisation considered...” [Māori, Male, 35–54 years]

“If my health information was not shared with other health professionals I would be most unhappy. I want every expert on the job if ever I need medical attention!” [No demographics provided]

Theme 4 – Consent is needed for sharing of health information

A small group of respondents expressed being uncomfortable with the use of their health information beyond their care or that their comfort was dependent on whether their consent was obtained first. These respondents stated that they wanted to provide consent for any use of their data. Some described their data as confidential and private so should not be used beyond their care at all or if to be used or shared that this should only be with their permission. Furthermore others specifically described not wanting their health information used once they had passed away.

“I’m not an open person to be honestly I rather have my health information keep it private.” [Pacific, Female, 35–54 years]

“I do not like my health information being used for any other purpose except to provide medical care for [me] or any other family members that may require it. I do not want it used for statistical purposes or to learn about health trends etc.” [Māori, Female, 35–54 years]

“I would only feel comfortable about sharing information if I was asked first.” [NZ European, Male, 35–54 years]

“I would not like my health information to be used once I have passed on.” [Māori, Female, 55–74 years]

Theme 5 – Sharing should not occur with organisations outside the health system

Respondents described being wary of the use of health information for commercial purposes or outside of the health system. This theme referred to respondents who stated that they were worried about specific parties that might have access to their data or for their data to be sold for commercial gain. Examples included private health companies, other healthcare services that were not part of their direct care, pharmaceutical companies, insurance companies, tech companies, the police, and researchers.

“I do not wish for my private health information to be sold to any private organisation eg Amazon or Google etc under any circumstances. They have the power to de-anonymise such data if they so choose.” [NZ European, Male, ≥75 years]

“As long as any organisation does not make a financial profit from it, especially in the future.” [NZ European, Female, 55–74 years]

“Information is scary especially shared information. As long as the information stays within the government and government services and is not sold or given to private health insurers etc I am okay with it.” [Māori, Male, ≤34 years]

“Happy to have anonymized health data used to advance science on the whole but I’m uncomfortable with individual companies commercializing this research. I think there needs to be considerations to access and treatment/drug pricing if data from public sources are used for free.” [Asian, Another gender, ≤34 years]

Theme 6 – There needs to be improved communication and transparency around the use of health information

Finally, respondents commented that regardless of their comfort they wanted to be informed on how their data is used. These respondents stated that they would like to be told when their information is being used, how it is used, and to be told what the results of a study are if they are involved in health research.

“How would I know my health information is being used appropriately, and at present who has access to my personal information?” [Māori, Female, 55–74 years]

“It would be good to be informed when information is being passed on to another care provider/professional” [NZ European, Female, 55–74 years]

“Just as long as I’m made aware, or even ring me first before you do. As long as I’m in the loop then all goods.” [Māori, Male, ≤34 years]

“As long as I am aware of the processing of my information for various purposes, I am okay for it to be used but if my information is used for purposes other than it was collected and I am unaware of it, I am certainly disappointed.” [Asian, Male, ≤34 years]

3.5 Consent for the combining of health information

Respondents were asked if there were any situations where they would want to be specifically asked their permission before their health information is combined with the health information of other people to better understand the wider population. Of the 2,572 survey respondents, 1,492 (58%) responded to the question.

Of those that responded, 53% (n=789) said that permission was not needed. A further 19% (n=281) responded that that permission was not needed only if the data was anonymous, if the security of data was maintained, and that it was done for the right reasons. If any personally identifiable data (e.g. address) is used, then individual permission would need to be sought.

“If my name and identifying features aren’t being used I am 100% all for it being used, it’s so important to be using this data effectively for the greater good.”
[Māori, Female, ≤34 years]

“Not if the information did not identify me as an individual.” [NZ European, Female, 55–74 years]

“As long as it is used in a non-political way to enhance and improve future health services and health facilities for our country.” [Asian, Female, 55–74 years]

Of those that responded to this question there were 12% (n=186) that reported that individual permission/consent must be sought in some situations (response unspecific or specific), including:

1. That consent should be obtained if information is to be shared outside the New Zealand health system (e.g. researchers, pharmaceutical companies, tech companies, insurance companies, media), or will be used for commercial purposes.

“If there was any possibility of the information being used for commercial purposes I would not agree to data being used ie: if data was sold to outside agencies” [NZ European, Female, 55–74 years]

“Any data used for offshore purposes” [NZ European, Male, 35–54 years]

“Yes, when using my information for developing a new product/ service (where my PII is used as test data), especially when using AI/ ML.” [Asian, Male, ≤34 years]

“If you’re mixing it with non-health data (e.g. IRD data, MSD data), I’d like to have the option to know more about the research before giving/withholding consent” [NZ European, Male, ≤34 years]

2. When it involves sensitive information (e.g. DNA/genetic data, mental health, sexual health, rare diseases, specific medical conditions, gynaecology information, terminal illness, COVID-19).

“When data needed is related to serious conditions/diseases, e.g. cancer, degenerative diseases” [Asian, Male, 35-54 years]

“I think if there was any situation where mental health information, or sexual trauma was involved, permission to use this information should be explicit. Or it should be guaranteed it was anonymous.” [NZ European, Female, 35-54 years]

3. If the health information is about a specific subgroup of the population (e.g. Māori, children under 16 years).

“Yes. Anything that using my demographic as Māori.” [Māori, Female, ≤34 years]

“Only where information affects a single race of people.” [NZ European, Male, 35–54 years]

“No. Only if it involved my kids under the age of 16.” [NZ European, Male, 35–54 years]

“Yes – what it’s for, in particular anything related to Māori” [Māori, Female, ≤34 years]

A total of 9% (n=141) of the respondents reported that permission must be sought every time their health information is used beyond their immediate healthcare.

“Always ask permission and never assume that it’s okay to share private information. Give the patient a heads up first in any given situation.” [Asian, Female, 35–54 years]

A small number of respondents (2%; 33) were unsure or reported that they didn’t know.

For some respondents it wasn’t about being asked to provide consent/permission but more about being informed of the use of their health information including who it was being share with and why:

“Yes. I would want to know who will use/see my health data. e.g. just medical professionals, or does this include scientists, government officials etc.” [NZ European, Male, ≥75 years]

“... While I don’t mind the usage of, I’d want to know specifically what information is being used.” [Pacific, Female, ≤34 years]

“I should always be informed when information is being shared.” [NZ European, Female, 55–74 years]

“I am very open to sharing that information and helping others. Would be great to know retrospectively how data sharing has helped other patients to encourage it continually. [NZ European, Male, ≤34 years]

3.6 Concerns about health information

Lastly, survey respondents were asked if they had any further concerns about health services and organisations look after or use their health information. A total of 1,609 (63%) of respondents commented on their concerns. There were four major themes identified from the responses.

Concerns over security risks

The largest theme raised was concerns for the security of health data. Respondents wanted to ensure that their data was safe from hacking and cyber-attacks. Respondents specifically stated that the Waikato DHB data breach and ACC incident last year contributed to their concerns for the security of their data. Further to identifying security as a key concern, many commented that there was a need for more resources, updated systems and training to go into ensuring that these data breaches never happen again.

“I would expect secure protection of the information provided, only accessed by appropriate researchers and professionals. The recent ACC news article of information being accesses and shared around staff was unsettling!” [MELAA, Female, 35–54 years]

“I’m concerned generally about how slack the data security is in the public sector including health. I’m also shocked at how behind the hospital is still using pen and paper files and paper prescriptions.” [NZ European, Female, 35–54 years]

“It is important DHBs have adequate protection of the data by investing in excellent anti hacking software. It was concerning what happened with the Waikato DHB recently.” [Māori, Female, 35–54 years]

“Money needs to be spent to update systems continually in order to keep them safe. We all know what happens when this is allowed to slide. Our data, along with yours, must be stored, and used, as safely as humanly possible.” [NZ European, Female, 54–74 years]

Concerns over confidentiality of personal health information

Respondents raised concerns about the confidentiality of their data, especially in regards to having their name, address and any personal information kept from people who do not need to see it.

“I would hope that any information you may have available would be kept securely and confidential and only used for health and medical purposes.”
[European, Male, 55–74 years]

“I would hope all of my information was used and shared appropriately under the Privacy Act and anonymised if there was any risk to me or my privacy. NZ is a small place.” [Māori, Female, ≤34 years]

“Yes if personal details are shared but no if it is anonymous” [NZ European, Male, 35–54 years]

Others were concerned about people having access to their information who were not authorised. Respondents wanted only the healthcare professionals directly involved in their care to see personal details and the full details of their medical history, and there to be audit processes in place. There were also concerns about sensitive information such as mental health records and life restricting conditions being available to people not involved in their care to see. Importantly, there were many references again to the Waikato DHB Cybersecurity threat, and to the ACC privacy breach which occurred over Snapchat. Many respondents discussed their distress at the possibility of their information being shared in this way.

“Absolute privacy is essential. Recent news re the abuses at ACC of health information are extremely concerning and provoke serious distrust. There needs to be a system to check who has accessed data and why, similar to Police and Justice records.” [NZ European, Male, 55–74 years]

“I would be concerned if people not directly involved with my care have access to my personal details and records, or that there is no trail of who has accessed my information that I can request.” [Pacific, Female, 35–54 years]

“I wouldn’t like to think that just anyone in the health system could access my information but only those involved in my actual care.” [NZ European, Female, 35–54 years]

No concerns if health information is appropriately used, respected, and protected

There were many respondents who reported no concerns about the use of their health information but highlighted that health information should be protected, kept confidential, respected and used with integrity, and used for good to help/benefit others. Respondents wanted assurance that their data would only be used when needed and for the right reasons for example, to better the health of New Zealand, for health or medical purposes only, or to help with research.

“No but I expect a high standard of accountability and integrity when handling such information. eg would they hesitate to share the information if it was their own whanau?” [NZ European, Female, ≥75 years]

“If used for the right reason, the. It shouldn’t bother me.” [Pacific, Female, 35–54 years]

“People who are using this info must be mindful of the person’s required respect by using this info.” [NZ European, Female, 55–74 years]

“Not really. I’m confident it’s used as a means to understand and help all of us. That should always be the aim at least. I feel reassured.” [Māori, Female, 55–74 years]

Concerns for commercial use or third-party use, or sharing of health information outside of health

Similar to responses to earlier questions, respondents raised significant concern about their data being shared with third-party organisations outside of the health system or shared for commercial gain. Again respondents mention concern over their data being shared with ACC after their privacy breach last year.

“Concerns over my information being hacked and misused by outside entities.” [NZ European, Female, 35–54 years]

“No information should be sold or used for commercial gain.” [Pacific, Male, 35–54 years]

I wouldn’t want my information to be shared with people who weren’t involved in health services. Or commercial entities like pharmaceutical companies.” [NZ European, Female, 55–74 years]

“If it’s used for a third-party that profits somehow from using the information.” [NZ European, Female, Age not provided]

Further to the major themes, other themes identified from the responses include:

Lack of access for consumers/patients to their health information

Some respondents raised concerns about the fact that they cannot access their own information.

“Yes. That they use it for whatever agenda they have that day and ironically, if I want my information, I cant access it” [Demographics not provided]

Concerns about the accuracy of information

Another concern raised was about the accuracy of their health information. Some stated that they had instances where their information is not correct or have had difficulties correcting it.

“... I also don't think that some of what is recorded is correct but it's not easy to correct it” [NZ European, Female, 35–54 years]

A need for better communication

There is a desire for more communication and transparency of how information is shared, when or to whom. Some respondents raised the concern that they have no idea how their information is stored, used, or to whom it is shared.

“Yes. Patients are never told how and what info with whom is shared.”
[NZ European, Female, 35–54 years]

“Yes! Especially if my information is shared without my knowledge and an explanation as to why and what for!” [Māori, Female, 35–54 years]

Concerns arising from mistrust

In response to this question there were respondents who identified mistrust in the health system to manage their health information and concerns over mismanagement. Similar to the earlier question around comfort, some respondents commented that they had mistrust of the healthcare system in New Zealand, Ministry of Health, and current government. Some of these concerns stemmed from personal mismanagement of information or mistreatment from healthcare professionals or the healthcare system. Others expressed concern at the government's actions in regards to COVID-19 and vaccination passports.

“I have 100% confidence that the Ministry of Health would misuse my information against me given half a chance.” [NZ European, Female, 55–74 years]

“Does it even matter? Health services will use and twist information to suit and fit their agenda. Its totally rubbish. Nothing is private.” [Māori, Female, ≤34 years]

"I don't want my information being used regarding COVID19 as this has been shown time and time again to be inaccurate and reported by media to skew people's view. i.e. putting someone on the COVID death registry when they didn't die from COVID." [NZ European, Male, 35–54 years]

Health information should not be used without consent

In line with the previous questions, a small group of respondents answered this question by stating that they want to be asked their consent every time their health information is being used beyond their immediate care or do not want their health information used at all.

"I want to give permission before people can access my health information"
[Māori, Female, 55–74 years]

"Yes. I do not receive any information or notification about use of my person data at present. This should be mandatory and my agreement confirmed before it is used for anything." [NZ European, Male, 35–54 years]

"I don't want none of my information shared at all, thanks." [Māori, Female, ≤34 years]

The need for greater sharing of health information

Finally, some respondents raised concerns that there should be more sharing of data between hospitals and other health organisations. For example, some stated that they have had to re explain very important medical information to doctors when sharing had not occurred.

"I think it is very siloed and sometimes I think there should be more information sharing so that people can get the best care they need." [NZ European, Female, ≤34 years]

"It is not shared enough throughout NZ medical care providers." [Demographics not provided]

"I believe there is not enough sharing of information e.g. hospitals cannot access GP records for acutely admitted patients." [NZ European, Female, ≤34 years]

4 Discussion

This report presented the results of a cross-sectional survey conducted to gather the perceptions of the public of Aotearoa New Zealand on the use of their personal health information by health services and organisations. A total of 2,572 previous respondents of the New Zealand Health Survey completed the survey.

4.1 Summary of results

While many respondents reported that they believed the health service was using their health information in the ways presented (range: 62–81%), there were many who were unaware their health information may be used in these ways including being used to make decisions about their health care now and in the future, or that their health information could be used to make decisions about improving the health service.

Although over 70% of respondents were comfortable with their health information being used across the scenarios presented (range: 74–76%), between 7–11% of respondents were *uncomfortable* with their health information being used in these ways. When focusing on the items relating to the combining of individual health information with the health information of others, respondents who identified as Māori or Pacific were significantly more likely to be *uncomfortable* with the combining of their health information than non-Māori or non-Pacific.

For many respondents to feel comfortable with the use their personal health information the following conditions needed to be met:

- The use of their data is for the greater good and to benefit others.
- Their data is stored securely to prevent breaches.
- Their privacy is prioritised, and only anonymised data is shared beyond their immediate care.
- That data is not shared outside the health system or used for commercial gain.
- There is communication and transparency around its use.
- The information is up-to-date and correct.

Although the majority appear comfortable there are a significant proportion of respondents who are uncomfortable because of mistrust in the health systems or health services. Further there are some respondents who would only be comfortable with the use of their health information if they have provided specific consent or others who would be uncomfortable with any use beyond their immediate care.

In relation to the need to seek permission for the use of health information, the majority of respondents reported that if the health information was being used under the following conditions, then they did not require their consent to be sought:

- The data is anonymous, personal privacy is maintained and no personal or identifying information is shared.
- The use of the data is for the right reasons (to benefit others).
- That the security of the data is assured.
- That the data (or the combined dataset) It is not shared outside the health system.

Respondents indicated that the use of health information in the following situations would require personal consent/permission to be sought before its use:

- When personal (identifiable) information is included in the dataset.
- When data is being sent or shared outside of the health system or used for commercial purposes.
- When data is sensitive in nature e.g. DNA/genetic data, mental health, sexual health, rare diseases, specific medical conditions, gynaecology information, terminal illness, COVID-19.
- When the data is specific to a population group e.g. minors, ethnic groups.

Respondents expressed concerns over security risks, privacy and confidentiality, the use of health information outside the health system and the lack of transparency and communication around health information. Many respondent concerns could be addressed if:

- There is increased communication and transparency around the use and protection of personal health information.
- Health information is secure and protected from data breaches and hacking.
- Privacy and confidentiality are prioritised, and only anonymous data is shared beyond immediate care.
- Health information is not shared outside the health sector or for commercial uses.
- Health information is respected as taonga and only used for good.
- That patients are given access to their health information and the ability to correct their information.
- There is good governance of health information including clear processes and approvals for its use, with auditing and monitoring.

4.2 Comparison to previous work

The findings from the current study add to growing evidence indicating public support, though conditional, for secondary use of health information when used for the greater good or public benefit.⁴⁻⁶ Similar to the results of this survey, individual privacy and data security alongside trust in the health system/services have been key themes in previous surveys of members of the public.^{4,7} Although there is support for the use of health information, similar to this study, other work has highlighted consumer concerns around misuse of data and concerns around the sharing of data outside the health system, including with commercial companies and where there is potential commercial gain.^{4,7,8} The findings from this survey are also in line with other surveys internationally that indicate that individual consent is not always necessary,^{4,7} but assurances around the security and privacy of health information are paramount for people to be comfortable in the use of their health information.^{4,6,9} The findings also highlight the need for better communication and transparency on the use of health information.
4,7,10-14

There are some interesting differences in the results of this survey compared with the same survey conducted in Waitematā DHB patients in 2020.¹ Of note were the lower rates in the current survey of overall comfort with the use of health information (range 71–79%) compared to the DHB patient sample (range 81–89%) and alongside this the greater proportion of respondents in this current survey who were unsure and/or neutral about the use of their health information. This could be due to the current sample including the general population where some respondents had very little contact with health services. In comparison the previous survey was administered in current DHB service users. It has been reported internationally that current users of health services are more likely to have better understanding of health information and its use. Additionally this current survey was administered after two high profile data breaches (Waikato DHB and ACC) which may have led to a greater awareness of the potential security and privacy risks and more concerns about the security and privacy of health information in these findings.

Further, there were differences between the surveys in levels of comfort for people from Māori and Pacific ethnicities. In line with previous work by the New Zealand Data Futures Forum,¹⁵ in the current survey Māori and Pacific had lower levels of comfort with the combining of health information compared to non-Māori or non-Pacific, where the opposite was found in the DHB based survey.¹ The reasons for this difference are not clear, although factors contributing could include that it was a general population sample rather than patient sample, that the sample for this survey was younger with fewer respondents from the older (75 years and over) age group, and/or that this survey was only able to be completed online and in the English language whereas the previous DHB survey was available for completion online, in person with assistance and on paper, and was available in 10 different languages including Te Reo Māori and Pacific languages. Ongoing in-depth interviews in the DHB research project may provide more information regarding this.

4.3 Limitations of the current work

The findings from this survey must be interpreted with consideration of its limitations including sample characteristics, recruitment and administration methods, and the timing. The sample for this survey were a convenience sample recruited via email through the New Zealand Health Survey database of people who had agreed to be contacted for future surveys, participants therefore are biased to those who are already engaged with research/surveys and have the necessary digital access and digital literacy to take part. The survey was only available in English which will have deterred or prevented those New Zealanders who primarily speak other languages from participating. Furthermore, the sample included few participants from the younger (<25 years) and older (75 years and over) age groups. Interpreting the findings in relation to young adult and older adult populations, non-English speaking New Zealanders, as well as those with low digital literacy and access must be done with caution.

It is also important to consider that the timing may have influenced how people responded to the survey. The survey was administered at a time when vaccine mandates and vaccine certificates were front of mind for many New Zealanders. Those with little prior experience of the health system, and therefore collection of health information, were suddenly in a position of having to report/display COVID information for employment or access to venues. For some this may have influenced their responses to questions in relation to the sharing of health information with others.

4.4 Conclusion

Understanding how people want their health information used is important for health services to consider as the digitisation of health records progresses and opportunities for the use of health data grow. This survey has found that members of the public are largely comfortable with the use of their health information to benefit others with the conditions that the data is respected, stored securely, their privacy is maintained, they have access to it, it remains within the New Zealand health sector, is not used for commercial gain, and that there is good governance over access and use. It appears that many of the concerns expressed around the use of health information could be mitigated with increased communication and transparency from health services and organisations.

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