

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 Pikiao), 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).	○	○
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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.	○	○	○	○	○		
b	To make decisions about your healthcare 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.g., your GP, a private hospital, a hospital in another city).	○	○	○	○	○		
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).	○	○	○	○	○		
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).	○	○	○	○	○		
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.	○	○	○	○	○		

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.

<p>Q10</p>	<p>Are you descended from a Māori (that is, did you have a Māori birth parent, grandparent, or great-grandparent, etc)?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Don't know</p> <p><input type="checkbox"/> No</p>				
	<table border="1"> <tr> <td data-bbox="408 519 501 667"> <p>Q10a</p> </td> <td data-bbox="501 519 1394 667"> <p>Do you know the name(s) of your iwi (tribe or tribes)?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> </td> </tr> <tr> <td data-bbox="408 676 501 1131"> <p>Q10b</p> </td> <td data-bbox="501 676 1394 1131"> <p>Give the name(s) and region(s) of your iwi (tribe or tribes):</p> <p>Iwi:</p> <p>Region:</p> <p>Iwi:</p> <p>Region:</p> <p>Iwi:</p> <p>Region:</p> <p>Iwi:</p> <p>Region:</p> </td> </tr> </table>	<p>Q10a</p>	<p>Do you know the name(s) of your iwi (tribe or tribes)?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p>	<p>Q10b</p>	<p>Give the name(s) and region(s) of your iwi (tribe or tribes):</p> <p>Iwi:</p> <p>Region:</p> <p>Iwi:</p> <p>Region:</p> <p>Iwi:</p> <p>Region:</p> <p>Iwi:</p> <p>Region:</p>
<p>Q10a</p>	<p>Do you know the name(s) of your iwi (tribe or tribes)?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p>				
<p>Q10b</p>	<p>Give the name(s) and region(s) of your iwi (tribe or tribes):</p> <p>Iwi:</p> <p>Region:</p> <p>Iwi:</p> <p>Region:</p> <p>Iwi:</p> <p>Region:</p> <p>Iwi:</p> <p>Region:</p>				
<p>Q11</p>	<p>If you live in New Zealand but were not born here, answer this question.</p> <p>Which year did you first arrive to live in New Zealand? (e.g., 1974)</p> <p>Year:</p>				
<p>Q12</p>	<p>Do you have a family/whānau member or friend who has been diagnosed with mild cognitive impairment (MCI) or dementia? (yes/no)</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> I don't know</p>				
<p>Q13</p>	<p>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.</p> <p>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.</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p>				
<p style="text-align: center;">Thank you for taking the time to complete this survey.</p>					

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%