What is routinely collected health data?

Age

Gender

Ethnicity

District lived

Clinics attended

Hospitalisations

Diagnoses

Blood results

Medications

Scans and x-rays

Linkage to:

Community pharmacy data

Home care support received

Aged residential care

interRAI data

Date of death

Local data used for dementia research

Compared to NZ Europeans, Māori and Pasifika in Counties Manukau memory service

- present with dementia at younger age

- use care homes far less

- but do not get compensatory home-based support services

Is dementia care equitable in NZ?

Need for more culturally safe services

International Journal of
Geriatric Psychiatry

RESEARCH ARTICLE

Do community-dwelling Māori and Pacific peoples present with dementia at a younger age and at a later stage compared with NZ Europeans?

Sarah Cullum ✉, Katherine Mullin, Irene Zeng, Susan Yates, Vahid Payman, Mark Fisher, Gary Cheung

May 2018
1002/gps.4898

RESEARCH

Predictors of Aged Residential Care Placement in Patients Newly Diagnosed with Dementia at a New Zealand Memory Service

Sarah Cullum, Chris Varghese, Susan Yates, Lokomani Kolatau, Jasmine Appleton, Rebecca Knell, Camille Prigent, Madeline Christie, Kerry Appleton, Laura Hadfield, Bonnie Liu, Aakash Rajay, Brian Yeom, Bede Oulaghan, Rosie Whittington and Gary Cheung

International Journal of
Geriatric Psychiatry

RESEARCH ARTICLE

Predictors of mortality in Māori, Pacific Island, and European patients diagnosed with dementia at a New Zealand Memory Service

Sarah Cullum ✉, Chris Varghese, Christin Coomarasamy, Rosie Whittington, Laura Hadfield, Aakash Rajay, Brian Yeom, Bonnie Liu, Madeline Christie, Kerry Appleton, Susan Yates, Gary Cheung

First published: 19 January 2020
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Citations: 4

Do Māori and Pacific Peoples Living with Dementia in New Zealand Receive Equitable Long-Term Care Compared with New Zealand Europeans?

RESEARCH

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National data used for dementia research

Very little epidemiological information about dementia in New Zealand – never been a national dementia prevalence study (until now)

Combined 7 national datasets with dementia diagnoses to estimate dementia prevalence

Suggests dementia prevalence higher in Māori and Pacific Islanders (*Cheung 2022, BMJ Open*)

NB misses the 50% who are not on datasets

ABSTRACT

Objective Estimates of dementia prevalence in New Zealand (NZ) have previously been extrapolated from limited Australasian studies, which may be neither accurate nor reflect NZ's unique population and diverse ethnic groups. This study used routinely collected health data to estimate the 1-year period prevalence for diagnosed dementia for each of the 4 years between July 2016 and June 2020 in the age 60+ and age 80+ populations and for the four main ethnic groups.

Design A population-based descriptive study.

Setting Seven national health data sets within the NZ Integrated Data Infrastructure (IDI) were linked. Diagnosed dementia prevalence for each year was calculated using the IDI age 60+ and age 80+ populations as the denominator and also age–sex standardised to allow comparison across ethnic groups.

**Participants** Diagnosed dementia individuals in the health

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Routinely collected administrative health data are standardised and provide good national coverage but have limitations.
⇒ Dementia is under-recognised and underdiagnosed, so not all cases will be captured by administrative health data sets.
⇒ New Zealand does not routinely collect primary care dementia data, so this study likely underestimates the prevalence of dementia.
⇒ A community-based dementia prevalence study is needed to determine the true prevalence of dementia.
⇒ Community-based dementia prevalence studies are expensive. This study provides New Zealand-specific dementia estimates.

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Can we use AI to predict risk of dementia?

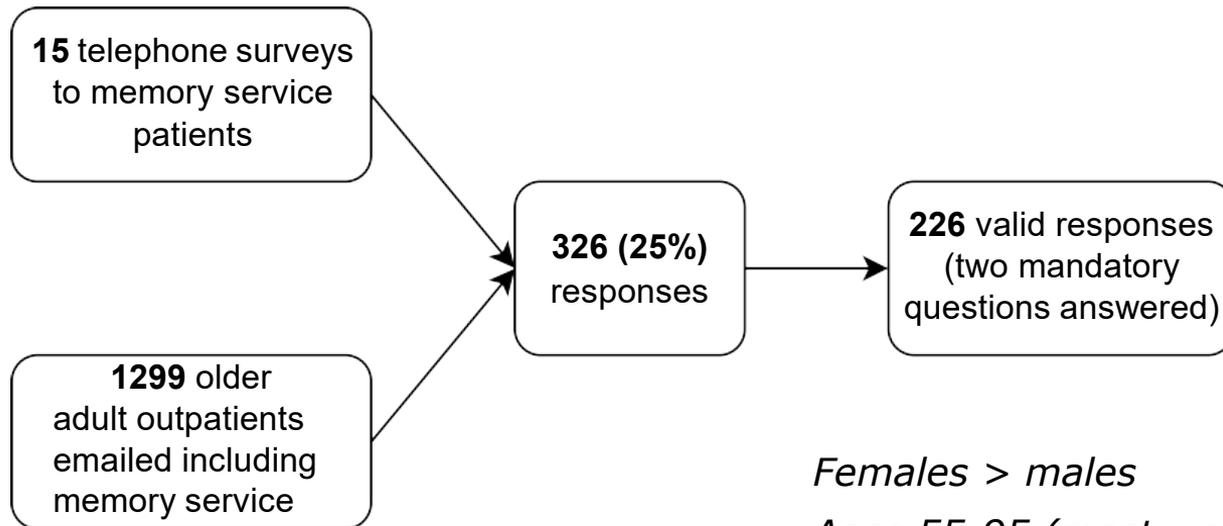Combine data and see if can predict future dementia
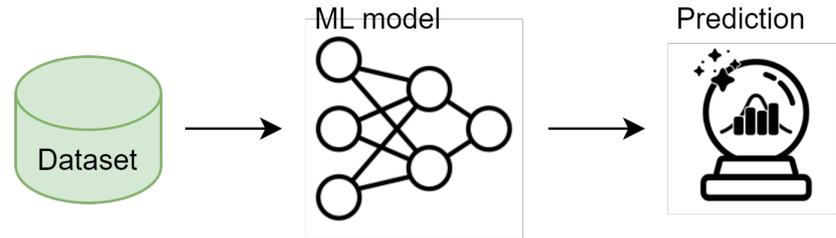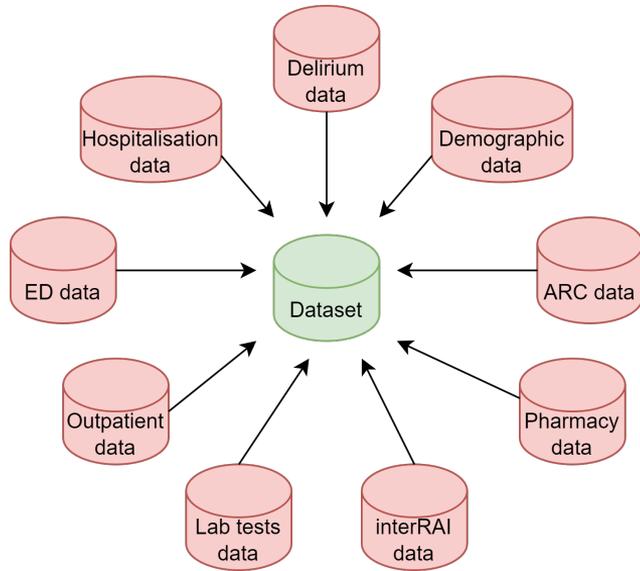
Using your data for brain health research?

➢ Routinely collected data useful for research and health service development

➢ But healthcare data used without individual consent for specific research

➢ Data deidentified but your personal data

➢ Will it be used to predict dementia?

➢ How do people feel about this?

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Online survey of Middlemore hospital outpatients

15 telephone surveys to memory service patients

1299 older adult outpatients emailed including memory service

326 (25%) responses

**226** valid responses (two mandatory questions answered)

Females > males

Ages 55-95 (most were 65-85)

*NZ European (64%), Māori (12%), Asian (11%) and Pacific (6%)*

How do you think we use your 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 in Middlemore Hospital

D. To share with other health professionals in other organisations

E. To make decisions about improving Middlemore Hospital services

F. To investigate the population by combining information
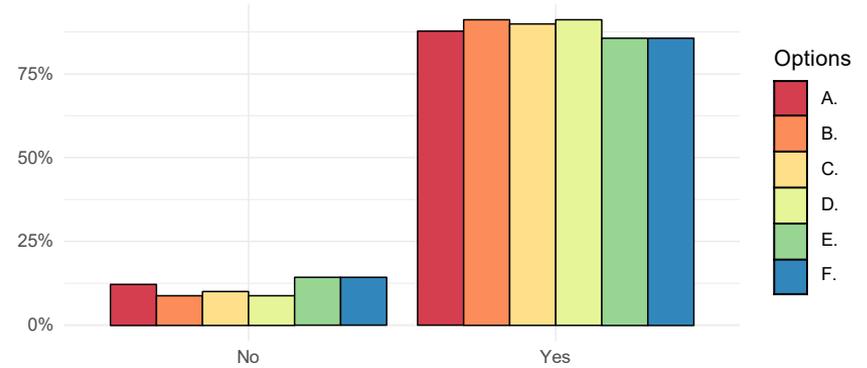
How comfortable are you with this use?

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 in Middlemore Hospital

D. To share with other health professionals in other organisations

E. To make decisions about improving Middlemore Hospital services

F. To investigate the population by combining information

G. To continue to help others even after you have died or moved out of area
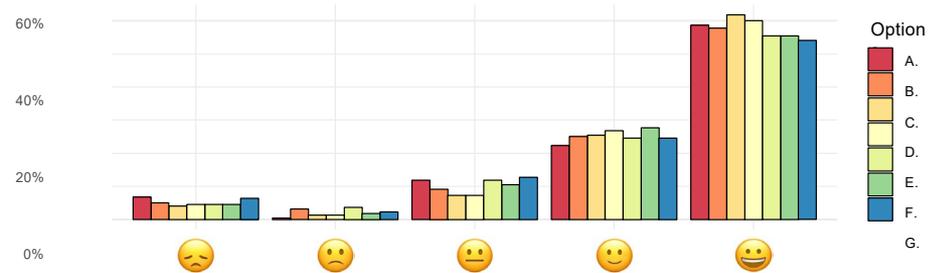
Individual in-depth interviews
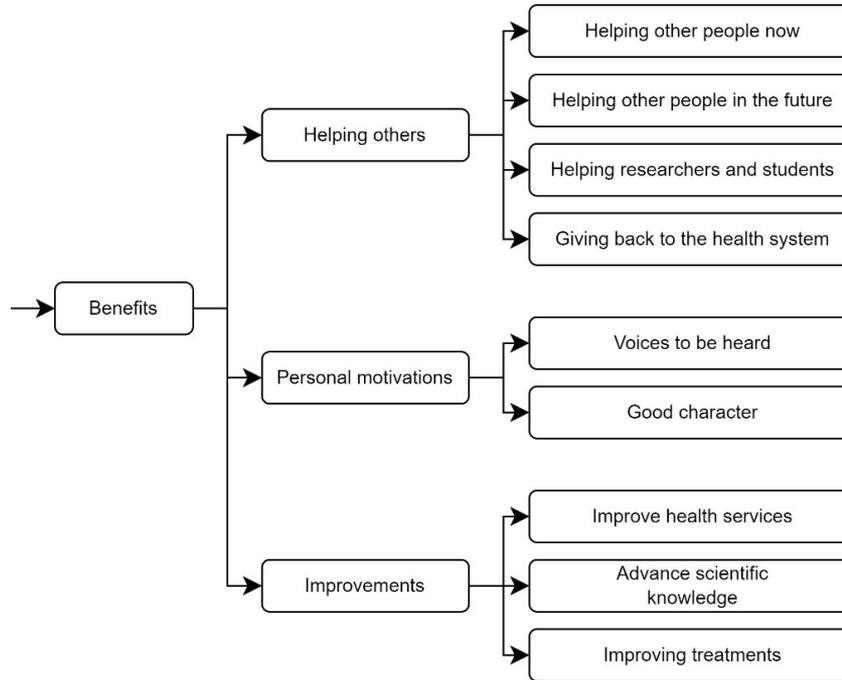
28 interviews

Service users from survey

Conducted on Zoom

Using a topic guide

Thematic analysis

- Focusing on issues around brain health research

- Sharing data with academic partners local and overseas?

- Linking with other health data (e.g. mortality data)?

- Allowing private companies to use the data to develop new medical equipment (possibly for profit)?

- Using data from people who are unable to consent (e.g. due to severe dementia or have died)?

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Benefits: contribution and legacy

Contributing to others

I'm okay with it being used for research because it's only going to help people…possibly not myself, but certainly other people. So why not?

I mean, it's a learning facility and most public hospitals are, …you know, every little bit helps, doesn't it?

For me doing this is a way of maybe, in some way, paying back for all the help and all the consideration I've had, especially from people and medics at Middlemore Hospital
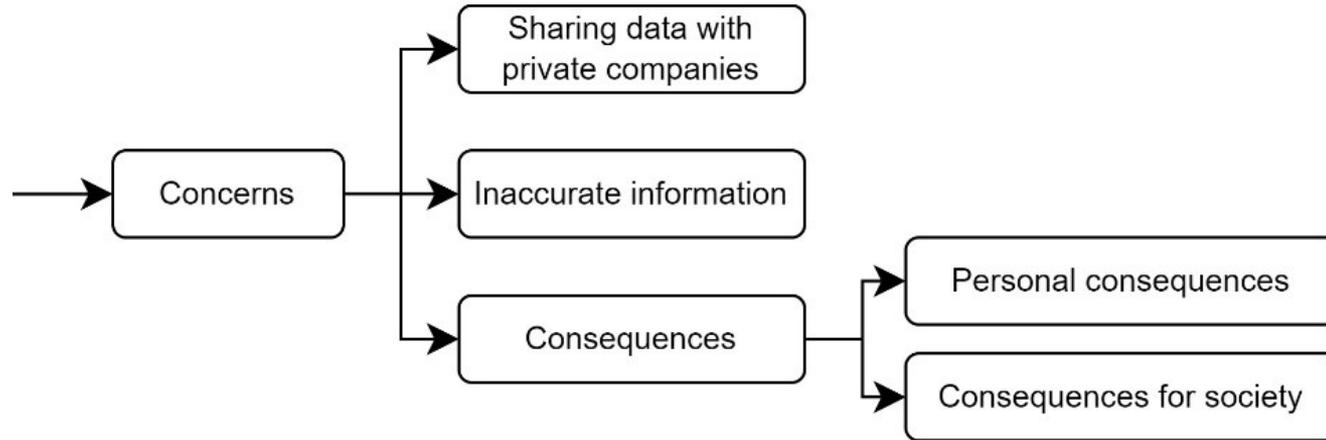
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Leaving a legacy

Well, I'm 88, and so I've not got many years left in my life, but you've got to store this information. It's not dead. The patient's not dead. It's a person

There's got to be a reason why more people are getting dementia. It's going to be one in three. You know, that's really high. So what is the core of it? Yeah, combining information from all parts is again beneficial in the long run…

My mother developed it (dementia). And she always, always said, "I'm going to donate my brain to science. If someone can learn from it, that's great"

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Concerns: privacy and consequences

Private companies: profits & consequences

I don't trust private companies. I think they'd be using it for profit

It's basically the thing of it being used to make a company money rather than being used to help other people

If there's a company out there, they want to make a profit. And if they are making a profit, it makes their product better

I worry about the ethics of how will it be used in the future and how will that information affect insurance and all those other things

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Expectations: conduct and collaboration
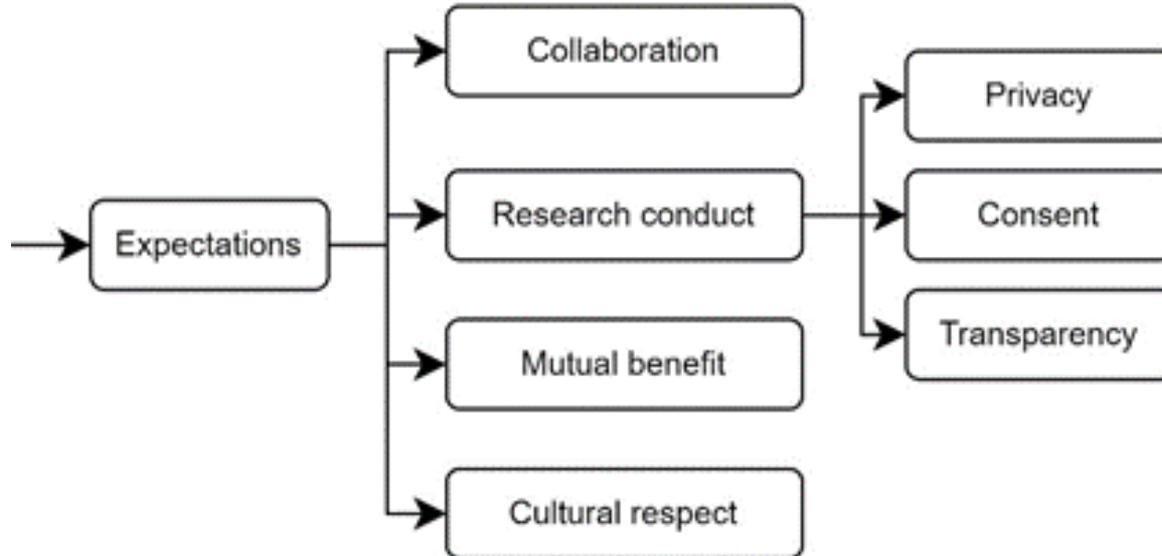
Conduct and collaboration

As long as New Zealand got some benefit back from the research…I'd expect New Zealand to get benefit out of any research like that…that's been shared

As long as they don't know who I personally am or where I live, that's fine

If you feel like there's a huge transparency around it, I think you may get public buy-in. That we're all working to the same good

This is what happened when we had COVID, that there was a collaborative work together. Look, look, we've got fantastic vaccines

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Consent and cultural respect

If you're going to do that, just ask for consent, just say, this is what we're doing it for. How do you feel? Just a courtesy call to say, this is what we're doing

Our tangata whenua, they might have a problem with that (using data after someone's death). Because their remains are tapu. So maybe that is something that should be considered. You see, I'm okay with that. But other cultures may not be okay with that

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Conclusions and questions

Older people want to contribute to brain health research in NZ

Many prefer that research uses their data rather than depending on the results of research carried out in other countries

Our findings reflect Pākehā values, but we need to represent all views

What do we do about consent to use routine health data?

How do we keep people updated about health research projects?

What about AI? How to keep people involved in the discussions?

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Thank you

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