Exploring older people's attitudes and preferences around the use of their routinely collected healthcare data in brain health research in New Zealand.

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More than 85% of participants were aware of how their health information was utilized for service development and assessing population trends. Approximately 80% of them expressed being comfortable or very comfortable with their data being used in this way.

INTRODUCTION

Up to 50% of dementia cases in New Zealand (NZ) may be linked to common risk factors such as hypertension, diabetes, and cardiovascular disease. Exploring routinely collected health information could help gain a better understanding of these relationships and potentially find ways to reduce the risk of dementia. In NZ these deidentified data are often used without individual consent.

Aim: to explore the attitudes and preferences of people aged 55+ living in Counties Manukau (CM) regarding their knowledge about the use of their deidentified health data and their degree of comfort in different scenarios with a specific focus on brain health.

METHODS

An anonymous online survey was conducted with people aged 55+ who had engaged with older adult health services in CM in 2022. We assessed knowledge about the current use of their deidentified health data and their degree of comfort in the following scenarios:

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 CM.
D. To share with health professionals in other organizations.
E. To make decisions about improving CM health services.
F. To investigate the population by combining information.
G. To help others even after you have died or have moved away.

RESULTS

326 responses were received from 1314 emails (response rate 24.8%). 226/326 responses were rated as "valid" due to no missing data.

Respondents: European (64.9%), Māori (11.9%), Asian (10.9%) and others (12.3%). Mean age: 74.2 years. 42% knew of a family member or friend living with MCI or dementia.

Knowledge about how health data is currently used
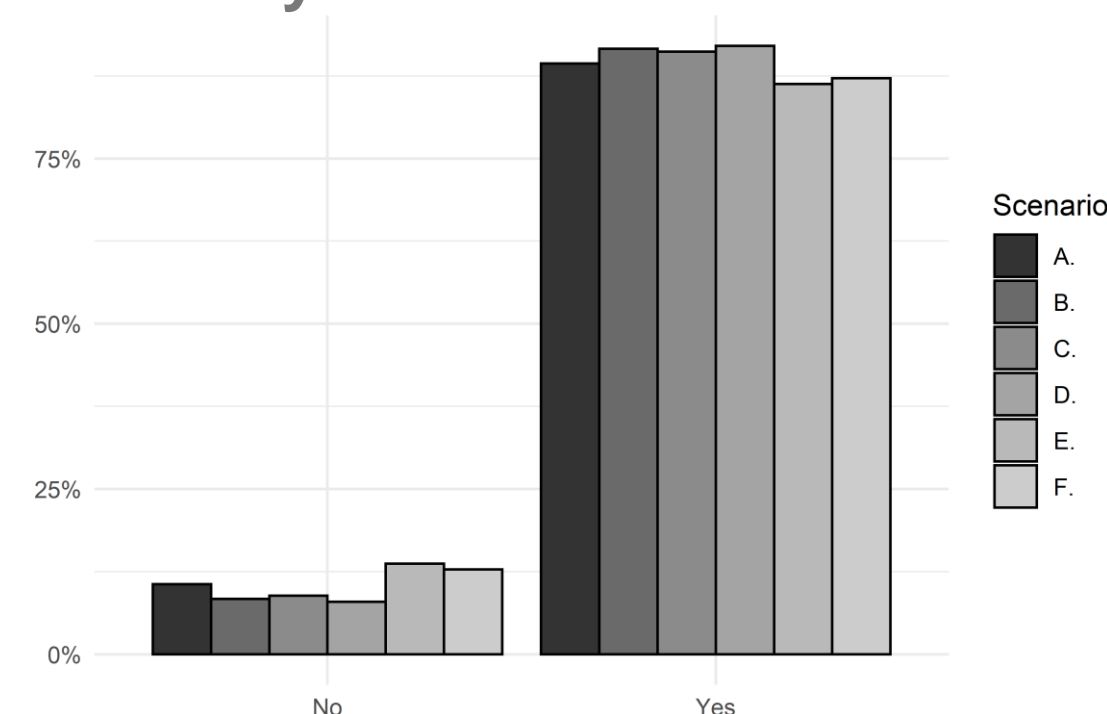
Level of comfort regarding how health data is currently used
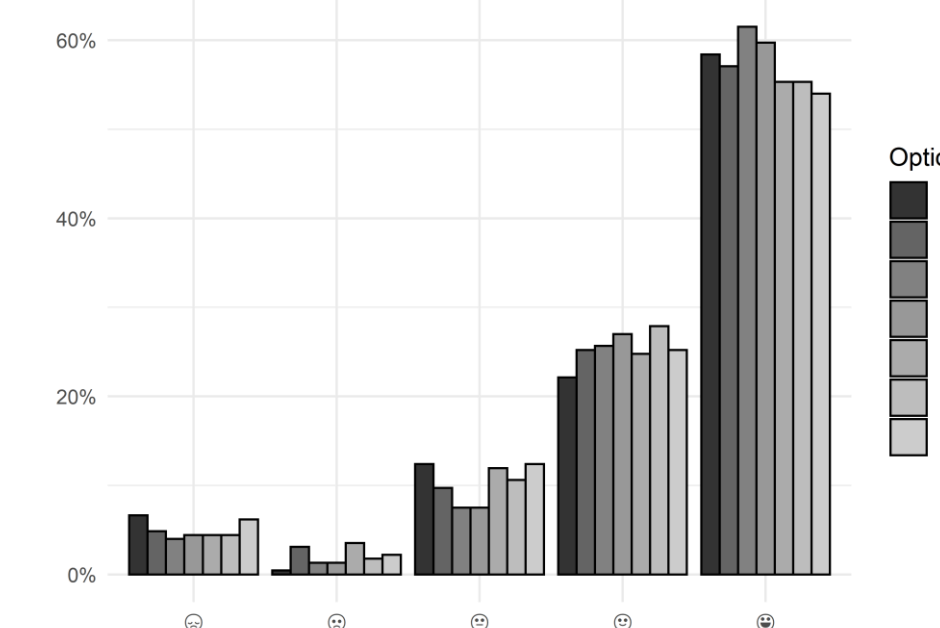
There were some concerns about Māori data being used after death.

CONCLUSIONS

The local population is generally supportive of their deidentified routinely collected data being used for brain health research purposes that will benefit the population from which the data were taken. Specific cultural concerns for Māori need to be explored in more detail.

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