

New Zealanders support the use of health records after death, if it helps others

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New Zealanders are supportive of their health care records being used after they die if it will benefit their whānau and the wider community, new research from the University of Otago has found.

It is the latest study by Senior Lecturer Dr. Jon Cornwall, from the

Center for Early Learning in Medicine in the Otago Medical School, who has been researching possible uses for posthumous electronic health care data (PHCD) for nearly five years.

Society has entered an era where having [digital information](#) recorded about us is considered normal, he says.

Yet, despite its increasing volume, it has not been decided what should happen with that data after someone dies and there is no guide as to what society views as acceptable.

Dr. Cornwall's study, funded by the New Zealand Law Foundation and published in Friday's edition of the *New Zealand Medical Journal*, aims to fill that gap by exploring the attitudes and perceptions of New Zealanders towards the use of the deceased's health care data.

Participants were asked to explore a range of topics focused around PHCD utilization, including family access, consent models, infrastructure, anonymity, governance, and commercialization.

The results indicate there is conditional support for a centralized, government-managed PHCD repository allowing controlled, no-cost access for health care and research purposes.

Public benefit from data is important, and participants prioritized any benefits being directed to family, then New Zealanders, and then others.

Commercialization from data-use is viewed as likely and acceptable and Māori PHCD is considered preferably managed by Māori. Participants, however, struggled to define appropriate levels of family access, anonymity, and consent models.

Dr. Cornwall says he is not surprised by these results. "The Kiwi attitude

of helping others came through strongly—we are a beneficent bunch."

This latest step in Dr. Cornwall's research is vital as these insights will help shape exactly how PHCD should be used in a socially responsible manner, he says. "Death is an important social construct and deciding how to respectfully address information from those that have died had not yet been discussed. This is particularly important when [medical information](#), which has personal and societal value, is being utilized."

It is important a system is developed to ensure the culturally, ethically and socially appropriate use of PHCD, and to maintain trust between [medical professionals](#) and the wider public, he says.

Dr. Cornwall's interest in researching potential uses for PHCD began in 2017, when he was working on research related to body donation and the digitization of human remains. "The leap to considering health care records in posthumous context was an 'aha' moment, where a colleague and I wondered 'what if?'" he says. "From there, the idea grew."

Dr. Cornwall says there are many ways this data can be used, including utilization of genomic data to process and develop personalized medicine. "That will directly benefit family in certain circumstances, as well as the wider community."

More information: "An exploration of Aotearoa New Zealanders' attitudes and perceptions on the use of posthumous healthcare data" [journal.nzma.org.nz/journal-ar ... are-data-open-access](http://journal.nzma.org.nz/journal-article/2022-01-01-are-data-open-access)

Provided by University of Otago

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