

## **Understanding the privacy concerns of participants in longitudinal studies: A summary of findings from interviews with members of the Dunedin Study**

### **Contributors to this report**

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- Moana and Richie also worked on the project. Moana has expertise on Māori health research and advised throughout the project. She is a Co-Investigator on the Dunedin Multidisciplinary Health and Development Study and is the Director of the National Centre for Lifecourse Research within the Department of Psychology at The University of Otago | Te Whare Wānanga o Otāgo.
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### **Overview of this project**

- When people take part in research they are increasingly being asked if it is ok for the data they provide to be shared with other researchers or on public websites.
- This is known as data-sharing and can sometimes be helpful because it can help make sure researchers are open about what they have done by allowing others to check the data. Data-sharing can also enable other researchers to use the same data to answer other questions that contribute to public good.
- Data-sharing raises lots of questions about privacy for people who take part in research, particularly long-term studies like the Dunedin Study.
- We held interviews with 25 members of the Dunedin Study from a range of groups to hear views about data-sharing.
- We found that data-sharing requires more thought than simply asking a yes/no question of each individual participant in long-term research like the Dunedin Study.
- Certain types of research data collected in big studies like the Dunedin Study are extremely sensitive and different participants might not be willing for certain data to be shared with other researchers.
- Interviewees suggested that it might be best if specific decisions about sharing data are based on a unanimous view across the whole group of study members.
- Overall, the increasingly common ways of sharing data with other researchers have big implications for the privacy of participants, particularly those in long-term research like the Dunedin Study.

## **What is data-sharing and how does it relate to the privacy of people who take part in long-term research like the Dunedin Study?**

Data-sharing is the process of making raw data from research available to other researchers, usually via online repositories. It is a component of the 'open science' movement, which advocates for openness in all components of scientific research. This sharing of data can be really helpful when research is needed to create urgent solutions to problems like Covid-19. However, the privacy of participants has to be thought through, and there are lots of privacy issues to think about before data can be shared from long-term research like the Dunedin Study.

Data-sharing has started to become common in recent years because it allows researchers to access the raw data collected by other researchers and check what the data show and answer other questions using the same data. Many journal editors are adopting data-sharing policies, and many funders of research that comes from public money (like the UK Medical Research Council and US National Institutes of Health). It is quickly becoming a requirement that researchers will make plans for sharing data, but this raises lots of questions about privacy for participants.

There has been a lot of discussion amongst researchers about whether data-sharing is a good or bad thing. Advocates for data-sharing describe benefits such as i) making it easier for groups of researchers around the world to collaborate on big projects, ii) greater care taken during the initial data collection and analysis, iii) an increased likelihood of identifying mistakes in health research before they have an impact in clinical settings, and iv) maximising the value gained from data that have already been collected by using them to answer other questions.

On the other hand, some researchers have raised concerns about how time-consuming it is to find safe ways to share the data they collect, with very little benefit in exchange for their efforts. Some researchers are concerned that data-sharing can even lead to data being misused by other researchers, and this could have negative implications for the researchers who originally collected and analysed the data.

## **Why is research needed to ask participants of long-term research like the Dunedin Study what they think about data-sharing?**

Lots of research has been dedicated to understanding the views of researchers, journal editors, and government agencies that fund research hold about data-sharing. However, there has been surprisingly little research about the views of research participants about data-sharing, meaning that their voices are missing from the debate about how data should be shared (if at all).

People who take part in one-off studies like a survey or clinical trial of a new treatment have spoken about creating public good as a motivation for contributing data, but these people also feel that the way data-sharing is currently implemented lacks transparency about the types of data that may be shared, and with whom they are shared. Furthermore, there are specific concerns about data collected from Māori research participants, particularly the need for specific consultation and culturally appropriate research processes, and that Māori retain governance over Māori data.

The Investigators of the Dunedin Study are open to certain aspects of data-sharing in principle, but have concerns about what consequences could arise for Study Members if data-sharing is implemented without appropriate consideration. In particular, there are concerns about what happens when databased are linked together such as data from a study and databases from the Census or other official records. Therefore, until this point, data-sharing has been deemed inappropriate in the context of data collected for the Dunedin Study. In ongoing longitudinal research like the Dunedin Study, the volume and range of data collected about the Study Members has to be thought through before any data are shared.

## **What did we find from this project about views on data-sharing among people who are members of the Dunedin Study?**

Twenty-five members of the Dunedin Study took part in a one-on-one interview with Richie, who is the Director of the Dunedin Study. We invited a variety of study members to take part in an interview in order to ensure we heard lots of different perspectives. All of the members of the Dunedin Study were born between 1<sup>st</sup> April 1972 and 30<sup>th</sup> March 1973 and participants were aged between 45 and 48 at the time of the interview. Sixteen of the interviewees are non-Māori (eight women and eight men) and nine are Māori (six women and three men).

The study members who were interviewed were asked about imaginary data-sharing scenarios to help us understand when they would have concerns about their privacy. Based on these interviews, the research team developed a new way of thinking about how longitudinal research participants feel about data-sharing with other researchers, funders, journal editors, and the New Zealand government.

The main thing that we found from the interviews is that consent for data-sharing cannot be addressed by simply asking a yes/no question of each individual participant in long-term research like the Dunedin Study. The people who we interviewed felt that decisions about data-sharing should be unanimous across the whole group of study members rather than based on making an agreement with each individual about whether they would or would not let their data be shared with other researchers.

The people we interviewed also explained that certain types of research data collected in big studies like the Dunedin Study are extremely sensitive. For example, lots of people noted that data about mental health can be very sensitive for some people and therefore many study members may not want this information to be shared. Also, Māori participants indicated that some data is culturally sensitive and this will have implications for whether data-sharing is appropriate overall.

A strong sense of trust in the Dunedin Study researchers was described by the people we interviewed. This meant that people thought it should be the research team who decides whether or not it is appropriate for data to be shared or linked in any particular situation. The people we interviewed also felt that decisions about data-sharing should ensure that those using the data are doing so to help the public good by tackling problems that affect people in Aotearoa New Zealand or around the world.

## **What are the key findings from this project?**

The messages we heard from members of the Dunedin Study who were interviewed demonstrate the kind of concerns about privacy that need to be addressed for participants of long-term research like the Dunedin Study.

The first key finding is that longitudinal research is more complicated than one-off studies for many reasons, so there need to be careful consideration before asking participants whether they agree to their data being shared with other researchers. Considerations about the sheer volume of data, the types of data that have been gathered, and loss of anonymity are all amplified in long-term research like the Dunedin Study.

The second key finding is that there would need to be ongoing consultation about any sharing of data with participants of long-term research like the Dunedin Study in order to maintain the trusting relationship with the research team. This finding is also relevant to people who are deciding whether to take part in any kind of research because the different possible uses of data always need to be made clear before the person starts taking part in the research.

Overall, this project has raised ongoing questions about the implications of data-sharing for the privacy of participants of long-term research like the Dunedin Study and demonstrates the need to hear from participants themselves about whether data-sharing is acceptable in the kind of scenarios increasingly required by journal editors and funders of research.