# Storing and sharing qualitative social data

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publication.

#### Introduction

Natural Hazards Research Australia (the Centre) is implementing a program to support the effective collection, use, curation and sharing (where feasible) of research data guided by its Research Data Management Framework.<sup>1</sup> Under this framework, the Centre expects all research providers and researchers undertaking work funded by the Centre to comply with the FAIR data principles (Findable, Accessible, Interoperable and Recoverable), as well as the CARE data principles for Indigenous data management (Collective benefit, Authority to control, Responsibility, Ethics) and that research is conducted following the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research.2

When it comes to qualitative social data, adhering to the FAIR principles can present ethical, epistemological and methodological challenges and complexities that are different to other types of data. The Centre aims to be a leader in the careful, ethical, safe and appropriate application of the FAIR and CARE data principles to natural hazards and disaster research involving human subjects and qualitative social data. To help the Centre achieve this, this project explored the benefits, concerns and challenges associated with the sharing and storage of qualitative and sensitive data in the context of disaster research and developed guidelines to overcome these. The purpose of this report is to promote guidance for researchers for the storing and sharing of qualitative social research data. For context, the report first provides a brief overview of the research methods, findings and guidelines made for the Centre to consider.

#### Research overview

#### Methods

A scoping review was undertaken to explore the most recent challenges and approaches to storing and sharing qualitative social data in Australia and internationally, drawing from peer reviewed and grey literature, along with related websites and key informant perspectives. The scoping review also included a review of 11 publishing house policies and was conducted in January 2023.

At the commencement of the project, a workshop was held with more than 40 participants at the 2023 Natural Hazards Research Forum in Melbourne. The workshop introduced the idea of qualitative data sharing and explored 3 questions:

- 1. What are some of the benefits to data sharing which would encourage you to either share or use shared data?
- 2. What are some of the barriers you can think of which would limit qualitative data sharing with other researchers?
- 3. Can you suggest any solutions which could resolve some of the barriers to qualitative data sharing?

To further examine these questions, interviews were conducted online using Zoom between July 2023 and January 2024 with academic researchers, including postgraduate students, government officials and consultants involved in the collection and/or use of

- Natural Hazards Research Australia Data Management
  Framework, at www.naturalhazards.com.au/sites/default/
  files/2022-05/NatHazResAus%20Data%20Management%20
  Framework.pdf
- 2. AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research, at https://aiatsis.gov.au/research/ethical-research/ code-ethics

qualitative social data. To ensure a good cross-section of the typical population groups that are the focus of natural hazards and disaster research involving human subjects, invitations were targeted to those working with Indigenous communities, disaster-affected communities, youth groups, vulnerable groups and CALD<sup>3</sup> communities.

Data management frameworks and policies from 13 Australian and one New Zealand university were reviewed in terms of providing information and resources related to the sharing of qualitative social research data.

Findings from these activities were collated into a set of draft recommendations. A member checking process, involving review of acceptability and sensitivity of the draft recommendations, was conducted in a final workshop with members of the Centre and its social science research community, some of which were interviewed as a part of this project.

The final workshop was held online using Microsoft Teams on 30 May 2024. Invitees were provided with an overview of the findings prior to the workshop to ensure they had time to consider these in relation to the draft guidelines. A total of 13 people participated in the final workshop, which included 6 social researchers and 6 Centre staff.

#### Findings and guidelines

The project identified that universities and publishing houses are adapting their policies where the sharing of data is an expectation of all researchers (not just within the qualitative social research community). To support the effective collection, use, curation and sharing of research data, universities have developed data management plans, policies and frameworks while publishing houses have developed supporting materials and guidance.

Workshop participants and interviewees identified a range of benefits, challenges and concerns for data sharing:

- · Benefits:
  - reducing costs
  - · reducing impact on participants.
- · Challenges and concerns:
  - costs associated with de-identifying data
  - · difficulty protecting identities and confidentiality
  - possible future use of data outside of the intention of the original project.

Overall, protecting the participant drives researcher concerns. However, universities and publishers advocate that by using the appropriate processes and following the procedures set out in their policies and guidelines, participants can be protected and data can be shared.

Based on these findings, guidelines are proposed:

- Commit to data sharing as a first principle: the scoping review and review of current thinking and practice relating to university data management frameworks and policies revealed that data sharing in relation to the FAIR and CARE principles are being adopted across the academic sector. The Centre would remain at the forefront of this agenda by its commitment to data sharing as a first principle.
- 2. Implement a policy that requires any research proposal to include a data management plan: the interviews revealed a lack of awareness among researchers of current practice and supporting frameworks and policies related to data sharing. Implementing a policy that requires any research proposal to explicitly include a data management plan would help to increase awareness of current thinking relating to data sharing and promoting associated best practice. This action would also help researchers address concerns raised in relation to costs and additional resourcing required to ensure data is accessible (e.g. cost of researcher's time needed to de-identify data) as it requires they plan for these at the outset.
- 3. Researchers work with their respective institution according to their data management policy, using their resources for upskilling: the review of university data management frameworks and policies, and the work being progressed by the Australian Research Data Commons (ARDC), revealed the evolution that is taking place within the academic sector to promote and encourage data sharing. Researchers should be advised to work with their respective institutions and seek further advice from ARDC as required. Working within the policies and practices of the researchers' institutions would avoid duplication (and possible conflicting practices) thereby minimising researcher concerns.
- Follow best practice as outlined by universities and/or the ARDC: this will mean:
  - data management plans are tailored to the individual project in collaboration with ethics committees
  - participants have the right to say how, if at all, their data is shared
  - researchers have the right to argue the extent to which their data is shared.
- 5. Support the culture change needed by promoting training, upskilling and sharing as an expectation: this includes encouraging researchers to access shared data alongside sharing any new data collected.

<sup>3.</sup> CALD – culturally and linguistically diverse.

While this research was designed for the Centre and its social science research community, these guidelines are relevant to the broader academic sector and associated funding bodies.

#### Guidance for researchers

#### Data management policies and frameworks

Universities have been progressing work in this direction with the development of data management policies and frameworks outlining the requirement for researchers to submit data management plans. Many of the universities provide video guides, training and education to help generate awareness of their data management policies and procedures, along with 'how-to guides' and toolkits. For example:

- Massey University Create your research plan, at www.massey.ac.nz/study/library/researcher-support/ research-data-management/create-your-researchdata-management-plan
- Monash University Data collection and management, at www.monash.edu/library/researchers/datacollection-management
- University of South Australia Research data management, at https://guides.library.unisa.edu.au/ ResearchDataManagement
- University of Western Australia Research Data Management Toolkit: Data management, at https:// guides.library.uwa.edu.au/RDMtoolkit
- University of Western Sydney Research Data Management, at https://library.westernsydney.edu.au/ researchers/data-management.

In relation to disaster-affected communities, CONVERGE (Natural Hazards Centre at the University of Boulder, Colorado) provides detailed guidance, tools and training resources for members of the natural hazards research community about possibilities for managing, storing, curating and publishing data, instruments, protocols and other materials (see CONVERGE website https://converge.colorado.edu/data/publish-your-data).

Examples of data management plans for the sharing of data include:

- Digital Curation Centre, United Kingdon, at https:// www.dcc.ac.uk/resources/data-management-plans/ guidance-examples
- DMT Tool Public Plans, USA, at https://dmptool.org/ public\_plans.

#### Accounting for FAIR and CARE principles

When creating a data management plan, many universities note researchers need to consider the FAIR and CARE principles and treatment of sensitive data. The ARDC provides advice and guidance:

- Making Data FAIR, at https://ardc.edu.au/resource/fair-data.
- CARE Principles, at https://ardc.edu.au/resource/thecare-principles.

Universities also provide links to resources on applying the FAIR and CARE principles. For example:

- Massey University includes CARE Principles for Indigenous Data Governance, at https://static1. squarespace.com/static/5d3799de845604000199cd24/ t/5da9f4479ecab221ce848fb2/1571419335217/ CARE+Principles\_One+Pagers+FINAL\_Oct\_17\_2019.pdf
- FAIR Principles, at https://www.go-fair.org/fair-principles.

Other ARDC related information can be found via:

- Indigenous Data, at https://ardc.edu.au/resource/ indigenous-data
- Working with Sensitive Data, at https://ardc.edu.au/ resource/sensitive-data
- Identifiable Data, at https://ardc.edu.au/resource/ identifiable-data.

#### How sharing is done

Many journals encourage researchers to attach a data availability statement to their published articles. As described by Taylor and Francis (2024)<sup>4</sup>:

A data availability statement (also sometimes called a 'data access statement') tells the reader where the research data associated with a paper is available, and under what conditions the data can be accessed. They also include links (where applicable) to the data set.

Many universities provide how-to videos and resources explaining how sharing can be done. For example, Central Queensland University's webpage 'Using Data Manager'<sup>5</sup> has a 'Publishing your dataset video' that demonstrates how to publish a dataset. Central Queensland University also provides guidance on what details can be included in a dataset record to ensure it is comprehensive and therefore more readily findable by other researchers.<sup>6</sup>

- Taylor and Francis (2024) Writing a data availability statement. Informa UK Limited, an Informa Group Company. Taylor and Francis website https:// authorservices.taylorandfrancis.com/data-sharing/share-your-data/data-availability-statements, accessed 25 April 2024.
- 5. Using Data Manager, at www.cqu.edu.au/library/managing-research-data/using-data-manager
- Dataset records: Fields published in aCQUIRe, at https://deliverycqucontenthub.stylelabs.cloud/api/public/content/data-publication-checklist. pdf?v=c4720398

### Where is research data stored and published?

Many universities have their own databases. For example, the University of Western Australia has the UWA Profiles and Research Repository.<sup>7</sup> Datasets (either open access, mediated access or citation only) are published on Central Queensland University's aCQUIRe with a digital object identifier (DOI). These datasets are also discoverable on:

- Google Dataset Search, at https://datasetsearch. research.google.com
- Figshare, at https://figshare.com
- Research Data Australia Find data for research, at https://researchdata.edu.au.

Other storage facilities in Australia include the Australian Data Archive<sup>8</sup> and CSIRO Data Access Portal.<sup>9</sup>

Internationally, the publishing company *Nature* provides a list of various data repositories including those related to the social sciences. <sup>10</sup> Within this list is the Qualitative Data Repository <sup>11</sup> where researchers can discover or deposit data.

In relation to disaster-affected communities, CONVERGE is linked with the DesignSafe Data Depot. 12

Researchers also have the option to publish their datasets in data journals. The University of Queensland<sup>13</sup> states:

Data journals are emerging as another channel for researchers to publish their research outputs, including data. Data journals are publications whose main aim is to expose datasets more widely, and allow researchers to share their research data outputs.

## Incorporating guidance for research during disaster into the national statement

All researchers are familiar with the requirements of the *National Statement on Ethical Conduct in Human Research* 2023<sup>14</sup> and work within these guidelines. Historically, the statement has not included details on the ethical challenges involved in disaster research. This, however, may change. In 2023, the National Health and Medical Research Council proposed changes to Section 4 of the statement. The section deals with ethical considerations where research participants may be at greater than normal risk. The proposed changes to Section 4 include a new chapter providing guidance on the conduct of research 'during natural disasters, public health emergencies or other crises'.<sup>15</sup>

Among the wide-ranging considerations for research conduct in these situations, the proposed guidelines explicitly recognise there may be need for rapid sharing of data among and between researchers and affected communities. The message is clear. Sharing of data from disaster research can be done ethically and should be considered. Consultation on the proposed changes to the *National Statement on Ethical Conduct in Human Research 2023* was completed in September 2023.<sup>16</sup> To date, an announcement on when the proposed changes will be introduced has not yet been made.

- Profiles and Research Repository, at www.uwa.edu.au/library/help-andsupport/support-for-uwa-researchers/uwa-profiles-and-research-repositorysupport-and-fags
- 8. Australian Data Archive, at https://ada.edu.au
- 9. CSIRO Data Access Portal, at https://data.csiro.au
- 10. Nature scientific data, Data Repository Guidance, at www.nature.com/sdata/policies/repositories
- 11. Qualitative Data Repository at, https://gdr.syr.edu
- 12. CONVERGE DesignSafe Data Depot, at www.designsafe-ci.org/user-guide/managingdata
- 13. University of Queensland (2024) Research data data journals. UQ website https://guides.library.uq.edu.au/how-to-find/research-data/datajournals, accessed 31 August 2024.
- National Health and Medical Research Council (2023) National Statement on Ethical Conduct in Human Research 2023. NHMRC website www.nhmrc. gov.au/about-us/publications/national-statement-ethical-conduct-humanresearch-2023, accessed 5 November 2024.
- 15. NHMRC Invitation to make a submission, at www.nhmrc.gov.au/public-consultation-section-4-national-statement.
- 16. National Health and Medical Research Council (2024) Public consultation on Section 4 of the National Statement. NHMRC website www.nhmrc.gov.au/public-consultation-section-4-national-statement, accessed 24 October 2024.