

## Participant Information Sheet

### Project Lead Investigator:

My name is James Ansell and I am the Research & Policy Officer for the Consumers Health Forum of Australia (CHF).

**Project Title:** Access to Consumer Medical Records and Health Data

### General Outline of the Project:

- **Description and Methodology:** The ‘Access to Consumer Medical Records and Health Data’ project aims to understand Australian health consumers’ experiences with accessing their medical records and their views on appropriate ways to gain and retain consent for secondary usage of their health data. There is currently limited data on consumers experiences with and attitudes towards these subjects which this research aims to address. For this part of the project we are looking to conduct interviews with consumers who have attempted to access their own medical records or the records of someone they care for or have experiences with the idea of sharing health data for secondary usage e.g. research, population datasets etc.
- **Participants:** We intend to run 15 one-on-one interviews with participants recruited from CHF networks.
- **Use of Data and Feedback:** The data collected in this research will be used to produce a report for the Australian Department of Health (the Department) to assist them in designing public policy and shape CHF’s advocacy efforts. The report or a results summary will be posted on the CHF website [www.chf.org.au](http://www.chf.org.au) where participants will be able to access it.
- **Project Funding:** This project is being funded by the Australian Department of Health.

### Participant Involvement:

- **Voluntary Participation & Withdrawal:** Your participation in this research is voluntary, and you may decline to take part or to withdraw from the research without providing an explanation at any time until the work is prepared for publication. Within the research, you may also decline to answer any question. If you withdraw, the data you have provided prior to withdrawal will be destroyed and not used. At any time you may be provided a copy of your data, including audio transcripts, for your review.
- **What does participation in the research entail?** You are invited to be interviewed about your experiences of consumer access of medical records and health data sharing consent. With your consent, we will record the interview so that it can be accurately transcribed. The recordings will be destroyed after transcription. During the interview may be asked some personal questions about accessing your medical records and history, or that of others you care for, or being asked to consent to that health data to be used for other purposes. In response to these questions you may or may not choose to disclose specific details about your health data, your health status or your broader healthcare experiences.
- **Location and Duration:** The interview will be held at a mutually convenient time. We expect it will go for approximately one hour but recommend you allow up to two hours in case the discussion takes additional time. The interview will be held via teleconference or videoconference so you may attend via a place that is convenient to you that has access to a telephone line or internet connected device. We do

**Protocol Title:** Access to Consumer Medical Records and Health Data

**Protocol Number:** 2020-04-341

**Version & date:** Version 2, dated 12 June 2020

request that you choose a location that has minimal ambient noise for the convenience of the other participants.

- **Remuneration:** In recognition of your time, we will provide you with a \$50 participation fee for your contribution to this research project in the form of a gift card. It is the responsibility of individual participants to review if this fee has any implications for their tax or income status.
- **Risks:** This research carries little risk, although you may feel uncomfortable or distressed if you have had negative experiences in the past with medical records or healthcare data. There is also a risk that despite our efforts to keep your identity confidential you may be identified, either through the stories and information you provide. Consequently, you should not share anything that you believe would incriminate you, cause others to take a negative view of you or have any other undesirable outcomes that you believe are unacceptable should you be identified.
- **Benefits:** It is unlikely that you will personally benefit from participation in this research. However, the work will improve the ability for all consumers to access their medical records and improve the mechanisms by which consent for health data sharing operate, potentially leading to other improvements in the healthcare system.

#### Exclusion criteria:

- **Participant Limitation:** This research is intended to get the perspectives of the general Australian public and as such the primary perspective of participants should be that of consumers, consumer advocates or custodians of consumer health data. People who wish to represent other primary perspectives such as those of healthcare workers or academic researchers are excluded from this research project.

#### Confidentiality:

- **Confidentiality:** We will keep your identity confidential as far as allowed by law, unless you elect to be named within the research. Published results will only be reported in aggregate, and you will not be identifiable within published outputs unless you have elected otherwise.

#### Privacy Notice:

In collecting your personal information within this research, the CHF must comply with the Privacy Act 1988. The CHF Privacy Policy is available <https://www.chf.org.au/privacy-policy> and it contains information about how a person can:

- Access or seek correction to their personal information;
- Complain about a breach of an Australian Privacy Principle by CHF, and how CHF will handle the complaint.

#### Data Storage:

- **Where:** Data will be securely stored on password-protected CHF Microsoft SharePoint. Physical records will be kept in a locked filing cabinet in the CHF office. Interview recordings will be provided to Typed Word for the purpose of transcription and stored on password protected computers. De-identified data will be provided to Urbis Pty Ltd for the purpose of data analysis and secured in the Urbis password protected Microsoft SharePoint.
- **How long:** All research data will be retained and securely stored by CHF and Urbis for seven years following the conclusion of this research project. Data held by Typed Word will be destroyed at the end of the project.

**Protocol Title:** Access to Consumer Medical Records and Health Data

**Protocol Number:** 2020-04-341

**Version & date:** Version 2, dated 12 June 2020

- **Handling of Data following the required storage period:** After the storage period, all identifying details will be removed from the data and the non-identified data will be archived by the CHF for use in later research projects, including potentially in collaboration with other researchers. Data held by Urbis will be destroyed.

#### **Queries and Concerns:**

- **Contact Details for More Information:** Any requests for information or queries regarding the study participants should be directed to [j.ansell@chf.org.au](mailto:j.ansell@chf.org.au) (+61 2 6273 5444) or the project supervisor Ms Jo Root ([j.root@chf.org.au](mailto:j.root@chf.org.au), +61 2 6273 5444).
- **Contact Details if in Distress:** If participation in this project causes distress, participants can receive support via the Lifeline service by calling 13 11 14 or by visiting [www.lifeline.org.au](http://www.lifeline.org.au).

#### **Ethics Committee Clearance:**

The ethical aspects of this research have been approved by the Bellberry Human Research Ethics Committee (Protocol 2020-04-341) and is project being conducted in accordance with the values and principles of human research ethics. If you have any concerns or complaints about how this research has been conducted, please contact:

Bellberry Limited  
123 Glen Osmond Road  
Eastwood, South Australia 5063  
T: +61 8 8361 3222  
E: [bellberry@bellberry.com.au](mailto:bellberry@bellberry.com.au)