

Information sheet: My Health Record Consumer Experience Survey

Consumers Health Forum of Australia (CHF) and the Australian Digital Health Agency (the Agency) invites you to participate in this survey to share your experience using My Health Record.

The Agency has provided funding for CHF to collect consumer stories about their experiences using My Health Record.

The Agency

The Agency is responsible for national digital health services and systems, with a focus on engagement, innovation and clinical quality and safety. The Agency's focus is on putting data and technology safely to work for patients, consumers and the healthcare professionals who look after them.

Consumer Health Forum of Australia

CHF is Australia's national non-government organisation representing Australian healthcare consumers. We work to achieve safe, quality and timely healthcare for all Australians, supported by accessible health information and systems.

Purpose of the Survey

The overall purpose of the survey is to better understand consumer experiences of using My Health Record in real life situations. An additional aim is to develop a series of case studies to capture opportunities for improvement and highlighted what is working well with My Health Record, from a consumer perspective.

Participants: and exclusion criteria

This survey is anyone in Australia who has used My Health Record, either for themselves or to assist another person. Anyone who does not reside in Australia or has not used My Health Record should not participate. In addition, only people aged 18 years or older should complete the survey.

Voluntary Participation & Withdrawal

Your participation in this survey is voluntary, and you may decline to take part or to withdraw, without needing to provide an explanation, at any time until the results are prepared for publication. Within the survey, 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.

What does participation in this survey project entail?

The primary task for this project will be completing the survey, which we expect will take no longer than 15 minutes. It will be completed online at a time and place of your convenience. While you may complete the survey in multiple sessions, we recommend attempting to complete it in one session as the survey software will not save incomplete survey responses if you close your web browser.

The secondary task may be, following the completion of the survey, being contacted by the Agency as required to review and approve any public case studies they wish to develop and publish based on your experience to use in public communications such as reports. Your personal information will be retained by the Agency in accordance with all applicable laws.

Collection of Information

The information you provide in the survey will be anonymous unless you choose to provide personal information. If you choose, personal information such as your name and contact information will be collected for the Agency to contact you directly to seek permission to publish your case study. Personal information will be handled in accordance with the privacy policies of [CHF](#) and the [Agency](#). If you decide not to provide your name and contact information, a case study will not be developed from your survey results, however your deidentified responses may still be used and quoted by the CHF and the Agency in aggregate with other participant data for activities such as public reports, submissions, presentations and other research projects.

Risks:

This research potentially carries notable risk to participants agreeing to be used in the Agency case studies as identifying information such as your name may be associated with your personal health experience information you provide in a public communication used by the Agency.

If you do not consent to be publicly identified in a case study, there is a risk that despite our efforts to keep your identify confidential you may be identified, either through the experience and information you provide. In addition, you may feel uncomfortable or distressed if you have had negative experiences in the past with My Health Record.

Benefits:

It is unlikely that you will personally benefit from participation in this research. However, the work will improve the understanding of consumer experiences using My Health Record, potentially helping to direct efforts and resources to improve My Health Record in the future and maximise the benefits of the system for all Australians.

Case study publication process

You will have an opportunity to review, provide comment and approve the draft case study content for publication. You will need to provide your contact details in the consent form for the Agency to contact you.

Confidentiality

We will keep your identity confidential as far as allowed by law, unless you elect to be named within the Agency public case studies. Access to the data you provide will be restricted to CHF and Agency staff and identifying details will be stored separately from the rest of the survey data. Published results will only be reported in aggregate, excluding the Agency case studies, and you will not be identifiable within published outputs unless you have elected otherwise in the consent form.

Data Storage

Data held by CHF will be securely stored on password-protected computers in CHF Office. CHF copies of physical records will be kept in a locked filing cabinet in the CHF office. All data held by CHF will be retained and securely stored for at least five years following the conclusion of this research project. After the storage period, all identifying details held by CHF will be removed from the data and the non-identified data will be archived by the CHF for use in later research projects.

Your personal information collected by the Agency will be retained in accordance with all applicable laws.

Questions

If you have any questions about the information contained in the *Consent Form*, or in this *Information Sheet* please contact:

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