



Consumers Health  
Forum OF Australia

SUBMISSION

**Development of a Framework  
for Secondary use of My Health  
Record Data**

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of My Health Record Data.* Canberra, Australia

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# Introduction

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The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian healthcare consumers and those with an interest in health consumer affairs. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems. We welcome the opportunity to provide feedback to the consultation regarding the Development of a Framework for Secondary Use of My Health Record (MHR) Data.

CHF supports evidence-based policy setting and believes the MHR data set represents a rich national data set that can be de-identified, aggregated and made available for analysis. Its use and application to research in the public interest should be balanced with security and privacy safeguards that meet high standards.

Accordingly, CHF has actively supported the Department's process in the following ways:

- promotion of the consultation process and discussion paper through our online channels, including our extensive social media presence, newsletters and website.
- advertisement of the opening webinar, including wide distribution of the recording of it.
- seeking feedback and promoting the consultation opportunity through our Digital Health Special Interest Group
- running the closing webinar, presented by healthConsult on Nov 15 that discussed the themes raised through the consultation process.

## On the Framework

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The development of a framework for to the secondary use of My Health Record data is a development of extreme value to the future of health care policy and administration. We value the wide consultation that is being conducted, and look forward to ongoing and clear consultation as the framework develops.

CHF recognises the immense public good that can be achieved through the secondary use of MyHealthRecord data. Analysis of de-identified data covering large numbers of people reveals nationwide trends of what works and what doesn't in medical practice, patterns of service utilisation, experiences of the system and health outcomes. Of particular importance to consumers and the community is that evidence-driven policy and health programs not only boost the delivery of patient-centred care but also give greater assurance that we are investing in high value care, not futile or ineffective treatments and services. De-identified, aggregated data from MHR will generate a rich source of knowledge as the data set builds over time.

As the data are consumer centred, the power of this dataset will only grow. Much of the research at the moment relies on either self-reported data or linked datasets. The MHR dataset will potentially combine service utilisation data such as PBS and MBS and notes by patients and clinicians about their health status, where these details are captured. For example, a researcher will be able to look at consumers' description of their situations then

link this with health service usage. The result should be that consumer perceptions, experiences of care and health care outcomes are placed at the centre more than they currently are.

Patient experiences with new drugs and medical devices which show up unexpected results -- - bad or good --- will be potentially ascertained much more quickly because of the monitoring power of a population-wide data basis.

But the other side of this beneficial development is the equally powerful risk if the system is compromised and/or public trust is eroded through lack of a sufficiently robust framework. We would urge that the framework contains a clear and unambiguous set of principles to guide the secondary use of data and welcome that the need for these is acknowledged in the consultation paper. These should be developed in consultation with consumers and other interested parties.

The key guiding principle should be that the decision maker should be assured that the release is in the public interest. The data harvesting required needs to be balanced with protections and controls that are obvious to the public and give people trust that personal clinical and other information about them is protected to extremely high standards, and that there is appropriate recourse if there are privacy or security breaches. Under no circumstances should data be released to be directed to purposes where the gain is solely commercial.

It is a value that must also be protected from abuse, such as invasion of privacy. So the contribution of the consumers' perspective cannot be understated. Without rigorous, transparent safeguards governing the use and security of MHR data, a breach of privacy or security lapse could seriously undermine the integrity of and public confidence in MHR and its value to society.

Given the importance of getting this process right, and the broad potential for consumers, we make the following series of recommendations about what the framework should encapsulate:

### *Recommendation 1: Further consultation with consumers to validate the framework*

Consumer support and validation of the draft framework will be essential to its success. In order to build on the present extensive consultation we recommend that a specific consumer validation workshop or roundtable is conducted following the drafting of the framework. This consultation could be targeted and directed to key consumer groups, but we suggest it should be done prior to the proposed stakeholder validation workshop to recognise the importance of consumer views.

### *Recommendation 2: Governance*

Governance arrangements for secondary use need to be strong and clear. The data custodian and the functions that accompany that role should be undertaken by a single governing body separate to the MHR system operator – the ADHA.

While existing processes such as health research ethics committees can be an important protection, they are far from consistent across institutions and the Government has a responsibility to ensure best practices are implemented.

CHF strongly recommends that nationally consistent and appropriate governance arrangements within the framework are developed and maintained. This process should also be apolitical.

The concept of 'public good' is central to these discussions and it must be in reality an absolute feature. The public interest test must be the number one principle governing the release and use of My Health Record data.

As outlined in Chapters 4 and 6 of the discussion paper, the Office of the Australian Information Commissioner (OAIC) regulates the handling of personal information under the My Health Record system by individuals, Australian Government Agencies, private sector organisations and some states and territories. We support this role, and suggest that it is more widely promoted to the public because one of the omissions in the current paper is an office, or location, through which consumers are able to complain or query how their information is being used. A dispute resolution process such as this will be essential to helping consumers feel more confident about how their data are being used and that they are being listened to and their views considered.

The framework should make a clear and unambiguous statement about who is the owner of health data. We note that the framework is being developed ahead of any Australian Government action in response to the Productivity Commission's Data availability and use inquiry. We would expect that the advice and recommendations from the Commission are taken into account as the framework is shaped and finalised.

### *Recommendation 3: Public Registers and transparency of data use*

Where and how consumers' data is being used must be clearly and transparently reported. One mechanism through which this could be achieved is public registers. Public registers of where and how MyHealth record data is used should be created and maintained. Consumers have a right to know how their data are being used. Public accountability would promote effective measures to reduce the risk of non-publication bias. Proposals concerning publication so far largely centre around the methods and analysis, not necessarily the outputs and results. Work created from this data should have to be published, and publicly so (not in a pay per view journal) regardless of outcome.

### *Recommendation 4: Consumer Membership of governance structures*

There should be strong consumer participation in governance arrangements. This consumer membership should be adequately resourced, through payments to consumers on committees and training provided to consumers.

## *Recommendation 5: Consent mechanisms*

Consent mechanisms should be dynamic, with specific case-by-case consent preferred for clinical trials specifically.

Consent given to third parties for access should include a time limit after which all data the third party holds must be destroyed.

Consent must be able to be revoked by the consumer at any stage, except in clearly defined situations where the data is de-identified and aggregated such that revocation is no longer possible.

Changes to consent must propagate throughout the system in as near real-time a manner as possible.

Interactions where consent is being asked for should be used as an opportunity to improve health literacy where practical, to both ensure the consumer is making an informed choice and improve health literacy in general.

The Government must facilitate the communication of results back to consenters where practical.

Particular consideration should be given to how to best implement these practices for those consumers who are deemed unable to consent. The NHMRC's national ethics statement currently provides a framework and guidelines for how groups such as young people and people with significant illnesses which may impact on their ability to consent should be considered in these cases. We recommend that similar guidelines are built into the Framework to ensure that these vulnerable populations are adequately protected.

## *Recommendation 6: Data safety*

Data safety is a key issue for consumers. A balance between security and convenience must be found. The dangers that identifiable health data being released presents places the balance far closer to security than convenience, and convenience can be gained through appropriate implementation of Recommendation 2: Public Registers and Recommendation 7: Information Clearinghouse.

CHF supports the provisions outlined in section 3.3 of the discussion paper with regard to data safety, such as the five safes framework currently used by the ABS. An appropriate combination of these existing examples should be included in the framework.

## *Recommendation 7: Information clearinghouse*

Government departments which hold and analyse large data sets (such as the Department of Health, the Australian Institute of Health and Welfare and the Australian Bureau of Statistics) currently have in place mechanisms for sharing de-identified aggregated data. These departments also play key roles in enabling effective policy development and decision making based on that data. As usage of My Health Record increases, the granularity and volume of data available to the Government will far exceed the data that is currently collected.

We recommend that an information clearinghouse function be created, internal to the agency or department that oversees the dissemination and use of secondary data, including creating the de-identified aggregated data sets for secondary users and managing how health information data is shared between departments.

This Clearinghouse could also play a role in enabling innovation based on data without the innovator requiring access to the data. For example, a small business that designs medical devices for coping with a particular illness might want to know which city has the highest density of consumers with that illness. For a fee, they submit their question to the clearinghouse for processing, the clearinghouse runs a search on their data and returns a response to the small business, including margins of error and their confidence in the quality of the answer. The expertise required already exists within the Government in organisations like CSIRO's Data61.

### *Recommendation 8: Use of Aboriginal and Torres Strait Islander Data*

Specific consideration should be given to how data relating to Aboriginal and Torres Strait Islander people is used. We note that within the NHMRC national ethics statement such a sentiment already exists. We would like to see this carried across to the Framework and strengthened where practical.

## **Our position on My Health Record**

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CHF has consistently welcomed the introduction and development of digital health endeavours, and specifically the My Health Record. We are interested in issues around privacy and ownership, as they are subjects that consumers hold a wide variety of views on. We also have strong views on the importance of a digital health information management system as an enabler of the innovations needed for a consumer-centred health care system to be successful.

For some consumers, total control and being able to write into their records is an essential part of having ownership of their records. Other consumers believe that only trained health professionals should be able to input into the record, but feel they should be able to see what is on there. The majority of consumers we have spoken to about the subject feel strongly that at the very minimum they should be able to see the contents of the My Health Record and ask their health professionals to amend this information if needed.

Consumers also feel that they are not being consulted as to where and how their data is being stored. One consumer has said to us:

*I have been writing and lobbying in this area for some years. As someone with a disability, I increasingly take the view that too much of my personal information is on-line with Centrelink and other agencies. While I am obliged to use some of these environments, governments are increasingly cost-shifting both access to information and even sometimes the holding of information to third parties like NGOs. As a consumer with chronic conditions, I have never felt like I have ever really been asked*

*whether these outcomes were desirable, nor that my dissatisfaction was something government wanted to hear.*

This consumer raises the importance of communicating to consumers not only what information is being collected and stored, but how it is being collected and stored. As shown last year by the ABS, consumers feel that there is a real risk that their data is not being stored safely and that, despite the best assurances of the government, that it might be captured and used by organisations they have not explicitly agreed to sharing it with. The very personal nature of health data adds weight to this concern, as stigma and discrimination against people with certain medical conditions (e.g. severe mental illness) does exist, and having medical records being able to be accessed may have prejudicial outcomes against consumers.

By choosing to make My Health Record 'opt-out', the Government has to meet a high level of responsibility to consumers to engender trust and uptake in the record. While the results of the opt-out trials have shown broad support for the My Health Record, work must continue to encourage use of and confidence in the Record by both health practitioners and consumers. Effort needs to be made in promoting confidence that arrangements put in place to govern the release and use of MHR data for secondary purposes are equally robust and serve the public interest.