

A consumer perspective on the intersection of healthcare and data

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If anything positive has come out of COVID-19 it is increased trust and respect in the community for science and the vital importance of access to and appropriate use of good data. With the speed of the introduction of digital innovations, including in health, there has been a noticeable and positive shift in consumer attitudes to sharing their data though important caveats still exist.

The increasing use of digital health and related innovations has the potential to deliver significant and rich sources of data that can contribute to and enhance vast areas of health and medical research, including health policy and service delivery, identification of health priorities and improved health outcomes.

CHF, while supporting the sharing and use of health data, does so on the basis that it is undertaken in a safe and consistent way, and in compliance with privacy legislation, privacy principals and rules.

An overriding principle for us is that the sharing, access to and use of health data must be for the public good.

Research on consumer attitudes consistently illustrates a tension between consumer's privacy concerns and a general willingness to share data for the public good in terms of

health service delivery, development of health polices and priorities and improved health outcomes.

Individuals are likely to be more willing to allow data about themselves to be used provided they understand why and how the data is being used, can see tangible benefits, and have control over who the data is shared with

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Consumer health data – clinical and socio-demographic – is increasingly collected, linked and used, both with and without consumers’ knowledge and informed consent. There is increasing focus on ‘big data’, evidence-informed policy, and the value of data-driven service development and improvement. Recent examples of this include consultations about the secondary use of health data, incentivising the capture of data at the point of care delivery, and the My Health Record (MHR).

While discussions continue on the benefits to be realised by collecting data and using it more effectively, limited attention has been paid to how consumers feel about this new data era and to assessing their data literacy.

We looked at this in 2017 in a collaborative research project on consumers’ attitudes to data with NPS MedicineWise. It highlighted a number of key themes.

Consumers want ownership of and control over their own health data and they want control over which organisations have access to their data for secondary purposes like research and want to be asked for consent when organisations want access to their health data.

Developing models of consent that are both acceptable to consumers and feasible for research and health communities should be considered a priority.

Consumers are highly segmented and not a homogeneous group. Involving consumers is key to building trust and willingness to share their data for benefits realisation. Consumers are more willing to share data when it is for public or individual good and are significantly less likely to share it if it is to be used for commercial gain.

Consumers were more likely to accept the sharing of their health data if there is an element of a quid pro quo; that is sharing their data in exchange for outputs that are meaningful, useful and of value to them as consumers, and that enable them to hold data custodians/users (eg healthcare providers) to account.

Secondary data use tends to be driven by what matters to providers rather than recipients of care, and this non-consumer-centric view is often problematic to gaining consumer trust and willingness to share their data.

To redress this, consumers need to be involved in defining what outputs they would like to see from use of their data and how they would like to be kept informed about the use of their data. There are specific population subgroups with different needs that should be explicitly addressed including appropriate consultation, communication, and involvement. These include Aboriginal and Torres Strait Islander consumers, particular cultural groups, consumers who have previous experiences that may impact on their levels of trust, and those who are concerned about discrimination due to their health or other circumstances.

Consumers value having an understanding of the purposes to which their data is to be put, who is requesting it and how it will be used.

Studies where consumers were asked to discuss and reflect on their need for consent processes have found that as the perceived transparency and value of the research

increased, views typically shifted from an explicit opt-in consent system to a more flexible opt-out or circumstantial consent

Ultimately the onus is on organisations that wish to use consumers' data to put in place clear, transparent, open, and two-way communications about the purpose for which the data is to be used, how and by whom it will be used, and the benefits and risks. Involving consumers in designing these communications will ensure they meet consumers' needs, building their trust and willingness to share data.

Consumers continue to have concerns about 'function creep' highlighting the importance of establishing clear and stated ranges of purposes and perhaps even anticipated purposes of health data collection.

To illustrate the strength of this concern, a 2020 survey by the Office of the Australian Information Commissioner (OAIC) found that 84% of Australians considered supplying information to an organisation for a specific purpose and the organisation using it for another purpose to be misuse.

The initial OAIC research survey, undertaken prior to the pandemic impacting Australia in early March 2020, also demonstrated that:

- 40% of Australians are comfortable with government using data collected for research, service, or policy development. And that
- 83% of Australians want government to provide more protection of the privacy of their data.

However, the change in behaviours during the current COVID-19 pandemic had privacy implications as governments sought and introduced technology solutions to prevent and

manage COVID, including treatment, and disease prevention and control. Consequently, the OAIC decided to undertake a second survey after COVID hit Australia, to gauge how attitudes may have changed.

This found that 60% of Australians agreed that during the covid-19 pandemic some concessions must be made in relation to privacy protection and confidentiality for the public and national good but only if they are not permanent.

So the view is very clearly that the use of data is very much situational.

Further changes in attitudes are evident in very recent research undertaken by Curtin University as part of a collaborative project with CHF. While this research is not yet finalised and not yet public some initial insights are relevant. In a national survey of more than 1800 Australians as a component of this project, 95% of respondents said they were comfortable sharing their health information with health providers. In terms of the use of their health information for research over 50% said they were willing to share their health data if the research was being undertaken by non-government or commercial not for profit generating enterprises. Indeed, the level of unwillingness to share their data with the for-profit sector is consistent with consumer attitudes that CHF has identified through other consultations.

There is another source of health information that holds great promise in terms of health delivery, preventative health and health management across all areas of the health system.

That is My Health Record.

Given the commitment to restrictions on sharing of MHR data it is difficult to comprehend a situation as to why - or when - such information would be exposed beyond sharing between a consumer's health providers in relation to their care.

This, of course, relates to the purpose of MHR of ultimately creating a seamless “journey” through the health system in terms of providing continuity and improved quality of care for consumers moving across all levels of the health system.

Consistent themes in all research on consumer attitudes have significantly identified that

- Health providers are those most trusted by consumers in terms of maintaining the privacy and confidentiality of their health information and
- A willingness of consumers to share their health information with their health providers.

In late July 2021, the Australian Digital Health Agency advised that 22.9 million Australians had a MHR. This figure, however, given the opt-out strategy adopted when MHR was introduced, should not be interpreted as a willingness on the part of around 9 out of 10 Australians to share their health information.

It does appear that the mandatory recording of COVID vaccinations in the Australian Immunization Register, subsequently recorded in the MHR, and access to a vaccination certificate via the MHR, has driven increased interest in and access to their MHR by consumers. COVID has been a case study in the utility MHR can offer.

That they frequently find their record empty or near to empty, except for this data, has come as a surprise to many.

The one area where consumers’ willingness to share their health information is the highest is somewhat neglected in terms of ensuring the information is loaded by providers.

Creating doubt in consumers' minds is that they are yet to see tangible benefits to them as individuals particularly when they think about the many new digital health innovations that have been or are being developed which can potentially feed into an individual's MHR - such as home monitoring data from wearables.

With MHR we already have the trust and willingness of consumers to share information which provides a strong basis on which to build improvements. In this context I would commend to you the report of a collaborative project between CHF, Curtin University and Deloitte titled "Reimagining health care in Australia; the journey from telehealth to 21st Century design – rapid review of virtual health". This report is available on CHF's website.

It is very clear that more research needs to be done on consumer attitudes to sharing their health information and importantly how to build and maintain consumer trust.

This is an edited version of the keynote address Leanne Wells, CEO of the Consumers Health Forum of Australia, gave to the national conference of the Health Information Management Association of Australia on 25 October.