

# Our Data, Our Health

How knowledge, understanding and trust are central to the success of the AIHW's National Primary Health Care Data Asset.

## *Leanne Wells*

The Consumers Health Forum joined with AIHW to help raise consumer awareness and understanding about the institute's significant and long-awaited entry into the gathering of information about primary health care.

A paradox of the Australian health system is that despite the routine use by most people of primary care --- mostly visits to the GP --- there is relatively little known about the activities and outcomes that can be translated into useful information for the community at large.

The Data Asset is proposed to fill in that gap by collecting data on primary health care usage and outcomes akin to existing AIHW reports on Australia's hospitals. It is envisaged that the Data Asset will facilitate a better understanding of what happens to patients in the primary health system including their diagnoses, treatment, outcomes and patient experiences, by bringing together a range of data from various sources over time, including not only from GPs but also from allied health practices.

The focus group and two webinars we held to explore the Data Asset development tended to revolve around three themes: knowledge, understanding and trust.

At the two webinar panels, we were very fortunate to have a group of well-informed and articulate consumers and health professionals to join the discussion.

A common view of participants was that there was minimal community **knowledge** about health data projects generally and even less **understanding** of their potential for benefit to the community. Given episodes where personal and sensitive data had been breached, there was widespread suspicion which would undermine a health data project unless **trust** could be nurtured.

These themes came through in different ways in both webinars. In the second webinar on 11 November, Consumers Health Forum CEO, Leanne Wells, who chaired the webinars, in her introductory comment spoke of the importance to consumers of having primary care practice and policy better informed by data.

Michael Frost, who heads primary care at AIHW, said primary care accounts for about a third of national health spending yet we don't know a lot about why people see the doctor, what happens when they do and the results of the consultation.

He said AIHW was working through data sources to identify gaps and build data-based knowledge that could be used, for instance by Primary Health Networks, to identify where improvements could be made.

Sydney general practice leader, Dr Charlotte Hespe, said her experience of previous GP survey results was that they had provided an "ah ha" moment for her when she realized she was not doing as well as some other doctors in patient outcomes, and learned solutions as a result.

Melbourne consumer health advocate, Jen Morris said the advantages of the Data Asset should be thought of in the same way as the Census. We all contribute our little bit to the Census for population-wide benefit. Our individual experiences collected in the Data Asset would produce evidence about variations in care, uneven patterns of practice and the like, all contributing to a more equitable system.

Elizabeth Carrigan CEO of the Australian Pain Management Association said that for the 20 per cent of Australians with chronic pain, it would be fantastic if the Data Asset could show what treatment was working and what wasn't. An example would be the results of taking people off medication as a result of concerns about pain killers. We did not yet know what the outcomes had been for the cohort of people who had been "de-prescribed".

Tracking diagnoses becomes a real challenge for the system when people may suffer for many years because of incorrect diagnosis, said Jen.

Leanne said another challenge was the common case of people with two or more chronic conditions and also whether the Data Asset would cover allied health care.

Michael said the aim was to build linkable data that covers areas such as optometry, physiotherapy and psychology and to link prescriptions and

hospital care. Data needs to cover the field if we are to have full understanding.

Charlotte said many patients had complex conditions, multiple medications and different social issues and while having rich data would be wonderful the problem was the system did not fund doctors for the time required to spend with individual patients.

But is the community ready to support activities that would see de-identified information about their health care used to improve health care for all?

Leanne asked.

Elizabeth said she was not sure people were ready and it would need a big public campaign involving groups like CHF to change that.

Jen said what was needed was open and frank discussion to distinguish between the population-wide benefits of the Data Asset and the more individually focused benefits of the My Health Record. This was not just a matter of saying 'trust us' but of being seen to be trustworthy.

Charlotte said there was also a need to have the trust of doctors. There was "huge paranoia" about collective data and how it might be used by government to penalise doctors. But she said she found the availability of data to be "extraordinarily refreshing" in helping to improve how she worked, and this was what everybody should hear about.

Michael said AIHW was seeking to build community trust and to talk more about the benefits of the Data Asset, such as better cancer care results through the benefit of screening. AIHW also needed to show how it was bound by privacy and confidentiality provisions preventing the release of identifying data.

An online questioner asked what would be done to remedy medical problems such as doctors using outdated approaches. Charlotte said PHNs would get would have the task of reporting on gaps in service.

Michael said such issues as to how the data would be used and from where it was sourced was part of current proof of concept work.

Jen said an important part of the social contract involved in asking people to be part of the data project was that it would improve outcomes for individuals. Yet while the data could tell us about "what, where and how" of health care, it could not tell us about the "why".

Elizabeth said people were getting stuck in health care and their health was not improving, often because best practice care was not being provided because of resource gaps such as the scarcity of allied health providers in regional areas.

The potential of Patient Reported Experience Measures (PREMs) and Patient Reported Outcome Measures (PROMs) to be part of the Data Asset was an aspect AIHW was considering as it was aware of widespread interest in making this part of the patient record, Michael said.

At the first webinar on 30 October, Michael said AIHW was working through key themes on which to engage with consumers. The institute was forming a steering group and proposing consumer consultation.

Pip Brennan, executive director of Health Consumers Council WA, said the value of health care data to the community was huge. As she put it: “Data is the new oil.”

Tasmanian GP and Associate Professor of General Practice, Dr Jan Radford, said doctors could see the benefit but were also wary about issues such as patient privacy.

On the issue of consent and privacy, Adam Johnston, Health Consumers NSW member, said patient consent had to be “active and explicit”. Revelations of the Cambridge Analytica’s mining of election data had frightened a lot of people because it showed how we are now part of a data-dependent world. He said he did not have a My Health Record because he was waiting to see how it would deal with its first crisis.

Given trepidation around developments like My Health Record, there was a need to engage the community about the benefits of having information on patient experience, the president of the Australian Primary Health Care Nurses Association, Karen Booth. This information could help guide improvements in care and, where demonstrated, to change health service providers.

Michael said using health data for the public good was “built into the DNA of AIHW”.

***The public will be able to keep informed on development of the data asset by going to the AIHW website on the [Data Asset development](#).***

***To watch the videos of either webinar, here are the links.***

**Webinar 1: <https://youtu.be/aGQVv56gjA0>**

**Webinar 2: <https://youtu.be/qrpo8bWNKV8>**