E-health and old-health

a hippo, happening relationship for the noughties

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By Julie Roediger, AIHW Deputy Director

For health statisticians the e-health agenda engenders both excitement and trepidation. On the one hand, the prospect of timely reporting, rich in clinical data and joined up across the service-delivery silos, is stats heaven. On the other, the transition threatens to disrupt good time-series data, consent models present the prospect of unrepresentative collections and it's unclear how we will keep supporting public health research, policy development and program management.

The AIHW has a lead role, on behalf of the nation, to ensure that statistical reporting functions—which also support accountability arrangements—can continue through the changes to e-health. Up to now attention has, understandably, been on clinical uses.

But the National E-Health Transition Authority's (NEHTA) realisation work has revealed substantial potential benefits in the secondary uses arena such as better planning and demand management, better epidemiology and public health. As well as improving outcomes for the patient, the data generated by e-health could provide a rich research base.

This represents a substantial complication. The number of stakeholders, even for narrow definitions of clinical use, is great and the diversity of opinions is even greater, with many people, myself included, having different visions for e-health on Mondays, Wednesdays and Fridays.

Bringing in the secondary users could invite a clash between two large, ponderous entities each committed to their cause. Hippos are not known for happily sharing their waterhole and the resultant thrashing about could threaten the fragile accord between the layers of government, and lose hard-won momentum.

When NEHTA was first established, it started with the essential foundation elements of an e-health system: an architecture, a benefits framework and information-sharing standards, while the Department of Health and Ageing was rolling out broadband connectivity and a range of functions. These activities didn't bring them to any great extent into the same pond as the old-health statisticians. We met, we spoke, we cared, but afterwards we returned to our respective ponds.

But some of the greatest benefits will come from the secondary uses, and some of the greatest assets to the e-health agenda have been developed within the old-health structures that have evolved around those secondary uses.

Let's consider some of the functions performed by the old-health system that could be performed by the emerging e-health system and how failing to consider these at the beginning will undermine the long-term benefit of e-health.

Consider, for example, reimbursement. From a clinical perspective it may not matter whether a vaccination is delivered by a GP or a practice nurse. But the distinction is critical for reimbursement.

Monitoring compliance with, and outcomes of, best practice protocols is a clear potential benefit of e-health, but if patient preferences cannot be recorded then deviations from evidence-based protocols can't be explained.

In Australia, improving the health of Aboriginal and Torres Strait Islander Australians is a critical priority, but if Indigenous status is not recorded, then the information has limited utility for policy development and program management.

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If access to the clinical elements of a de-identified record is limited by the consent model, then the data have limited utility for population health monitoring.

For pandemic monitoring it will be essential for records to include current contact details as well as usual place of residence.

If these secondary uses are not considered during design then it will be very hard to retrofit them. In working collaboratively with the e-health developers, the custodians of secondary uses in the old-health world are working to ensure that our agenda is not taken backwards on issues such as these. But we also have a lot to offer in taking the e-health agenda forwards. Many of the challenges facing e-health are the same challenges that old-health has been managing for years:

- balancing the appetite for more information against the cost and workforce needed to collect and analyse it
- simultaneously managing the need for agile responses to questions of the day while supporting the methodical process of ensuring that what is asked for can be collected, will be comparable and will actually measure what it's trying to measure, and
- the need to protect individual privacy without unnecessarily tying up information that promotes the health of all Australians.

The old-health governance system has developed a strong practice of balancing these tensions across a wide range of use-cases with disciplined cost-benefit analyses. There is much of value to be built upon in terms of knowledge, process and relationships.

So perhaps these two hippos can build on some of the existing strengths while redressing some of the shortcomings of the existing system, and replacing some of the parts that will no longer fit. The old challenges are still there for e-health and some of the existing responses will work. But there are new challenges too, such as:

- The glacial pace of old-health won't work for e-health and less bureaucratic ways of ensuring quality and stakeholder engagement are needed.
- Old-health usually saw government owning the software development activities and therefore didn't require vendors at the table. That won't work in e-health.
- Old-health managed the health information environment by dividing it into manageable chunks—admitted hospital patients, GP visits, pharmaceuticals—and managed these in stove-pipes. E-health as it is managed in Australia also does this. Standards, term sets etc. are developed for each separate discipline. But now they are developed within an overarching architecture.

What is emerging slowly and still needs to be nurtured, is a single, multi-polar system where it is acknowledged that decisions about privacy and consent in one part of the system have flow-on ramifications for other parts of the system. Ideally, maps that bridge between old-health and e-health will be developed and implemented under a single governance system. It's only a fledgling idea and has only recently made tentative inroads into the governance system.

The e-health agenda is starting to bring together a wider range of stakeholders and develop a common language and habit of communication. I'm optimistic about this and the AIHW will be working hard in 2008 to bring these two strands of work together. E-health won't be a big bang technology change. It will be an evolution, building on the strengths of the current system, because it works and because people only change incrementally and, ultimately, this is all about the people. ■