

Submission to Senate Committee Inquiry: Healthcare Identifiers Bill 2010 and Healthcare Identifiers (Consequential Amendments) Bill 2010

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Author's background: Beginning in 1980, I worked as an IT professional for over 20 years: programmer, systems analyst, technical writer, systems designer, business analyst and IT manager, working for government, academic and commercial organisations. For more than half of that 20-year period I worked on database applications. In 2002 I joined the Department of Health and Ageing (DoHA) to work on the Better Medication Management System (subsequently known as MediConnect) and worked on e-health projects within and outside DoHA for about 6 years between 2002 and 2009.

A healthcare identifier is not an end in itself. We all have multiple healthcare identifiers, although we may not be aware of them. You have an ID number within your GP's clinical records system, a different ID number in your pathology provider's system, a different ID number inside the local hospital system if you have been cared for there, and so on. A national identification system will facilitate the smooth and accurate transfer of clinical information between these various systems. It would support a system of sharable electronic health records, when such a system is developed, but the identification system has a much wider applicability.

To the extent that I did contribute, formally or informally, to development of a health identifier policy, my advice was consistently that the only practical solution is a single, national system. I believe it is imperative that each individual participating in the system, consumer and provider, has one and only one unique identifier.

The main technical objection to such a scheme appears to come from the people who believe it is unnecessary and that probabilistic data matching on existing data is sufficient. Their experience is obviously different from mine. I have worked on establishing a database that relied on probabilistic data matching (1st AIF records), and while perhaps 98% or more of the records from different source files could be unambiguously identified and matched, a small percentage required further research and some of those ultimately required guesswork or had to be marked as unidentified.

The very term "probabilistic" implies a degree of uncertainty. That uncertainty could lead to non-identification or, perhaps worse, misidentification of health records, with potentially fatal consequences. As analyst or designer I would consider it unprofessional to advocate a system that does not use the best possible approach to minimise this risk, and that best possible approach is a single, national identification system.

Some of the objections to the concept of a national health identification scheme come from those who apparently value privacy – their own and that of others – above all other considerations. Let me pose a question to those objectors – do you believe that better communication and access to health records has the potential to improve healthcare, particularly for people with complex and/or chronic conditions? If so, are you prepared to deny those people the opportunity to have improved healthcare because of your own obsession with privacy?

However, while I firmly believe that the only technical solution is a single, national identification scheme, there is much room for debate about how this should operate.

Should Medicare Australia assign identifiers to providers? Yes, they have many of them in their system anyway. The only reservation I have about the role of Medicare Australia in assigning individual (i.e. consumer) identifiers is that uptake of the individual healthcare identifier might be limited by a public perception that health data will be used to cross-check claims data. Tempting though this would no doubt be to some within Medicare Australia, there must be an absolute separation between the two. I am confident that Medicare Australia could handle this separation – my concern is with the public perception and its impact on uptake.

Do we need to have a big-bang approach to assigning identifiers to healthcare consumers? I do not believe so. My preferred approach would be to make it easy for anyone to apply for an identifier – I once suggested, not totally facetiously, that the commercial rewards cards could be used as a model, with individuals picking up a pre-numbered card from GP, pharmacist, hospital, clinic, etc. and activating it with their details. For children, I would propose assigning identifiers at birth (and in some cases healthcare needs might make such assignment desirable before birth).

I see no need for a proof-of-identity process beyond perhaps a driver's licence or similar to confirm spelling of name and address. The healthcare identifier serves no purpose beyond ensuring that your health records are linked to you and only you.

This opt-in approach also addresses the concerns of those who see the healthcare identifier as back-door approach to an Australia Card, because it makes participation clearly optional (except for the aforementioned newborns, of course). Those who see the system as a threat to their privacy need not participate, but they make this choice in the knowledge that their healthcare providers may, in an emergency, be unable to access their records.

People with complex or chronic conditions are the most obvious beneficiaries from improved accuracy and availability of their medical records, and this should be the group initially targeted to get them to sign up. Does it matter if people who are currently healthy do not sign up yet? Probably not.

It could be argued that the low-impact, opt-in model for registration poses a risk to data quality. I believe the reverse is the case, for two reasons:

- there is no data source of guaranteed, 100% accuracy for the big-bang model, and even Medicare Australia does not claim that its data are perfect
- people who provide their own data take responsibility for the quality of those data and are made aware of the need to keep them current rather than relying on some unseen, big-brother system to take care of it for them.

At a technical level, incremental growth of a system presents a lower risk than the big-bang model when the inevitable problems occur.

Finally, do we need legislation to define the structure and *modus operandi* of the identification scheme before there is a practical use for the identifiers? The Medical Software Industry Association might be best placed to comment on this, but as a (former) software developer, I would answer yes. I would need to know what information my software will need to process so I can ensure that the capability is there when people want to use it. Enshrining this specification in legislation would at least provide developers with a solid basis for their work.

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