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To <mail@health.gov.au>

cc <Niall.Johnson@health.gov.au>

bcc

Subject Australian Clinical Quality Registries [No Protective Marking]

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Dear Australian Commission on Safety and Quality in Healthcare People,

At the outset, would you please note that all of the following are my personal comments as a Medical Specialist in Public Health Medicine. They do not represent my employer and/or any other organisation.

Thank you for the opportunity to review the "Guidelines for the Establishment and Management of Clinical Registries", the draft Nehta "Architecture Overview" and the draft Nehta "Standards Map". In general, I think all the documents are very good and cover the relevant points very well – especially the "Guidelines for the Establishment and Management of Clinical Registries" document.

However, the following are a few brief comments:

1. Governance – Legislative Under-pinning

I strongly suggest that in any prospective development of an integrated Clinical Registries system, that you seek specific Legislative under-pinning for the work you want to do; for example, like that under which Cancer Registries operate.

The legislation should include qualified privilege provisions. Otherwise, the data on the Clinical Registries will risk being discovered and potentially publicly divulged in any number of various types of legal actions. This is not reassuring for the people whose data are recorded on the Clinical Registries. Nor is this an incentive for those running the Registries to be operating in such an exposed position.

Voluntary arrangements which rely on goodwill and cooperation alone are unlikely to be reliable in achieving near-100 percent ascertainment, even if they are opt-out. You know already that without as near as possible to 100 percent capture of cases and the details about those cases, the Registry systems data and the reports which emanate from them will be at best misleading, or at worst, useless.

So it is preferable that you should seek legislative Mandatory data reporting so that you maximise ascertainment of cases and their data. If clinical safety and quality is an important political imperative, (as it seems to be), then I think that seeking the establishment of specific legislation for this purpose will be successful. This will take a year or two or more to do and will be resource-intensive on many fronts. So this process should be started immediately.

There are clear historical precedents for health-based registry systems without specific legislative under-pinning who ran into significant problems by relying only on administrative arrangements; for example, the major troubles of the British Cancer Registry systems in 2000/2001.

2. Change Management

I think it might be helpful if there were more details on Change Management issues surrounding the development of a Clinical Registries system. It is often the case that the technical aspects are only a small proportion of the whole story of a system development and implementation - and often are the easy parts. The political, social, psychological, economic and administrative factors often are far more important, more difficult and require more finesse to ensure a good result than the technical aspects.

3. Making Use of the Data on Pre-existing Registries

The Nehta "Architecture Overview" specifies both a "Short Term Architecture" and a "Long-term Architecture Vision". The Short Term Architecture describes the construction of a "Directory of Registries – National Portal". This is good as an inventory of Registries. It also describes Web-based methods for data capture, authentication etc – which is good also.

However, it is not clear to me how the Clinical Registries development can make use of the wealth of valuable data already recorded on the multitude of legacy systems, many of which have been around for decades. It is unlikely that these legacy systems will have the resources, or the will, to transform their legacy data to the new Nehta standards. In some cases, it may not even be technically possible?? However, it would seem essential to find a way of making use of these data in a systematic fashion.

4. Level 4 Automatic Registry Data Capture from Clinical Systems.

Clearly, this is the ultimate goal; but seems quite a way off for Australia as yet. However, it might be worth your looking at the Canadian British Columbia Cancer Agency <http://www.bccancer.bc.ca/default.htm> information systems. It is my understanding that their Cancer Registry system is merely a subset of their electronic Clinical Records system – and thus automatic registry data capture? If so, perhaps they could advise on how to achieve this in Australia?

I hope these comments are of some use.

With best wishes for your success in this most important project.

Regards

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