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Dear Chris

I write to respond to your request for comments on the Australian Clinical Quality Registries. I must say I am extremely disappointed in the quality of this product and in my view it does not respond to the issues I have raised constantly during the course of this project. The guidelines focus mechanistically about the *modus operandi* for the data side of a registry, with little consideration to issues of service quality, surely a **quality** registry's *raison d'être*.

Registries serve a number of purposes including descriptive epidemiology, to provide a sampling frame for research and/or to improve safety and quality. The cancer registries generally fall into the former categories servicing the purpose of descriptive epidemiology and providing a sampling frame for research. Much of the technical standards about registries are relevant to both. However, the Commission's focus should be on registries which are "clinical quality registries", that is registries for which the principal purpose is quality of care, hence the proposed designation.

As guidelines relevant to registry design for descriptive epidemiology or research purposes can be developed by others, then the flavour of the Commission's document should prescribe standards for the way in which the registry should contribute to improving the safety and quality of health care. Issues of data management etc, whilst critical, are about facilitating the quality management process and should be included but they should not be the principal focus of Commission guidance and standards.

The logical ordering of the standards should thus be as follows. First, in order to justify creation or maintenance of a *clinical quality registry*, a registry should first demonstrate that variation exists in clinical outcomes across Australia and that there are opportunities to reduce that variation. If the registry can not demonstrate that there is significant variation in safety and quality, I would argue that a registry is not an appropriate strategy to improve standards, even if Australian outcomes differ

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from international outcomes. The point of a registry is to improve Australian practice by comparison of one facility with another practising within the same environment.

Assuming variation has been demonstrated (and here the measurement and presentation of variation becomes important) then a clinical quality registry needs to demonstrate mechanisms for:

- Feeding information back to contributing facilities and funding bodies to be used in improving quality and safety in care. Standards should require feedback in a timely way (within 6 months at the outside) and presented in a way which is conducive to identifying variation and acting upon it. As you know I am an advocate of the use of statistical process control in this regard. If the registry can not demonstrate it is providing information within a 6 month period, it could be argued that information is of no relevance in the quality improvement process.
- Managing the identification of opportunities for improvement in the safety and quality of care. Here I would argue that there needs to be a structured mechanism by which the data are passed before the minds of peers and other health professionals and the responses of contributing facilities are reviewed. The registry should not simply be a data provision agency but the registry itself must contribute to a process by which action occurs as a result of the data provision. Simply providing information back to contributing facilities does not demonstrate that there is an economic case for a registry. The point of data feedback is to generate action and the action loop must be part of the design of the registry process.
- Incorporating specifically collected registry information into routine data collections where appropriate and conversely, minimising the cost of data collection by using routine data collection as a data source where appropriate. As the guidelines rightly point out, registries are expensive. It is obviously possible for the data on a single patient to be used in multiple registries (intensive care units, transplant registries). Contemporary best practice should ensure that the additional information collected on patients registered in more than one registry is accessible for analysis at a state or national level.
- The standards should also cover issues of data quality, data storage and privacy etc. This area is in the main relatively well handled in the current draft.

In my view these issues are fundamental to identifying, designating and funding clinical registries in Australia and should be highlighted both in the executive summary of the report and in the guidelines themselves. The present emphasis on the technical details of clinical registries misses the wood for the trees.

I would be happy to discuss these issues further if you so wish. I have copied these comments to my colleagues on the Inter Jurisdictional Committee.

Yours sincerely



S.J. Duckett  
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