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Subject Call for written submissions on draft operating standards
and technical design for Australian Clinical Quality
Registries [No Protective Marking]

DOCUMENT NOT YET CLASSIFIED

Thank you for the opportunity to provide feedback on the 'draft operating standards and technical design for Australian Clinical Quality Registries'

We have previously contributed to the development of the papers so the comments below are brief, in no particular order and intended constructively. They are also limited to the document titled 'CRE PS Guidelines for establishment and management of clinical registries 27 May08.PDF'. Architecture is being dealt with by others.

The tone of the document reflects a medical mindset. A more multidisciplinary view will encourage the involvement of other craft groups and improve the success of the registry especially given that the other groups often contribute data.

Dot point 25 of the executive summary states 'Consent must be obtained from participants or their next of kin prior to the collection of registry data.' This is inconsistent with '13.2. Consent' and current practice using 'opt-out' clauses.

Governance of a registry aiming to improve quality would benefit from expertise in quality and possibly management (e.g. hospital executive) to recognise opportunities and support implementation of initiatives.

A 'quality' registry must focus its attention on improving quality. Registries have often focussed on (the important) practitioner level performance but given little effort to system level improvement opportunities. This reason for a registry's existence should be explicitly described. This area of the guidelines needs to be strengthened.

12.4. Data custodianship: I suggest that this expanded. The area of adhoc data requests is often challenging and unexpected as requests come from researchers and for-profit industry where motive and ethical considerations are not always clear or consistent with the registries reason for existing.

The usability of the guidelines would be enhanced by the inclusion of a checklist of expected practice. This could be used by:

- funders in assessing submissions and
- developers in achieving good practice and success in funding submissions.

In the future the checklist could lend itself to application in the development of a set of standards.

In summary the document provides a broad and general insight into the area of registries that will assist existing and potential funders and custodians.

Regards

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