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Quality & Safety Review
Health Service Performance and Programs
Department of Health and Human Services
50 Lonsdale Street, Melbourne, Victoria, 3000

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Re: A review of hospital safety and quality assurance in Victoria

Please find a response to this discussion paper on behalf of the Registry Sciences Unit which supports and co-ordinates the activities of the Clinical Registries within the Department of Epidemiology and Preventive Medicine at Monash University.

Thank you for the opportunity to respond, and I would be very happy to participate in further stakeholder consultation if required.

Yours sincerely

Dr Susannah Ahern

Clinical registries (including Clinical Quality Registries) as a tool for improving quality and safety.

Improving quality and preventing adverse events requires a range of approaches; and measurement is essential to continuous improvement.

Administrative data has limitations for use in measuring quality of care – its primary purpose is for hospital funding; it has limited accuracy and clinical detail as is not recorded by clinicians; and does not provide outcome information post discharge

Clinical registries are designed to collect clinically relevant data about an individual's episode of care and its outcome. The data is collected systematically using standard procedures and definitions across multiple institutions. In clinical quality registries, outcomes are routinely measured following discharge at a time when the extent of recovery can be judged.

Clinical registry data is more likely to influence clinicians because of its greater granularity, reliability and more direct linkage to outcomes. When fed back in a timely fashion it may provide early warning of quality issues (e.g. outliers), and benchmarked amongst similar institutions it has a much greater likelihood of inducing changes in practice.

Who uses Clinical Quality Registries?

Monash University is custodian and operator of over twenty clinical registries. Multiple different stakeholders use this information in different ways, and registry reporting reflects this. In general, and as recommended by the Australian Commission on Safety and Quality in Healthcare's (ACSQHC) Framework for Clinical Quality Registries, mature Clinical Quality Registries have three 'levels' of reporting and use.

1. **Continuous access to data by participating clinicians**

Registries that have a web interface for clinician data entry can provide real-time information of individual clinician data that has been entered into the registry. This provides an ongoing clinical audit regarding their caseload, patient demographics and outcomes that can used for personal performance improvement and in some instances is a requirement for College professional development purposes.

2. **Regular benchmarked site reports – for clinicians and health services**

Clinical Quality Registries (CQRs) that have a sufficiently mature caseload and number of participating sites are provided with quarterly or biannual reports that comprise registry clinical indicators that where possible have been risk adjusted and are benchmarked. These reports are usually presented graphically as de-identified funnel plots, where outliers (e.g. beyond the 3rd standard deviation) are notified to the relevant participating site.

These reports are generally made available to the participating units, and to the site Chief Executive Officer or Director of Medical Services. Each registry has a policy regarding the management of any clinical indicator outliers, and this involves rigorous review of the data quality and analysis by the registry, and then internal review by the participating site. Reports for the following period are followed up to assess whether the outlier status has continued or whether the indicator has returned to within the statistically acceptable range (which occurs in most instances).

This quarterly report is thus an opportunity for (1) clinical units to receive benchmarked information regarding their performance in the registry and (2) health services including Board Quality Committees to be made aware of any potential quality issues within participating units. It may be considered that each time an outlier returns to within acceptable limits, that quality of care at that site has improved - with positive outcomes for patients, and the health service.

As CQRs continue to mature and have a number of years' data, registries are also starting to report time-series data e.g. trends in clinical indicators and outcomes over time. This is generally aggregated information at the registry/system level, and is a useful gauge of performance of the overall health system. Where clinical indicators are seen to improve over time across the whole health system the inference is that participation in the registry has contributed to an extent in the system improvement.

There is also the potential for CQRs to provide reassurance to jurisdictional governments that clinical care in a range of clinical disciplines is being monitored across the system in a standardised way, and that where the regular data review processes requires any outliers to be identified and addressed, that this model is unlikely to harbour unknown ongoing quality or safety issues.

3. **Annual Reports – for broader stakeholders including funders**

Registries after they have been established and embedded commence producing Annual Reports. These reports have a broader audience including across the range of funders and stakeholders – commonwealth and state governments, industry bodies, patient support organisations and foundations, clinicians, and the public. Their information reflects this and generally follow a format that comprises background to the registry, operations of the registry, demographic characteristics of the registry population, general commentary regarding data quality assurance and statistical approaches, and aggregated clinical indicators and other outcomes. This information is designed to explain the registry, its purpose, and its effectiveness in achieving its purpose.

There are examples of registries that have provided public health and policy recommendations such as the Victorian State Trauma Registry. There is opportunity for other registries as they mature to similarly identify areas for focused improvement across the health system.

What do Clinical Quality Registries measure?

Traditionally clinical registries have measured clinical outcomes that are clinically defined e.g. mortality; improvement in cardiac function; lung function. However increasingly a range of patient-centred measures (or Patient Reported Outcome Measures – PROMs) are being used. Where possible this may be through the use of validated questionnaires that are completed by the patient at follow up and which ask questions relating to patient well-being such as functionality, mood, and more subtle side effects of treatment. Such measures when used appropriately can be very useful indicators of long-term outcome and effectiveness of treatment.

What clinical conditions are appropriate for Clinical Quality Registries?

CQRs are appropriate for clinical conditions or interventions that have a clearly defined population, for which there is a commonly accepted best practice but where there is also likely existing variation in care, and where outcomes are clearly defined and measured. This has to date included implantable devices, high cost procedures, cardiac conditions, and rare diseases with expensive drug treatments. At this point in time it would be difficult to develop registries for predominantly community-based conditions due to the lack of uniform diagnostic criteria and data collection processes. This is a challenge for the future.

What can DHHS do to strengthen Clinical Quality Registries as an effective monitoring and performance improvement tool for the Victorian Health System?

DHHS can support the development and maintenance of Clinical Quality Registries in a number of ways:

- Identify clinical areas that may be considered high risk that may benefit from clinical registry development
- Support CQR participation by Victorian public and private sites
- Use CQR information to support the development and direction of its Clinical Networks and activities within the Quality and Safety areas of DHHS
- Provide funding to support CQRs and participate on CQR steering committees
- Educate health service Boards about the role of CQRs in continuous quality improvement and potential early identification of quality or safety issues
- Support data linkage efforts to increase the efficiency and effectiveness of CQRs
- Support opportunities to disseminate learnings from CQRs such as through local conferences or seminars