CLINICAL REGISTRIES AND QUALITY IMPROVEMENT

Geoff Sims
Australian Clinical Registries
• Clinical registries meet an information need that cannot be met by administrative data (Evans S et. al. MJA 194:7 April 2011)

• Australian Health Ministers endorsed *Strategic and operating principles for Australian clinical quality registries* in November 2010 (ACSQHC)

• ‘Australia has few registries capable of benchmarking outcomes nationally’ (Evans)
International perspective

• ‘Well-managed registries enable medical professionals to engage in continuous learning and to identify and share best clinical practices’

(Larsson S et. al. Health Affairs 2011)

• Three enabling characteristics:
  – Comprehensive, high quality data
  – A bias towards data transparency
  – Active engagement with the clinical community
Case study: cystic fibrosis

- Relatively rare disease
- Lifetime care for persons with cystic fibrosis
- Typically delivered by multi-disciplinary care teams working in integrated inpatient, outpatient and home therapy environments
- CF registries have a long history in several countries, notably US (1966), Canada (1970), UK
- Benchmarking studies across cystic fibrosis treatment centres have facilitated learning from strategies of best-performing centres (Stern 2011)
Findings from benchmarking

• Nutritional strategies – Boston/Toronto comparative study (Corey 1988)
• Treatment at specialised CF centres of minimum size (Mahadeva 1998)
• More regular clinic visits and aggressive administration of antibiotics (Johnson 2003)
• Neonatal screening – Australia/US registry comparison (Martin 2012)
Translation to Standards of Care
National CF QI programs

• US Cystic Fibrosis Foundation – quality improvement initiative / quality improvement toolkit. Accreditation of CF centers
• UK Cystic Fibrosis Trust – standards of care, peer review program, UK CF registry
• German CF Quality Assurance Project 2004 to 2007 worked from benchmarking to facilitated continuous quality improvement strategies (Stern 2011)
• Australia ...
Patient involvement

- New Yorker magazine article (Gawande 2004)
- Transparent outcome reporting – indicators published for CF treatment centres from US, UK and Canadian patient registries
- UK also makes centre peer review outcomes transparent
- Australian registry published one round of transparent indicators for 2010. Further work deferred pending improved risk adjustment.
Australian Cystic Fibrosis Data Registry

• Has operated since 1998
• Cystic Fibrosis Australia – trusted third party custodian
• A collaboration with CF Centre Directors
• All 23 specialist CF treatment centres contribute patient data to the registry
• Range of data collected meets ‘clinical quality registry’ requirements
• (CFA 2013)
Benchmarking reports

FEV1 %Predicted, Males 6-11 years
Australian Cystic Fibrosis Data Registry 2010

Annotations below:
* less than 90% reported

Stratified comparison
National ‘benchmark’
Quality labels
Identified centres

Major paed excludes outside values

PMH RCB SCH WCH* CHW MCH TAC RCM JHC

Australian Cystic Fibrosis Data Registry 2010
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Quality of care virtuous cycle

Standards of Care

Data registry

Peer reviews of Cystic Fibrosis Treatment Centres

Peer review

(data transparency)
Outcomes for CF patients

Sources: CFF 2013, CFA 2013
Acceptance of benchmarking

• Publishing identified centre-level data both requires and encourages good quality data
• Quality of submitted data has improved
  – ‘Missing data’ are becoming less prevalent
  – Good cooperation to correct data entry error
• Timeliness has improved remarkably
• Centre Directors showing sensitivity to ranking
  – Focus on factors influencing data
• Consumer discussion through social media
Developments needed

• Upgrade of CF registry software (under way)
• Data quality ‘benchmarking’ – linkage with National Death Index (imminent)
• Calculation of median survival (after NDI link)
• Risk adjustment model for centre comparisons
• Facilitated quality improvement program – needs funding
• E-health connections (another story!)
• International data harmonisation – pending
References

- Larsson S, et. al. Use of 13 disease registries in 5 countries demonstrates the potential to use outcome data to improve health care’s value. Health Affairs 5 31, No 1 (2012), pp 220-227
- Gawande A. The bell curve: What happens when patients find out how good their doctors really are? The New Yorker, Annals of Medicine. 8 December 2004
- Cystic Fibrosis Australia. Cystic Fibrosis in Australia 2012: 16th annual report from the Australian Cystic Fibrosis Data Registry. Baulkham Hills NSW: CFA 2013
- Gaskin K, Wilcken B. Long-term outcomes for patients with cystic fibrosis in Australia. MJA 195(7) 3 October 2011 (editorial)
Questions?

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