CLINICAL REGISTRIES AND QUALITY IMPROVEMENT
with case studies from cystic fibrosis

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Context

• 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)
Ten years of improvement innovation in cystic fibrosis care

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
excludes outside values

PMH RCB SCH WCH* CHW MCH TAC RCM JHC
Major paed
excludes outside values

Quality of care virtuous cycle

Standards of Care

Data registry

Peer reviews of Cystic Fibrosis Treatment Centres

(data transparency)
Outcomes for CF patients

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

Sources: CFF 2013, CFA 2013
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 S 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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