Using registry data to improve quality of care

Perspectives from the Australian Cystic Fibrosis Data Registry
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Australian CF Data Registry

- Operated by Cystic Fibrosis Australia
  - in collaboration with CF Centre Directors (22)
- Established 1996; annual data from 1998
- Online database system since 2006
- Reports include:
  - Individual patient reports, user selectable
  - Downloaded queries of ‘own patient’ data
  - Centre-specific trends for major indicators (offline)
  - Benchmarking comparison charts (offline)
Benchmarking reports

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

Annotations below:
* less than 90% reported

Identified centres
Quality labels
Major paed

Stratified comparison

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

excludes outside values
Implications and impact

• 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
Quality of care virtuous cycle

Standards of Care

Data registry

Peer reviews of Cystic Fibrosis Treatment Centres

(data transparency)
Outcomes for CF patients

• Clear evidence of patient benefit in US
  – ‘The Bell Curve’, New Yorker 2004
• Impact not yet clear in Australia
  – too soon?
• Has helped advocacy for CF centre resources
• Collaborative grant applications for quality improvement prepared, not yet successful
• Strong support for Data Registry – all parties