Emerging issues and opportunities for Clinical Quality Registries

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Clinical Quality Registries (CQRs)

- Feasible mechanism for collecting real-world longitudinal health data related to specific disease/procedure for improvement of patient care

- More clinically credible than administrative data

- Collected systematically using standard procedures and definitions across multiple institutions;

- Mature CQRs provide confidential, risk-adjusted and benchmarked data to participating sites

- May identify early warning of quality issues and be effective stimulus of practice change
Data Sets & Collection

DATA SPINE
from everyone
minimal
epidemiologically sound
no clinical judgement
unchanging
identifiable
linkable
risk adjustable
bench-markable

DATA RIB may be
time limited
from interested centres

ALSO

direct data feeds
tick and stick forms
integration with specialist software
Basic structure of a clinical registry

Clinical quality, devices, high cost drugs, rare diseases, research registries

- Governance process*
- Registry services provider
  - High security
- Quality control*
- Systematic outcome measurement
- Process for reporting & data access

IDENTICAL
Minimum data-set

clinic 1

clinic 2

clinic 3

clinic 4

Clinical Quality Device Registries

2nd April 2012
Benchmarking report from a clinical quality registry

Figure 5: Registry reporting - example of a funnel plot showing percentage positive margins following cancer surgery
Examples of Quality Improvement through CQRs

- Overall improvement in performance due to participation in registry
- Outlier management and review of clinical practices at sites leading to practice change
- Facilitate compliance with clinical guidelines or support development of new guidelines
- Identify system-wide issues and advocate for system response
- Monitoring trends over time – supports cost-effectiveness of registries
Emerging Challenges/Opportunities - Governance

- Increasing interest/funding from a broad range of stakeholders
  - Governments (C’th, state)
  - Private health insurers
  - Hospital groups
  - Pharma and industry
  - Consumer advocacy groups

- Co-ordination
  - Alignment of objectives
  - Governance of data
    - Access & reporting
Data Collection & Management

- Multiple tools
- System integration
- Consumer preferences
- Embedded in hospital information or additional
- Data linkages
- Custodianship of fragmented data journey
Data Reporting from CQRs

- Requires mature data sets (=time & $$)
- Demand for real-time data access & visualisation e.g. Qlik
- Health services, clinicians, patients
  - Data collection is not real-time
Clinician Outcome Reporting from CQRs

- Interest from range of stakeholders
- International experience esp cardiac, surgical
- Limitations – multidisciplinary teams, general, medical etc

Considerations:
- Procedural volume (Walker)
- Clinical indicator selection (Hall)
- Peer review of outliers
- Performance management
Public Reporting

- FOI requests from media
- Opinion divided re usefulness
- Meta-analyses suggest improves outcomes
- Issues as per previous re quality of outcome measures
- Risks of gaming, avoidance of high risk patients (importance of risk adjustment)
- Confidential reports initially to support required buy-in and evaluate

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1. Johns Hopkins Hospital, Baltimore
2. Massachusetts General Hospital, Boston
3. Mayo Clinic, Rochester, Minn.
4. Cleveland Clinic, Cleveland
5. UCLA Medical Center, Los Angeles
6. Northwestern Memorial Hospital, Chicago
7. New York-Presbyterian University Hospital of Columbia and Cornell, New York
8. UCSF Medical Center, San Francisco
9. Brigham and Women's Hospital, Boston
10. UPMC-University of Pittsburgh Medical Center, Pittsburgh
**What are PROMs?**

**Patient Reported Outcome Measures** - individual’s assessment of their health or wellbeing that comes directly from the individual without interpretation by a clinician, or anyone else

- No evidence-based guidelines for inclusion of PROs in registries
What are the aims/objectives of PROMs?

Must have defined patient population and be integrated with high quality clinical data (e.g. baseline) to best achieve the following aims:

- Improve patient outcomes
- Feedback & benchmarking
- Escalation of high risk patients
- Education and training
- Performance reporting
**PROMs collection**

**Methods**
- SMS and/or link to web portal,
- email,
- phone call
- Mail
- No. of attempts before lost to follow up
- May use different methods for different demographics and for follow-up
- Independent collection to reduce bias

**Frequency**
- Baseline – clinical & PROMs
- Post-event
- Clinical stability vs ongoing condition
PROMs - Challenges

- Significant amounts of data → more complexity to already complex registry data sets
- More data for clinicians to consider → onerous and burdensome
- If critical data does not receive appropriate response → a liability
- Patients expect PROs to be addressed → decreased satisfaction
- Unclear how PROs should be used to inform care and change daily practice
PROMs - Summary

- Variably useful composite outcome measure
- Requires clearly defined populations
- Requires measurement pre and post intervention
- Minimise instruments, and frequency of follow-up
- Meaningful data requires high patient numbers
- Independent administration and oversight to reduce bias
- Consumers involved in the process
CQRs – Emerging Issues & Opportunities Summary

- Broad stakeholder support
- Increasing technological products
- Increased transparency with clinical outcome reporting
- Consumer feedback
- Co-ordination & governance
- System Integration
- Volume & indicator considerations
- Risk adjustment to minimise gaming
- Significance and use
Thank you