Clinical Quality Registries

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Clinical quality registries

- Governance process*
- Registry services provider
- High security
- Quality control*
- Quality related outcomes
- Benchmarking reports
- Process measures
- IDENTICAL Minimum data-set
Clinical quality registries

Australian Clinical Quality Registries
The Australian Commission on Safety and Quality in Health Care

Clinical Quality Registries:
Who values the information? And for what?

- Benchmarking
- Appropriateness / compliance
- Variation
- Planning, trend analysis
- Access to care
- Credentialing
- Drug & device safety
- Clinical research
‘Opt-out’ consent

REGISTRIES ARE A DATA SPINE: ADDITIONAL DATA MAY BE SOUGHT FROM LIMITED SAMPLES OVER LIMITED TIME FOR SPECIFIC ADDITIONAL STUDIES TO ANSWER SPECIFIC QUESTIONS

REGISTRIES COLLECT MINIMAL DATA

registries are a data spine
Clinical outcomes: approaches

- Phone contact with standard script
- ‘Systematic’ clinical review
- Record linkage
- Information
  - Disease specific questions
  - Quality of life
  - Flags for further follow-up

Outcome benchmarking reports
(Risk adjusted)

Figure 5: Registry reporting - example of a funnel plot showing percentage positive margins following cancer surgery

NOTE: EARLY RECOGNITION OF PROBLEMS
Outcome benchmarking reports
(Risk adjusted)

NOTE: EARLY RECOGNITION OF PROBLEMS

Application of registries

• Defined illnesses
• Surgical procedures (esp new)
• Implantable devices
• Expensive/innovative drugs
• New therapies
• Rare diseases
New York State Cardiac Registry Review
Hannan JACC 2012

ESTABLISHED 1988

– **Cardiac procedural outcomes improved**
  • RR 0.66 compared with elsewhere in US

– **Better management of high-risk patients**
  • Some surgeons stopped operating
  • Some hospitals referred high-risk patients

– **Outlier avoidance a strong motivator**

– **Accurate data essential**
  • Requires ongoing audit

Swedish experience

• 90 Govt supported registries, cover 25% of health expenditure

• 2009 review by Boston Consulting concluded that a $70 million investment would reduce annual growth in healthcare from 4.7 to 4.1% & save 7 billion dollars in 10yrs

• 3 characteristics needed:
  – Active engagement of clinicians
  – Comprehensive & high quality data
  – Transparency
Registry governance

- Auspicing body
  - Independent chair & representatives of professional groups, registry staff, funders, consumers.

- Steering committee
  - Strong research environment
  - Independent of providers
  - ISO27001/2 & NEYHTA accredited for data

- Operations committee

REGISTRY

- Quality of care committee

Registry ‘data-supply’ MOU between registry & hospitals

Registry Funding Models

- **Central registry:** Government & key stakeholders
  - Quality assurance; reporting; actions:

- **Peripheral data collection:** Institutions
  - Initial data & outcome collection: Institutions
Priority registries

- High cost
- Major variation
- Economic case

**EXAMPLES**

- Renal transplantation (minimise dialysis)
- Coronary angioplasty (minimise heart failure)

Recent Australian developments
Summary

• Provide clinically credible benchmarking
• Data of value for multiple stakeholders
• Developing clarity in ethics, governance
• Rapid developments overseas
• Funding remains problematic