Using National Quality Registries to Guide and Evaluate Clinical Improvement Efforts – Encouragement from Sweden

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THE SRQ APPROACH
Sweden

- Population: 10 million
- Historical emphasis on egalitarianism
- Three levels of government:
  - Nation
  - Counties (21)
  - Municipalities (290)
The goal for the healthcare system is good health and care on equal terms for the entire population. Care should be given with respect for the equal worth and dignity of all individuals. The person with the greatest need for healthcare should be given priority.
Swedish National Quality Registries

National Quality Registries are used in an integrated and active way for continuous learning, improvement, research and management to create the best possible health and care together with the individual.

http://kvalitetsregister.se/englishpages.2040.html
Registries Contain Data On:

- Patient demographics
- Provider organization characteristics
- The Structure of care
- The Process of care (including patient-reported experience measures)
- The Outcomes of care (including patient-reported outcome measures)

In 2016: 96 National Quality Registries (NQRs); 12 NQR candidates; all initiated and led by healthcare professionals.

NQRs cover many areas of healthcare, from common to rare conditions, from nursing and primary to tertiary care.

Examples: Stroke; Ischemic heart disease; Heart failure; most forms of cancer; Bipolar disorder; Eating disorders; End-of-life care; Neurology with MS, Parkinson’s etc; Dementia care; HIV-AIDS; Diabetes Mellitus; Orthopedics; Pediatric care; Renal failure.
Financing and Governance

The Ministry of Health and Welfare (70%); the Swedish Association of Local Authorities and Regions (SALAR) (30%)

Each NQR is governed by a multiprofessional group of national experts, and often patients.

Funding is provided according to specified criteria; €60,000 - €700,000 annually/registry.

The more mature the NQR, the greater the expectations on it and the potential funding.
Quality improvement is “the combined and unceasing efforts of everyone — healthcare professionals, patients and their families, researchers, payers, planners and educators — to make the changes that will lead to better patient outcomes (health), better system performance (care) and better professional development”.

Batalden PB, Davidoff F. What is “quality improvement” and how can it transform healthcare? Quality and Safety in Health Care. 2007; 16:2-3.
Registries and Healthcare Improvement

1. Clinical epidemiology: National Quality Registries yield new knowledge regarding healthcare methods and health outcomes which can guide changes in clinical practice.

2. Public reporting of providers’ adherence to guidelines and of their patients’ outcomes. Providers can compare themselves with each other, find guidance on how to increase adherence and evaluate improvement efforts. Patients and other stakeholders can also compare providers and take action accordingly.

3. Clinicians and patients use NQR-related data collaboratively to guide the design of care plans for individual patients.

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Source: http://www.ucr.uu.se/swedeheart/
3. Clinicians and patients use NQR-related data collaboratively to guide the design of care plans for individual patients.

With POR (the Patient’s Own Registration), patients can record their own condition and monitor its progress and the effects of different treatments. This disease overview is used with the patient’s clinician to identify the best possible treatment. Together, we create better health for each patient. The Swedish Rheumatology Quality Registry: http://srq.nu/
Registries and Healthcare Improvement

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Case: Pediatric Diabetes

Average HbA1c by Department

Average HbA1c by age 2012-2014
Three Breakthrough Collaboratives with Swediabkids 2011-2016

All centers participated in a collaborative – all improved average HbA1c.
Case: Cardiac Care

• Work with a cardiology team, led by Karl Landergren, MD, from the Kalmar County Council in south east Sweden
• Set in a leadership development program concerning Value-Based Healthcare
• Drawing on the SWEDEHEART registry for cardiac care
• SPC analysis by Mark Splaine, MD, MS
Swedish Web-system for Enhancement and Development of Evidence-based care in Heart disease Evaluated According to Recommended Therapies
30-day mortality for MI patients age < 80, per county of patient according to population register, 2012–2013.

Data at Different Levels (For Same Measure)

The top funnel plot shows mortality in each unit without taking casemix into account. The bottom funnel plot indicates the difference between observed mortality and predicted mortality according to the patient’s background factors.
When asked "How does your service perform and how do your patients fare?" Dr. Landergren pointed to the SWEDHEART Quality Index.

The index includes 11 evidence-based actions known to influence patient outcomes where there is significant variation across the country. Each center is assessed for performance on these 11 actions.
OK; so you perform comparatively well but could still improve. How?
A lot of data....but hard to find the useful information in this format

How do I find and convey the important information in this "ocean" of data?
Kalmar: Time from ECG to PCI

Goal Achieved (61/75) = 81%

Average time is 70 minutes; two patients had significantly long times (>183 minutes).
Västervik: Time from ECG to PCI

Goal Achieved (9/32) = 28%

Average time is 126 minutes; one patient had a significantly long time (>321 minutes).
Events per year (total STEMI patient transports): 2012 = 0 (14), 2013 = 3 (20), 2014 = 5 (22)

Note: An event is an ambulance transport of a STEMI patient without ECG
How should clinicians and managers go from this...

...and this...

...to this?
Reflections

• NQRs *can* be used to guide and evaluate local clinical improvement efforts

• Access to data on its own does not automatically lead to healthcare improvement

• NQR data are limited – e.g. some data are only collected once a year – and may need to be complemented by temporary, local measurement

• Improvement efforts require access to current data; sometimes it takes time before data become available locally
What is a Quality Registry, Really?

A data base?  
A network, or Community of Practice, with dedicated and knowledgeable stakeholders?

Eventually, when Information Systems have reached sufficient functionality, the registry/data base will be less central – it is the networks of dedicated and knowledgeable stakeholders that are needed to measure, analyze and improve healthcare quality!
The perceived benefit of quality measurement must outweigh the perceived burden

**Perceived benefit**
- Better health and care
- Support for learning and improvement
- Professional development
- Ability to compare performance
- Valid measures

**Perceived burden**
- Data extraction from the health record
- Duplicate data entry
- Paper questionnaires
- Multiple log-ins
- Data feedback delays
- Inaccessible data that are hard to interpret
Literature


Literature

• Berwick DM. A primer on leading the improvement of systems. BMJ. 1996 Mar 9;312(7031):619-22.

• Batalden PB, Davidoff F. What is “quality improvement” and how can it transform healthcare? Quality and Safety in Health Care. 2007; 16:2-3.


Literature


