Swedish National Quality Registries and Their Contribution to the Best Possible Care for Patients

Johan Thor
Kristina Lidén Mascher
Staffan Lindblad

Vision
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.
Swedish National Quality Registries and Their Contribution to the Best Possible Care for Patients

Johan Thor, MD, MPH, PhD

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The Jönköping Academy for Improvement of Health and Welfare

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Affiliated researcher, the Medical Management Center, Karolinska Institutet
Chair, National Quality Registries’ Group of Experts
Sweden
• Population: 9.5 million
• Democratic monarchy
• Historical emphasis on egalitarianism
• Three levels of democratically elected government:
  • Nation
  • Counties (21)
  • Municipalities (290)
Swedish Healthcare

Universal access for all residents – paid mostly through taxes according to "ability to pay"; provided according to "need".

2 § 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.

The Swedish Healthcare Act (1982:763)
National Government
Laws and regulation; licensure of health professionals; national guidelines; oversight; Health Technology Assessment

County Councils & Regions
Responsible for most healthcare, provided either directly or via private contractors.

Municipalities
Social services, some home healthcare, elder care, community psychiatry

It isn’t all ONE system – it is 21, or 290, semi-autonomous systems!
Registries Contain Data On:

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

Initiated before the emergence of electronic health records (EHRs), most registries operate in parallel with EHRs. Integration is desired but occurring only slowly.
National Quality Registries

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.
Financing and Governance

• The Ministry of Health and Welfare (70 %); Swedish County Councils and Regions (30 %)
• Funding is provided according to specified criteria; $50,000 - $800,000 annually/registry
• The more mature the NQR, the greater the expectations on it and the potential funding
• Each NQR is governed by a multiprofessional group of national experts, and often patients
Case: Pediatric Diabetes


Average HbA1c, by Department

Average HbA1c by age 2012-2014

Enabler: The total population register – ”Personnummer”

Three Breakthrough Collaboratives with Swediabkids 2011-2016

All centers participated in a collaborative – all improved average HbA1c.

<table>
<thead>
<tr>
<th>Nation</th>
<th>Mean-HbA1c mmol/mol, 2010</th>
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Anette Peterson, RN, PhD
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
What is a Quality Registry, Really?

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

Mature Information Systems should enable the networks of dedicated and knowledgeable stakeholders to measure, analyze and improve healthcare quality!
SWEDISH QUALITY REGISTRIES - IN RESEARCH AND INTERNATIONAL PROJECTS

Tina Lidén Mascher
National Quality Registries, Sweden
Strategist-International projects and collaborations with the industry
Health and Social Care Division
Swedish Association of Local Authorities and Regions
REGISTERS: WHY AND FOR WHAT?

UNIQUE IS THAT WE CAN LINK AND COMPARE HEALTH DATA REGISTRIES WITH QUALITY REGISTRIES AND BIOBANKS

**Why**
- Safety and follow-up
- Patient outcome
- Clinical research
- Health economics
- Risk factors, prevalence, incidence
- Method development

**What**
- Development of guidelines
- International and local comparisons in healthcare-Benchmarking
- Industry follow-up of new drugs/devices
- Epidemiological studies
- Randomised studies (phase II, III, IV)
- Feasability studies

- Real world studies (medical effect and cost)
- Answering questions from Health Authorities
THE BEST POSSIBLE CARE FOR THE PATIENT

The ”new drug/devices: Hip arthroplasty Registry

Sweden's hip arthroplasty registry has defined international best practice

Feedback essential for continuous quality improvement

Sweden with lowest revision burden after total hip arthroplasty

- Share revised (%)
- Through documentation and feedback of data, important information from dearly-bought experience has been acquired.
- The main goal of open comparisons is not to expose single clinics but to invite local in-depth analysis and clinical improvement work.
- The key to success has been yearly feedback of data to all units, and yearly conferences.

THE BEST POSSIBLE CARE FOR THE PATIENT

Working procedures: Cataract Registry
Results of safety evaluation of initial use of TNF inhibitors in clinical practice

Relative Risk of tuberculosis

Consequence: Institution of screening for TB before treatment start reduces TB risk and enables continued use of the drug.

Relative Risk of malignant lymphomas

Consequence: Continued approval of the drugs after hearings at FDA and EMEA due to initial alarms of increased risk of lymphomas (with no information from comparator groups available).

Outcomes, Health Policy, and Managed Care

Improved adherence to Swedish national guidelines for acute myocardial infarction: The Quality Improvement in Coronary Care (QUIICC) study

Richard Carlbom, MD, MSc, Mats Bojestig, MD, PhD, Lars Wallentin, MD, PhD, Gunilla Lindstrom, RN, Astrid Petersson, RN, Christina Aberg, RN, and Bernt Lindahl, MD, PhD for the QUIICC study group

Uppsala and Linköping, Sweden

Background: The adherence to evidence-based treatment guidelines for acute myocardial infarction (AMI) is still suboptimal. Therefore, we designed a study to evaluate the effects of a collaborative quality improvement (QI) intervention on the adherence to AMI guidelines. The intervention used a national web-based quality registry to generate local and regular real-time performance feedback.

Methods: A 12-month baseline measurement of the adherence rates was retrospectively collected, comprising the period July 1, 2001, through June 30, 2002. During the intervention period of November 1, 2002, through April 30, 2003, multidisciplinary teams from 19 nonrandomized intervention hospitals were subjected to a multilocation QI-oriented intervention. Another 19 hospitals, unaware of their status as controls, were matched to the intervention hospitals. During the postintervention measurement period of May 1, 2003, through April 30, 2004, a total of 6726 consecutive patients were included at the intervention (n = 3786) and control (n = 2940) hospitals. The outcome measures comprised 5 Swedish national guideline-derived quality indicators, compared between baseline and postintervention levels in the control and QUIICC intervention hospitals.

Results: In the control and QI intervention hospitals, the mean absolute increase of patients receiving angiotensin-converting enzyme inhibitors was 1.4% vs 12.6% (P < .002), lipid-lowering therapy 2.3% vs 7.2% (P = .065), atorvastatin 26.3% vs 41.2% (P = .010), heparin-low molecular weight heparin 5.3% vs 16.3% (P < .010), and coronary angiography 6.2% vs 16.6% (P = .027), respectively. The number of QI intervention hospitals reaching a treatment level of at least 70% in 4 or 3 of the 5 indicators was 15 and 5, respectively. In the control group, no hospital reached 70% in just 4 of the 5 indicators.

Conclusions: By combining a systematic and multidisciplinary QI collaborative with a web-based national quality registry with functionality allowing real-time performance feedback, major improvements in the adherence to national AMI guidelines can be achieved. (Am Heart J 2006;152:1175-81.)

During the last decades, much of the worldwide effort to improve the quality of care has been focused on the development and dissemination of evidence-based guidelines. Despite these efforts, a number of well-designed studies from different countries and healthcare areas have shown that the gap between the recommendations in treatment guidelines and clinical practice is still wide. This also applies for the treatment of acute myocardial infarction (AMI), where the quality of care shows a large variation between centers both within and between countries. Even in the best performing hospitals, it is common that no more than two thirds of the patients receive a recommended treatment.

Because deviations from guideline recommendations increase morbidity and mortality, several programs with different approaches but common goal of improving adherence, have been implemented.
TO ACHIEVE BEST HEALTHCARE - INCREASE EFFICIENCY THROUGH COLLABORATIONS

- Working procedures
- Research & Development
- Quality improvement
- New drugs and medical devices
PARENT Framework: the tools

- Guidelines, Recommendations, Methodologies
- Best practices
- Information models, ontologies, vocabularies
- Services, SW tools repository
- Registry of Registries

Knowledge Management Platform
PARENT Framework
EXAMPLE OF TOOLS USED FOR ONLINE REPORTS THE HEALTH CARE IN NUMBERS”/VÅRDEN I SIFFROR
**SWEDEN’S EXTENSIVE EXPERIENCE WITH OUTCOMES MEASUREMENT HAS CONTRIBUTED ENORMOUSLY TO ICHOM’S WORK (EXAMPLES)**

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The Randomized Registry Trial — The Next Disruptive Technology in Clinical Research?

Michael S. Lauer, M.D., and Ralph B. D'Agostino, Sr., Ph.D.

POWERFUL NEW IDEA

The New England Journal of Medicine

BACKGROUND
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Thrombus Aspiration during ST-Segment Elevation Myocardial Infarction

Ole Frieslet, M.D., Ph.D., Bo Lagerqvist, M.D., Ph.D., Göran K. Olsson, M.D., Ph.D.,
Emil Caramori, M.D., Ph.D., Thorsten Schmidt, M.D., Ph.D.

METHODS
We conducted a multicenter, prospective, randomized, controlled, open-label clinical trial, with enrollment of patients from the national comprehensive Swedish Coronary Angiography and Angioplasty Registry (SCAAR) and end points evaluated through national registries. A total of 7244 patients with STEMI undergoing PCI were randomly assigned to manual thrombus aspiration followed by PCI or to PCI only. The primary end point was all-cause mortality at 30 days.
Distribution of areas for research

- Medical devices (10)
- Surgical procedures (12)
- Treatment guidelines (18)
- Pharmaceuticals (8)
- Patient questionnaires (8)
Global distribution of international collaboration

- Australia: 20
- Denmark: 24
- Finland: 18
- France: 10
- Ireland: 8
- Italy: 14
- Norway: 20
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-NATIONELLA KVALITETSREGISTER

2016-03-09
Gunilla Jacobsson Ekman
INTERNATIONAL COLLABORATION- A GOOD THING!

THING TO CONSIDER: POPULATION, DATA, ETHICS, LEGAL

DATA
- Definition of population: in-/exclusion criteria
- Data collection (guidelines, coding, ICHOM)
- Definition of variables, methods

ETHICS
- Patient information and consent

LEGAL
- EU New data protection law (2018) and implementation
- Third countries – assure adequate data protection
- Responsibility for Data (Norway data inspection)
- Agreements, Steering committees, Data analysis group

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- Technical specification, automatic data transfer
- Patient identity not revealed (coded)
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The emphasis of different registries may vary. Some focus on patients with a specific illness, others on a specific treatment or a risk group. The quality registries are therefore quite different, with different levels of coverage and data quality, which is important to keep in mind.

The registrar and steering committee members for a registry are responsible for development and operation, and have the greatest knowledge about the registry and how it can be used.
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The “new drug/devices: Hip arthroplasty Registry

Sweden's hip arthroplasty registry has defined international best practice

Feedback essential for continuous quality improvement

- Decrease seen in cumulative revision frequency for mechanical loosening after operation with cemented implant
- 3% revision for patients operated in 1987, 9% revision for patients operated in 1979

"Through documentation and feedback of data, important information from closely-bought experiences has been acquired"

"The main goal of open comparisons is not to expose single clinics but to initiate local in-depth analysis and clinical improvement work"

"The key to success has been yearly feedback of data to all units, and yearly conferences"

Sweden with lowest revision burden after total hip arthroplasty

- Sweden has a high share of cemented implants and low revision frequency compared to other countries
- In Sweden more than 90% of THAs done with cemented fixation
- Revision frequency for cemented fixation 7%, uncemented fixation 12%

Low revision frequency for cemented THAs due to use of well-documented types of implant
- 5 brands cover 80% of THA operations

THE BEST POSSIBLE CARE FOR THE PATIENT

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Research and Development: Reumatoid Arthritis Registry

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Contributions to individual health by National Quality registries in Sweden

Staffan Lindblad, professor, M.D.
Director QRC Stockholm – Quality Register Centre
THE SRQ APPROACH
> 22 Swedish national registers offer patient overviews

**Pediatrics**
- Cystic Fibrosis – USA
- Juvenile arthritis – Iceland, Croatia
- Obese children
- Epilepsy
- Kidney failure
- Congenital metabolic diseases

**Infectious diseases**
- HIV
- Hepatitis
- Immune deficiency

**Gastroenterology**
- Inflammatory Bowel Disease

**Psyciatric diseases**
- Eating disorders

**Rheumatology**
- RA*, SLE + 96 more diagnoses

**Cancer**
- Prostatic cancer

**Neurology**
- Multiple Sclerosis – Denmark
- Parkinsons
- Epilepsy
- Myasthenia
- MotorNeuronDisease
- Narkolepsy
- Neurologic headache
- Inflammatory polyneuropathy
- Cerebral Palsy

* [https://www.youtube.com/watch?v=Kmqzy1hqCOw](https://www.youtube.com/watch?v=Kmqzy1hqCOw)
HIV & Prostate cancer
Individual & group data, MS
Individual reminders, RA

Individual & group data, MS
Knowledge development

Decision support staircase

**Documentation- and visualization support**
- Documentation templates
- Patient overviews *(Data visualization)*

**Knowledge based systems**
- Active recommendations *(Reminders, alerts)*
- Computer-interpretable guidelines and care protocols

**Knowledge generating systems**
- Differential diagnoses/prognoses based on statistical and machine learning
- Individualized recommendations *(Personalized medicine)*

Functionality:
- Reduce cognitive load

Purpose:
- Standardization
- Knowledge generation

Knowledge development
Registry Based Learning Health System

Optimal Health and High Value Care for Patients and Populations

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The patient overview optimizes health and the care process in Gävle landsting

Open-Tight clinics emerge from three simple rules:

1. All patients in remission get no further appointment – they can call in for an immediate visit as needed

2. Patients with active disease get new treatment and a follow up visit to check the effect

3. Patients not calling in for 1(2) years are booked for a visit to a nurse or physiotherapist
CRP in all RA-patients Oct 2004 – Aug 2014

Blue Gävle  Red Sweden except Gävle
CRP in all RA-patients Oct 2004 – Aug 2014

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Open-Tight clinics started
Optimal improvement – both better than the rest of Sweden and less variation

Open-Tight clinics started

CRP in all RA-patients Oct 2004 – Aug 2014
Blue Gävle    Red Sweden except Gävle
Registry Enabled Shared Information Environment: Facilitated networks, clinical collaboratives, public reporting, & research

Patient-Family Conversations: Goals, treatment decisions, outcomes tracking

Patient-Clinician Conversations: Goals, treatment decisions, outcomes tracking

Clinical Team Conversations: Population management, Pre-visit planning

Accountability Conversations: Variations in outcomes, good value services

Research Conversations: New treatments, comparative effectiveness

Community of Patients Conversations: Helpful knowledge, support, resources

Partnership for Co-production

Patient & Family

Clinician & Care Team