

# Kliniske kvalitetsdatabaser som moderne informationsnetværk til gavn for patienterne og klinikken

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**JÖNKÖPING ACADEMY**

For Improvement of Health and Welfare



A city street scene with a car and a pedestrian crossing sign. The background shows a multi-story brick building with many windows. A silver car is driving across the street. A blue pedestrian crossing sign is visible on the right. The text 'THE SROQ APPROACH' is overlaid in white.

THE  
SROQ  
APPROACH

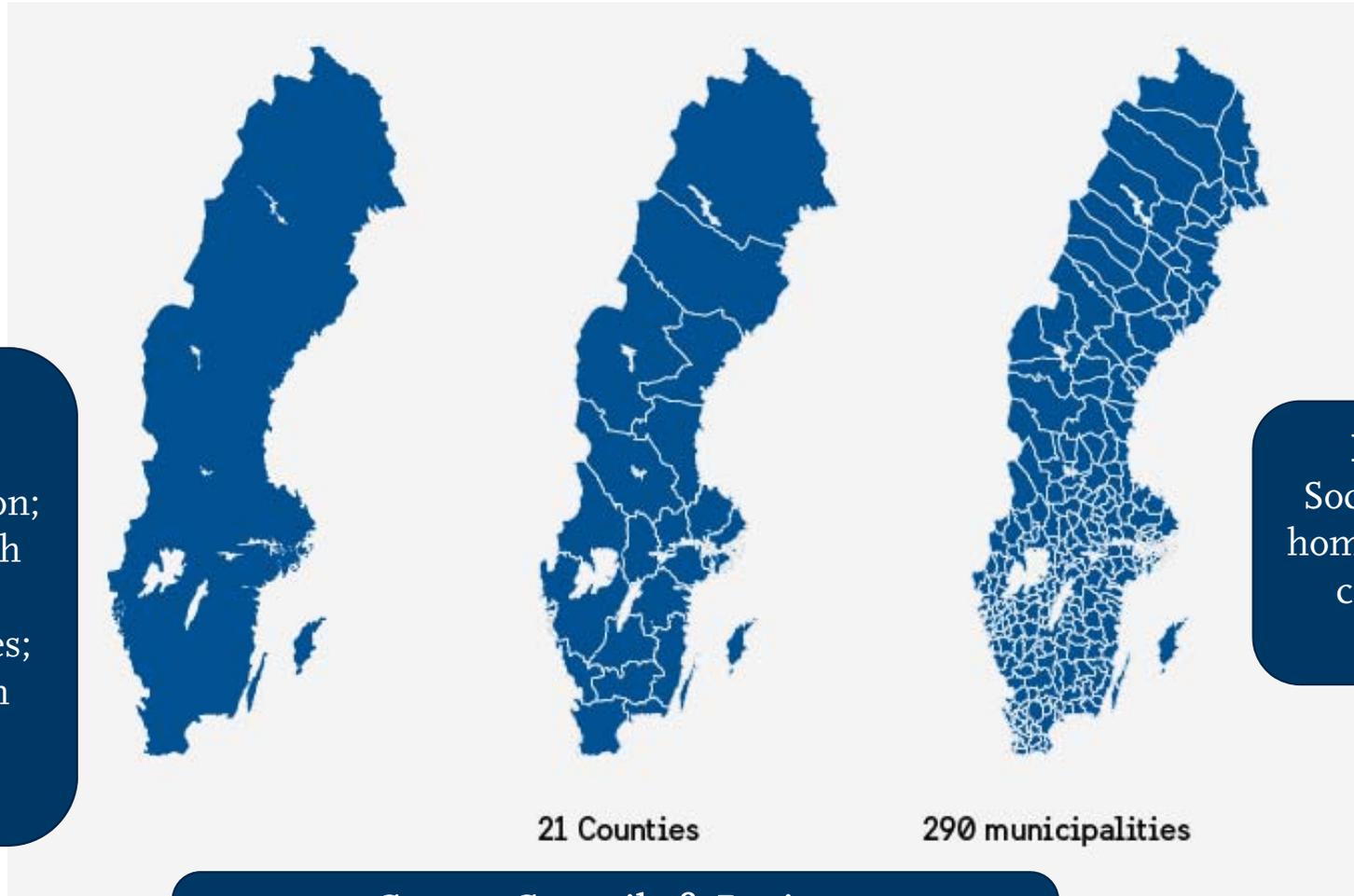
<https://youtu.be/KmqzyrhqcOw>

## Swedish Healthcare

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)





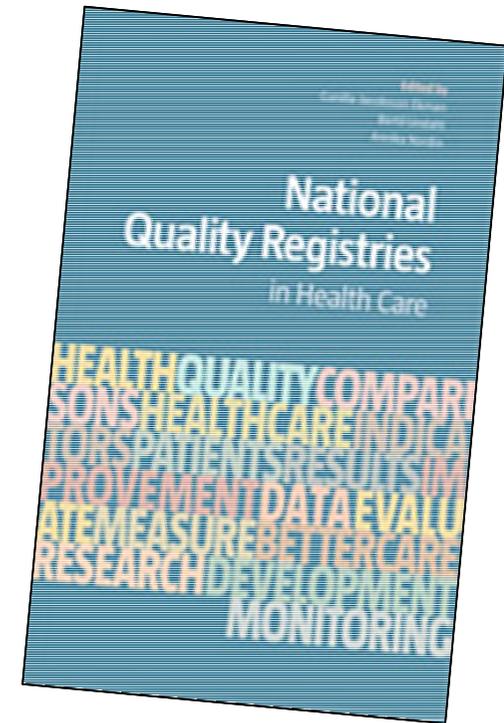
**National Government**  
Laws and regulation;  
licensure of health  
professionals;  
national guidelines;  
oversight; Health  
Technology  
Assessment

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

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

## 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)





## NATIONELLA KVALITETSREGISTER

Kunskap för bättre vård och omsorg

# Swedish National Quality Registries

### *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.

<http://kvalitetsregister.se/englishpages.2040.html>

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# 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; Pediatric care; Renal failure.



# Financing and Governance

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

Funding is provided according  
to specified criteria; 400 000 –  
7 100 000 annually/registry

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

The more mature the NQR, the  
greater the expectations on it  
and the potential funding



# What is a Quality Registry, Really?



A data base?



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

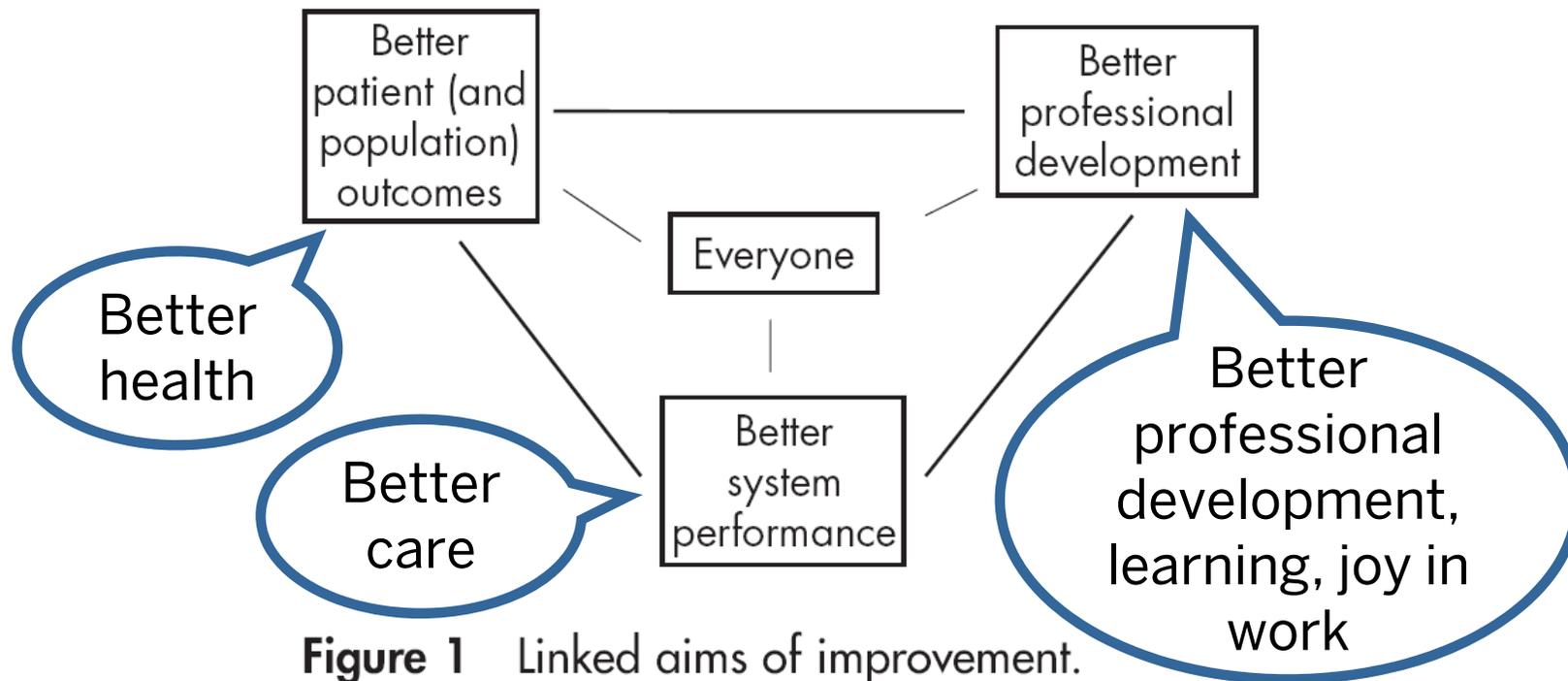


Eventually, when Information Systems have reached sufficient functionality, the registry/data base will be less central – it is the networks of dedicated and knowledgeable stakeholders that are needed to measure, analyze and improve healthcare quality!



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.

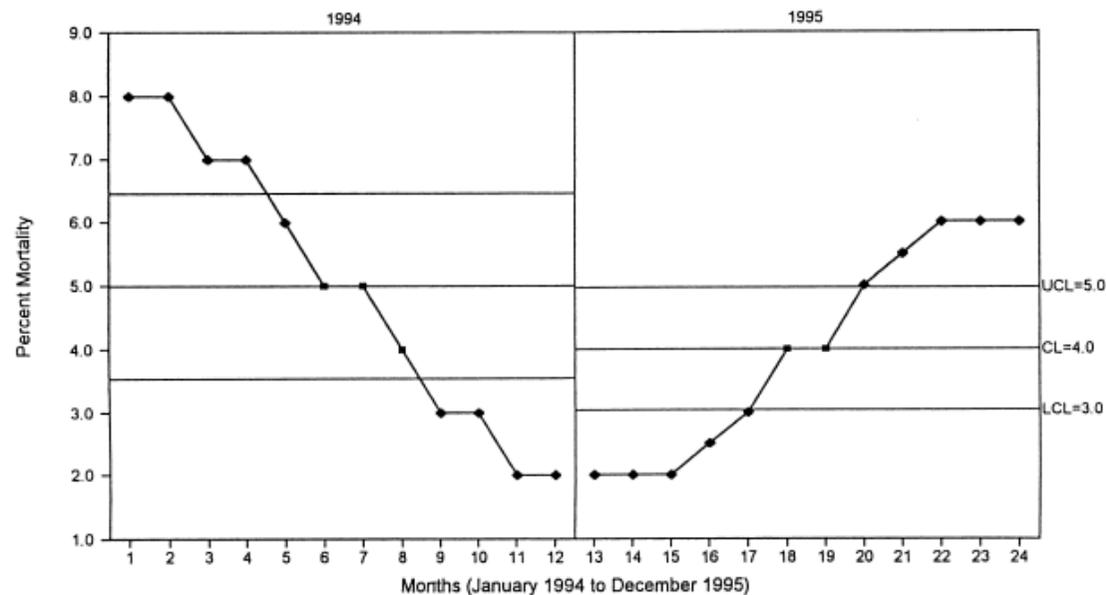


**Figure 1** Linked aims of improvement.

# Data to Support Improvement

*Patterns that can guide improvement efforts are best revealed by plotting data over time*

*Fig 2. Control chart of coronary artery bypass grafting (CABG) mortality before and after new protocol. CL = center line or mean; LCL = lower central limit; UCL = upper control limit.*



Levett JM, Carey RG. Measuring for improvement: from Toyota to thoracic surgery. *Ann Thorac Surg.* 1999 Aug;68(2):353-8.

# Variation in Health Care

- Variation can signal that care is not consistently in line with the best available evidence
- Variation can also indicate success in improving care by changing work practices
- Misinterpretation of variation can cause worse quality and higher cost



# Walter Shewhart



Walter Shewhart  
1891-1967

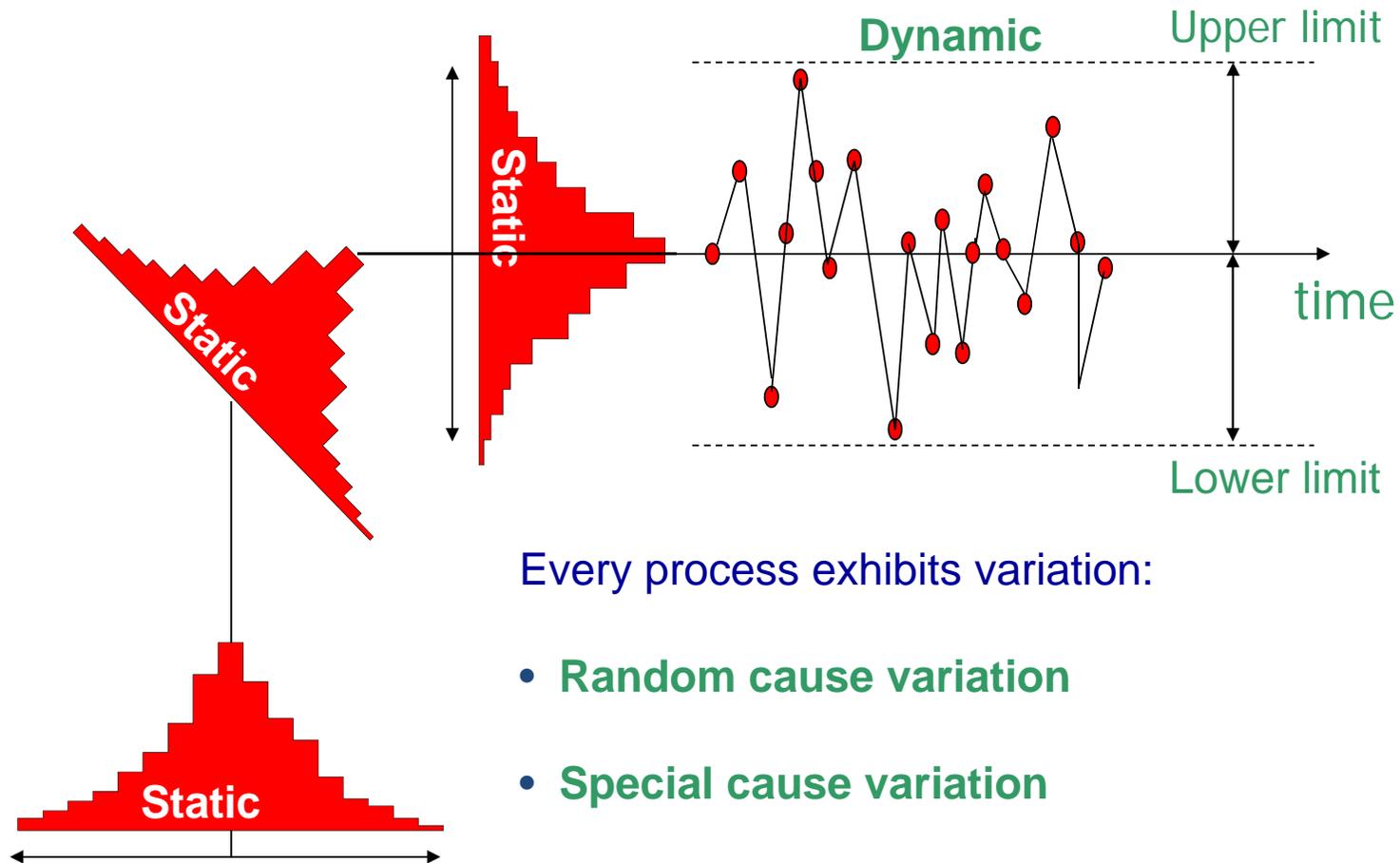
- Shewhart's data presentation rules:
  - Data have no meaning apart from their context.
  - Data contain both signal and noise. To be able to extract information, one must separate the signal from the noise within the data.

1. Best M, Neuhauser D. Walter A Shewhart, 1924, and the Hawthorne factory. Qual Saf Health Care. 2006;15(2):142-3.
2. [http://en.wikipedia.org/wiki/Walter\\_A.\\_Shewhart](http://en.wikipedia.org/wiki/Walter_A._Shewhart), accessed 2014-09-01.



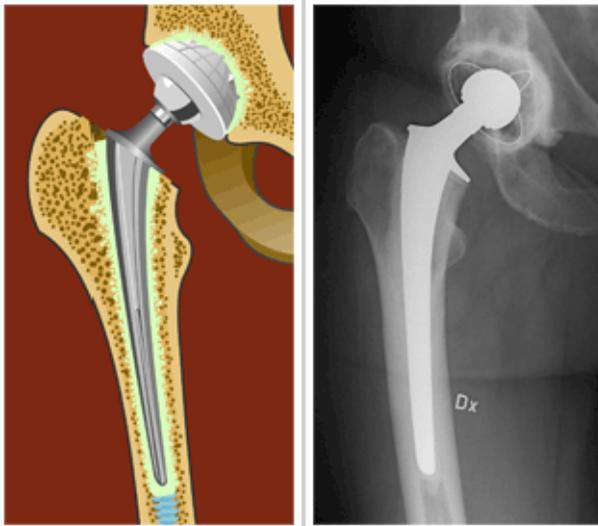
# “What is variation in a system over time?”

Walter A. Shewhart – 1920s, Bell Laboratories



# 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.



The Swedish Hip Arthroplasty Register:  
<http://www.shpr.se/sv/Default.aspx>



# Registries and Healthcare Improvement

1. *Clinical epidemiology.* National Quality Registers 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.

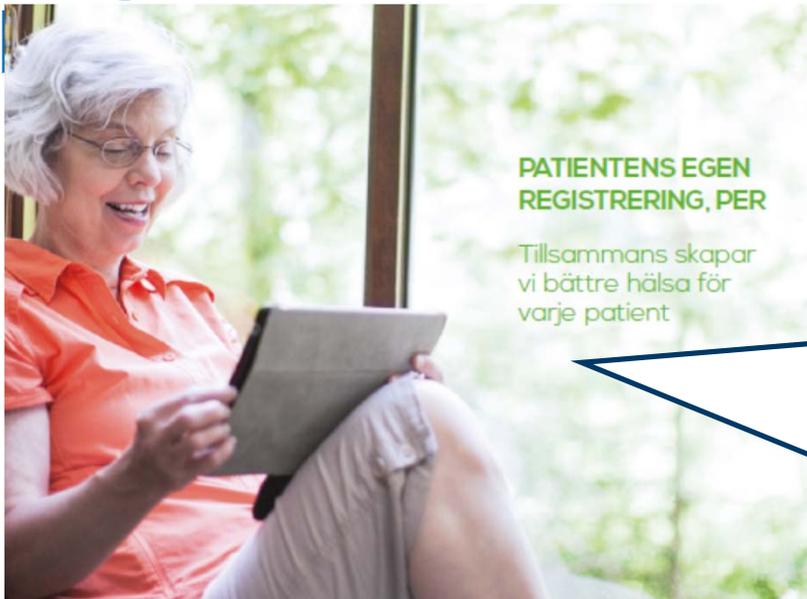


Association between adherence to evidence-based guidelines and patient outcomes. One-year mortality 1996: 21,0 %; 2007: 13,3 %. Public reporting prompted faster gains.

Source: <http://www.ucr.uu.se/swedeheart/>



## Registries and Healthcare



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/>

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



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## 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 SWEDHEART registry for cardiac care
- SPC analysis by Mark Splaine, MD, MS





# SWEDEHEART

## Annual report

### 2013

Issued in 2014

**Swedish Web-system for  
Enhancement and  
Development of Evidence-  
based care in Heart disease  
Evaluated According to  
Recommended Therapies**

#### **RIKS-HIA**

PRESENTED BY  
Tomas Jernberg, Claes Held and  
Erik Rydberg

#### **SEPHIA**

PRESENTED BY  
Kristina Hambræus,  
Margrét Leósdóttir and  
Lennart Nilsson

#### **SCAAR**

PRESENTED BY  
Stefan James,  
Bo Lagerqvist and  
Nawzad Saleh

#### **Swedish Heart Surgery Registry**

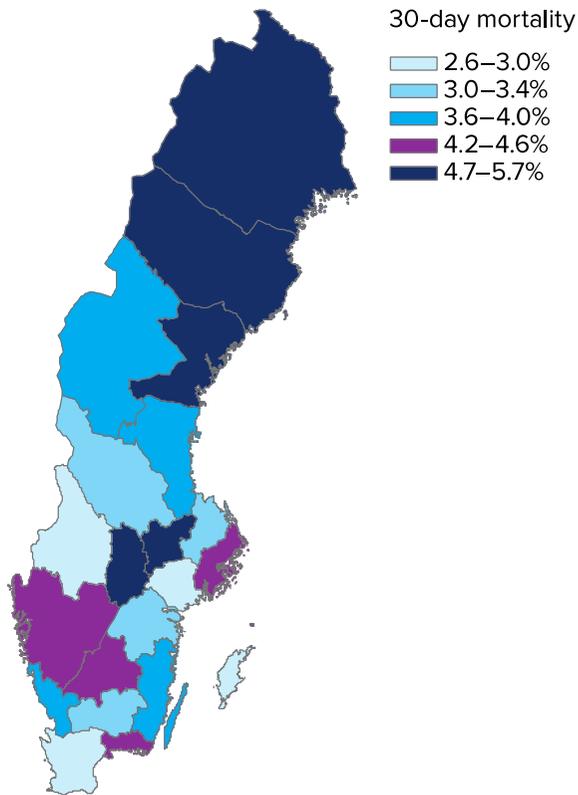
PRESENTED BY  
Örjan Friberg and  
Johan Nilsson

#### **Percutaneous Valve Registry**

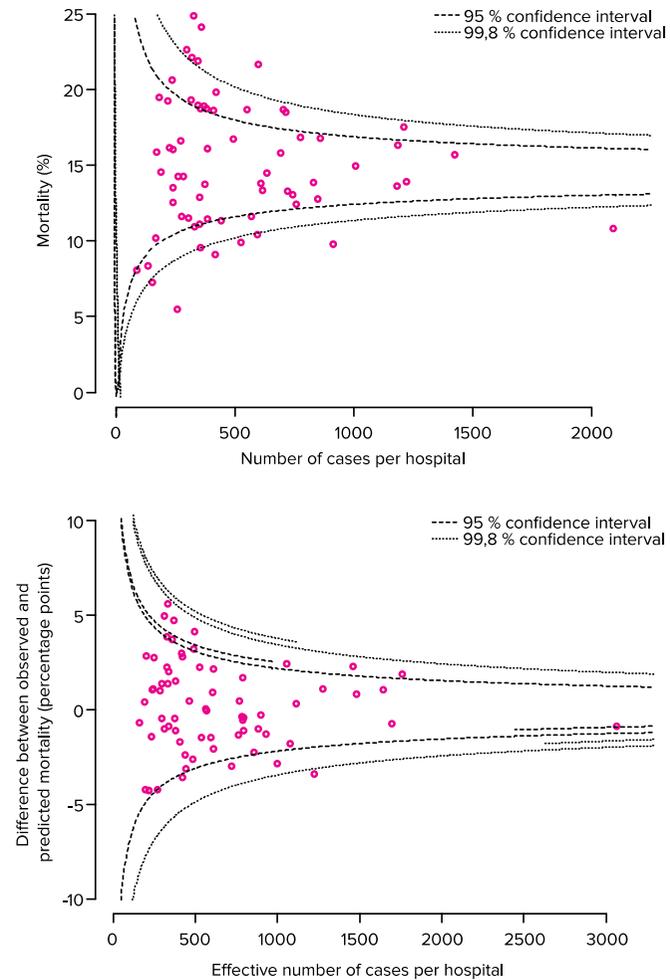
PRESENTED BY  
Johan Nilsson

# Data at Different Levels (For Same Measure)

30-day mortality for MI patients age < 80,  
per county of patient according to  
population register, 2012–2013.



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.



## The SWEDEHEART Quality Index

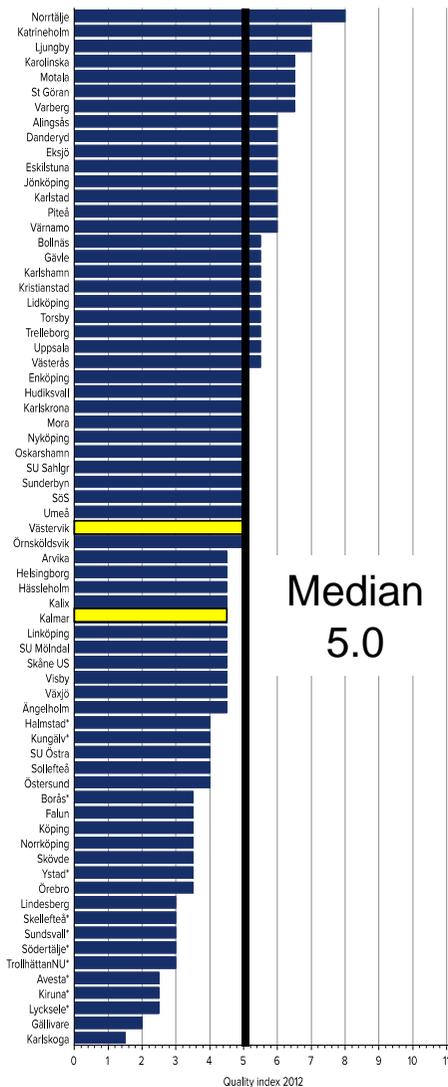
When asked *"How does your service perform and how do your patients fare?"* Dr. Landergren pointed to the SWEDEHEART Quality Index.

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.

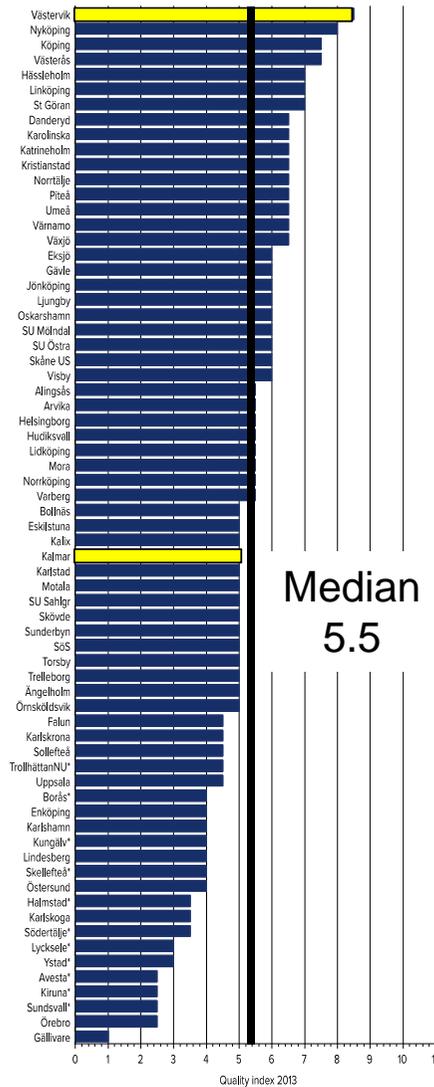
SWEDEHEART Annual Report 2013, Issued 2014, Table 1, p.13

Quality indicator	0.5	1
	points	point
	%	%
Reperfusion in STEMI/LBBB	80	85
Reperfusion in STEMI/LBBB within recommended time	75	90
Coronary angiography in target group in NSTEMI	75	80
P2Y12 blockers in NSTEMI	85	90
ACE inhibitors/ARBs in target group for myocardial infarction	85	90
Proportion with myocardial infarction as principal diagnosis (<80 years) included in RIKS-HIA	90	95
Proportion of myocardial infarctions <75 years in RIKS-HIA undergoing follow-up (SEPHIA)	75	90
Proportion of smokers who have stopped after 12–14 months	60	70
Proportion who have taken part in physical training programme after 12–14 months	50	60
Proportion with LDL cholesterol <1.8 mmol/L or > 50 reduction after 12–14 months	40	60
Proportion with systolic blood pressure <140 mmHg after 12–14 months	70	75

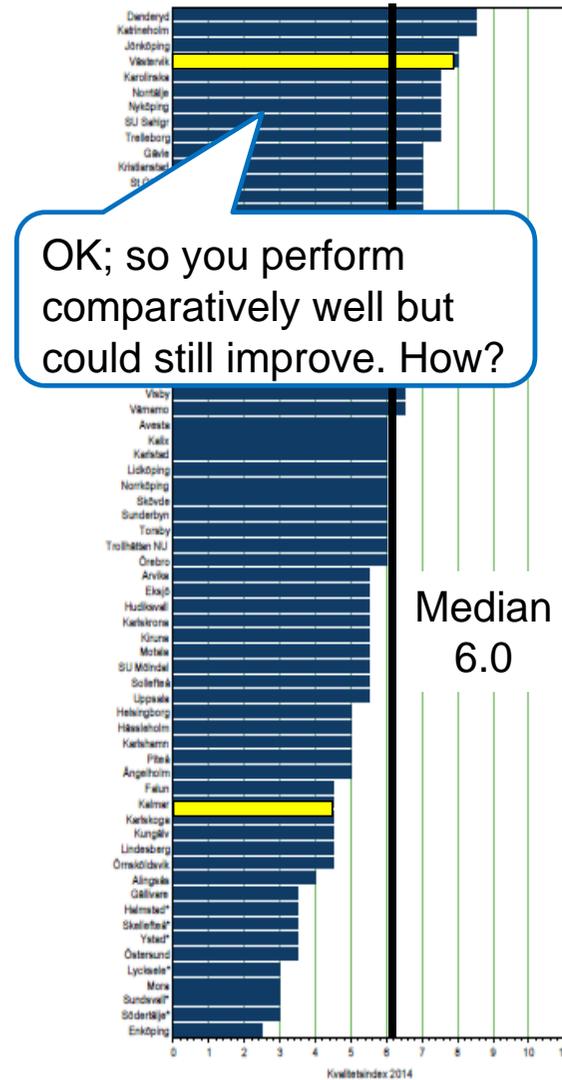
Quality index in 2012 per hospital  
(with > 10 patients in each target group)



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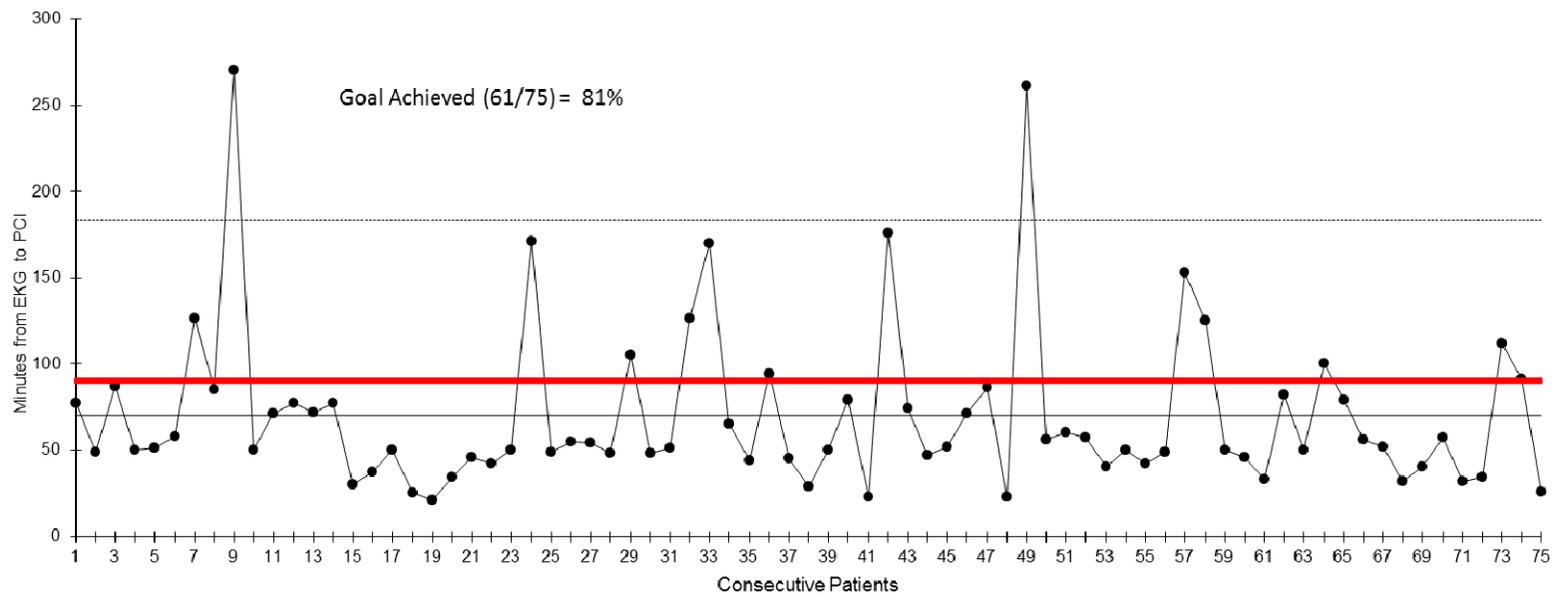
Quality index in 2014 per hospital  
(with > 10 patients in each target group)





# Kalmar: Time from ECG to PCI

Kalmar Hospital 2014 STEMI Patients (N=75)

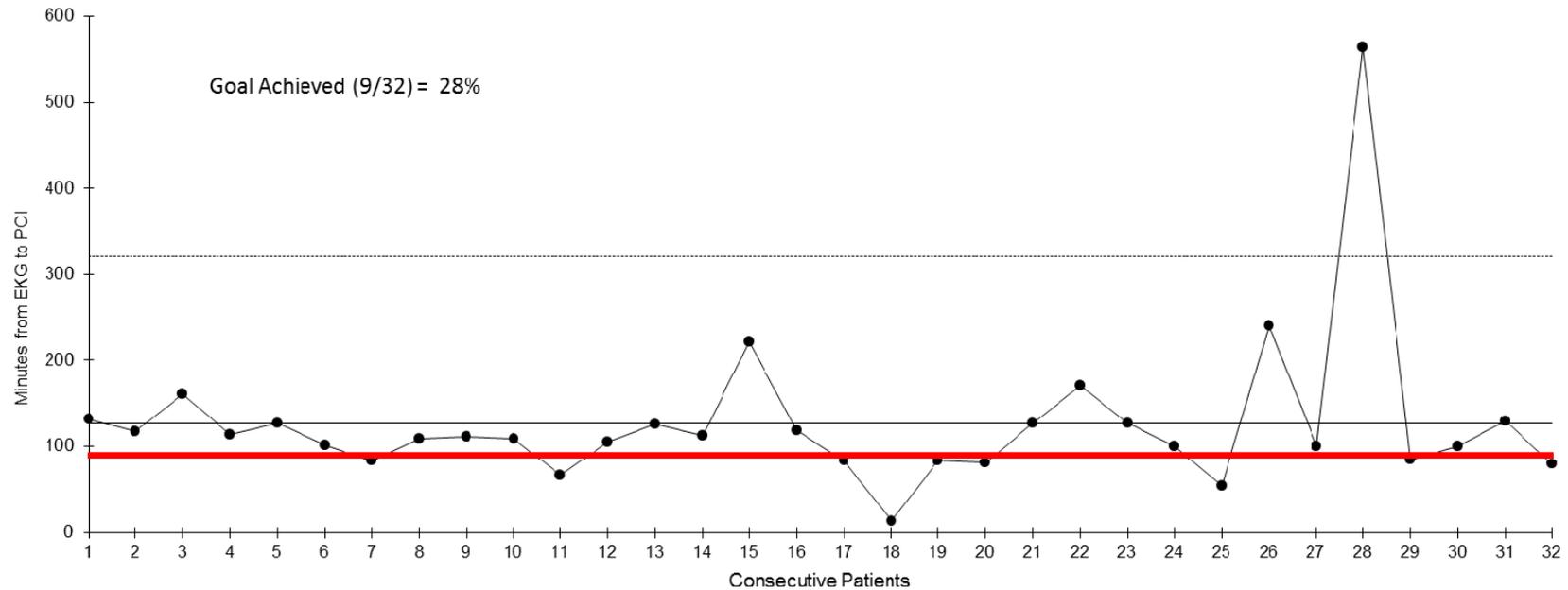


Goal Achieved (61/75) = 81%

Average time is 70 minutes; two patients had significantly long times (>183 minutes). 26

# Västervik: Time from ECG to PCI

Västervik Hospital 2014 STEMI Patients (N=32)

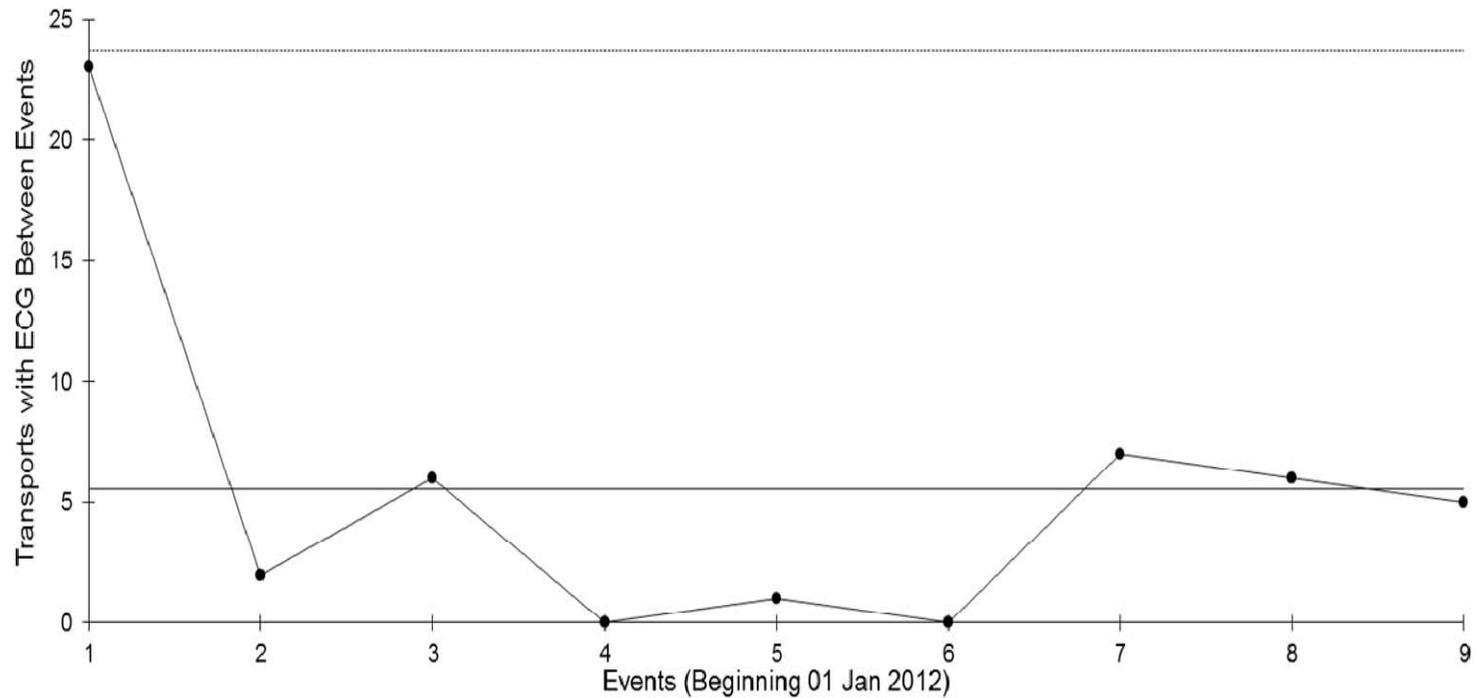


Goal Achieved (9/32) = 28%

Average time is 126 minutes; one patient had a significantly long time (>321 minutes). 27

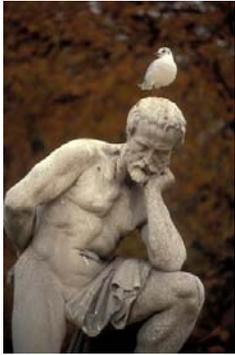
### Västervik Ambulance Pre-Hospital ECG (2012-2014)

Goal is 



**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



# 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

The perceived benefit of quality measurement must outweigh the perceived burden

Perceived benefit > Perceived burden

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

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



# Powerful New Idea

The NEW ENGLAND JOURNAL of MEDICINE

ORIGINAL ARTICLE

## BACKGROUND

The clinical efficacy of manual thrombus aspiration during primary percutaneous coronary intervention for ST-segment elevation myocardial infarction remains uncertain.

## Thrombus Aspiration during ST-Segment Elevation Myocardial Infarction

primary percutaneous coronary intervention myocardial infarction thrombus

Ole Fröbert, M.D., Ph.D., Bo Lagerqvist, M.D., Ph.D., Göran K. Olivecrona, M.D., Ph.D., Elmira Omerovic, M.D., Ph.D., Thorarinn Gudnason, 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.

N Engl J Med 2013.  
DOI: 10.1056/NEJMoa1308789

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*The* NEW ENGLAND JOURNAL *of* MEDICINE

# Perspective

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

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

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## Registry-Based Randomized Clinical Trials

”By including a randomization module in a large inclusive clinical registry with unselected consecutive enrolment, the advantages of a prospective randomized trial can be combined with the strengths of a large-scale all-comers clinical registry. We believe that prospective registry-based randomized clinical trials are a powerful tool for conducting studies efficiently and cost-effectively.”

James, S. *et al.* Registry-based randomized clinical trials—a new clinical trial paradigm. *Nat. Rev. Cardiol.* 12, 312–316 (2015)



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