National Quality Registers in Sweden
Sweden is not one country concerning health care!

21 independent counties /regions

- Different definitions of primary care
- Different financing systems (capitation, FFS) including different P4P systems
- Different medical record systems
- Different systems for follow up
- Different quality indicators
Swedish knee – and hip arthroplasty registers in an international perspective

Göran Garellick

Swedish Hip Arthroplasty Register

Swedish Knee Arthroplasty Register
the idea of a national register

...serious consideration should be given to establishing a central register to keep a finger on the pulse of total implant surgery on a nation-wide basis...

NJR in the US started in 2007

Sir John Charnley 1972
Artroplasty registers in the nordic countries

- Knee 1975
- Hip 1979
- Hip & Knee 1980
- Hip 1987
- Knee 1994
- Hip 1995
- Knee 1997
The lowest reported frequency of reoperations in the world
Fig. 4 Survivorship curves (with 95% confidence intervals) for total hip arthroplasty implant failures in the United States, Sweden, and Norway.

# Medical Device Alert

**Immediate action / update**

Ref. MDA/2010/069    Issued. 07 September 2010 at 13.00

## Devices

DePuy ASR™ hip replacement implants.

## Problem

Recall of ASR hip replacement implants due to increased rates of revision.

## Action

- Do not implant DePuy ASR hip replacements.
- Return all unused ASR hip replacement implants to the manufacturer.
- Inform all patients implanted with ASR hip replacements about this recall and schedule them for a follow-up visit.

## Action by

- Medical directors.
- Orthopaedic surgeons.
- Staff involved in the management of patients with joint replacement implants.

Note: the recommendations in this MDA replace the advice given in MDA/2010/044.
What happened later on?

- ASR surface replacement on 93,000 patients.
- Cost in the US $8,100,000,000.
- If US had had an artroplasty register these problems would have been detected in 6-8 months.
The successes of the arthroplasty registers

• Has created high expectations of the benefits from quality registers.

• They have become a model for quality registers
Differences between registers "surgical" and "medical"

- New procedures with lack of evidence
- What is the outcome of different procedures?
- The register is creating new evidence on the procedures studied
- Procedures based on evidence.
- Adherence to guidelines?
- Do the results in reality match those in randomised trials/guidelines?
Sweden
90 national quality registers

• Aimed for one diagnosis or one procedure

• Created and managed by hospital specialists / researchers with great knowledge about that diagnosis or procedure.

• Knowledge about primary care and improvement processes?
### Quality registers also for use in primary care

<table>
<thead>
<tr>
<th>Disease</th>
<th>% PC-units connected</th>
<th>Patients reported from Prim Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes</td>
<td>90 %</td>
<td>250 000</td>
</tr>
<tr>
<td>Heart failure</td>
<td>6 %</td>
<td>16 984</td>
</tr>
<tr>
<td>Chron. Obstr Lung Dis</td>
<td>25 %</td>
<td>1 739</td>
</tr>
<tr>
<td>Leg ulcers</td>
<td>2 %</td>
<td>500</td>
</tr>
<tr>
<td>Dementia</td>
<td>10 %</td>
<td>248</td>
</tr>
<tr>
<td>Palliative care</td>
<td>15 %</td>
<td>1 000</td>
</tr>
<tr>
<td>Risc detection in elderly people</td>
<td>??</td>
<td>(47 000)</td>
</tr>
</tbody>
</table>
Pressure and P4P is used to make primary care report to registers

- Diabetes  
  Mandatory
- Heart failure  
  P4P
- Chron. Obstr Lung Dis
- Leg ulcers
- Dementia  
  Mandatory - P4P
- Palliative care  
  Mandatory - P4P
- Risc detection  
  Mandatory - P4P

  in elderly people
GPs are reluctant:

• ”The most important qualities of general practice are not in the registers.”
• ”Registers are not aimed for people with multiple diseases.”
• ”The results are to often used to tell public and politicians that GPs are bad doctors.”
• ”Registers are not adapted for improvement in general practice.”
• ”Time is better spent curing patients than entering data twice”
Welcome to pvkvalitet.se

Here you can register your own results and get instant feedback, both comparisons with other health centres or over time. The aim is to make it more fun and easy to measure, compare and improve quality in primary care.
We offer quality indicators for prevention, investigation, treatment and rehabilitation of patients in primary care.
We will also provide tools for local quality improvement.

Det finns en styrelse och utvecklingsgrupp med representanter från de deltagande landstingen. 
Kontaktperson är Sven Engström Primärvården FoU enhet i Jonköping.

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Klicka här om du vill veta mer om pvkvalitet

Logga in

Användarnamn: 
Lösenord: 

Glömt lösen

eva.arvidsson@ltkalmar.se
sven.engstrom@lj.se
Here you can register your own results and get instant feedback, both comparisons with other health centres or over time. The aim is to make it more fun and easy to measure, compare and improve quality in primary care. We offer quality indicators for prevention, investigation, treatment and rehabilitation of patients in primary care.

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Welcome to pvkvalitet.se

- Easy to use
  - Spend time improving quality – not data registering!
  - analysis of a random sample of 40-60 patients

- Immediate feedback

- Compare results
  - with guidelines
  - with other health centres

- Easy to follow results over time
For each indicator there is a background of scientific references to the choice of indicators. There is also a detailed instruction on how measurements and data collection should be done. To get comparable results, please read instructions carefully before you start.

Selected diagnoses for benchmarking:

- Tonsillitis
- Cystitis in women
- Asthma
- COPD
- Heart failure
- Leg ulcer
- LRTI
- Atrial fibrillation
- Urinary incontinence
- Otitis media

Select the diagnosis you want to benchmark.
Criteria: What is important for good quality?

1. Att registrera diagnosen.
2. Rätt behandling.
3. Rätt uppföljning.

Indicators: What should be measured?

1. Andel av befolkningen 20-74 år som har diagnosen Astma.
3. Andel där rökning har dokumenterats på sökbara sätt.
5. Andel som har kontrollerats med pulsoximetern.

Measurement method

1. Sök i astmajournalen ur en lista på alla patienter med minst ett besök med diagnosen Astma (J45.9-P) under de senaste 2 åren.
2. Granska journalen på ett slumpvisval ur listan, 10-20 journaler per läkare eller totalt 40 per vårdcentral.
3. Notera på registreringssformulär
   a. Om det finns uppgift om att patienten sökt skut/öplanerat för astma under de senaste 12 månaderna. (Det som du kan utläsa ur journalen, oavsett om de sökt på VCIJC, sjukhuset eller någon annanstans).
   b. Om rökning dokumenterats med sökord tobak/rökning (med- och/eller utanmötande) de senaste 2 åren eller att de sedan tidigare är "dokumenterade icke rökt".
   c. Om patienten har inhalationssteroid.
   d. Om patienter med inhalationssteroid har kontrollerats med pulsoximetern under de senaste 24 månaderna.
4. Summariera registreringssformuläret och mata in resultatet nedan.

Standards: What goals should we aim for?
Asthma

Criteria: What is important for good quality?

1. To register diagnosis
2. The right treatment
3. The right follow-up

Measurement method

- To register diagnosis: It is important to have a clear protocol to ensure accurate registration of asthma (ICD-10) under the name of asthma.
- The right treatment: It is essential to have a treatment protocol that includes monitoring and adjusting the treatment based on patient response.
- The right follow-up: Regular follow-up visits are necessary to assess the patient's condition and adjust the treatment plan accordingly.

Standards: What goals should we aim for?

- Asthma diagnosis and management should be standardized across different healthcare settings.
- Regular monitoring of asthma control and medication adherence is crucial.
- Education and support for patients and caregivers should be provided to enhance treatment compliance.
- Continuous improvement in asthma management systems is necessary to ensure better outcomes.
Asthma

**Background**

**Criteria:** What is important for good quality?

1. Adherence
2. Prevention
3. Diagnosis

**Indicators:** What should be measured?

1. Percentage of population aged 20-74 who have the diagnosis asthma
2. Proportion who had emergency/unplanned visits for asthma
3. Proportion for whom smoking is registered in the records
4. Proportion treated with inhaled corticosteroids
5. Proportion who had a check up including spirometry

**Standards:** What goals should we aim for?

1. "Good practice guidelines for asthma management" (European Respiratory Society)
2. "Guidelines for the management of asthma" (European Lung Foundation)
3. "Best practice guidelines for asthma management" (National Institute for Health and Care Excellence)
Asthma

Measurement method

1. Search for all patients with the diagnosis last year in digital records
2. Select a random sample of 10-20 patients/GP or nurse or 50-60/ health centre
3. Check in the patient records for answers to each indicator

Check in the selected sample of patients with asthma:
• Emergency/unplanned visits for asthma in primary care or at hospital in the last year?
• Smoking documented with the keyword tobacco/smoking in the last 2 years (or already "documented non-smoker")?
• Treated with inhaled corticosteroids?
• Had a check up including spirometry last 2 years? (for patients with inhaled corticosteroids)?
# Asthma Registration Form

<table>
<thead>
<tr>
<th>Health Centre</th>
<th>GP</th>
<th>Period</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

### Elderly and Gender

For all questions, the patient's age and gender should be noted for each sample patient.

### Emergency/Unplanned Visits Last Year

<table>
<thead>
<tr>
<th>Patient</th>
<th>Emergency/Unplanned Visits Last Year</th>
<th>Smoking Registered</th>
<th>Have Inhaled Corticosteroids</th>
<th>Spirometry Last 2 Years</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Summary

- Note indicators in the form for each sample patient.
- Summarize the results.

---

### Notes

<table>
<thead>
<tr>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>
Background

Registration form
- Note indicators in the form for each sample patient
- Summarize the results

Input form
- Enter results into web form
- Feedback in 10 seconds
Proportion who had emergency/ unplanned visit for asthma last year

Proportion who had a check up including spirometry last 2 years

One click away every diagram has a background with references that motivates the indicator and the targets set.
pvkvalitet.se in March 2012

• 310 Health Centres participating
• 50 000 patients reviewed

= 1200 local improvement projects supported!
These initiatives from GPs have had difficulties to get economic support

Does not match the definition for a quality register.

- No personal identities registered and thus not possible to follow patients over time
- Aimed for improvement not for research.
2012 Governmental investment in quality registers

Increase in funding from 80 milj. SEK /year
To 320 milj. SEK /year
A great project initiated in primary care now has got funding..

Aims:

- Feedback adapted for the needs of practitioners in health care and of the stakeholders.
- Easy to deliver data from the medical record.
- No P4P
- People working in primary care must experience personal benefit from the register.

This creates motivation to deliver complete and true data for improvement and research.
Feedback

• Benchmarking with ideals and other units.

• Capacity to allow users to choose data and presentations.

• Identification of your patients needing change in care.

• Opportunity to regain your own supplied data

ADAPTED FOR USE IN ANY MEDICAL RECORD SYSTEM
### Diabetes Overview

#### How do we manage our patients?

**Goal attainment**

<table>
<thead>
<tr>
<th>HbA1c &lt; 6.0</th>
<th>Antal</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>All</td>
<td>182</td>
<td>49 %</td>
</tr>
<tr>
<td>Diet</td>
<td>24</td>
<td>92 %</td>
</tr>
<tr>
<td>Tabl</td>
<td>86</td>
<td>42 %</td>
</tr>
<tr>
<td>Insulin</td>
<td>28</td>
<td>25 %</td>
</tr>
<tr>
<td>Insulin + tabl</td>
<td>28</td>
<td>36 %</td>
</tr>
</tbody>
</table>

#### Controls made

<table>
<thead>
<tr>
<th>HbA1c</th>
<th>99,5 %</th>
<th>%</th>
<th>%</th>
<th>BT &lt; 130/80</th>
<th>Antal</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>BMI</td>
<td>95 %</td>
<td>%</td>
<td>%</td>
<td>All</td>
<td>170</td>
<td>58 %</td>
</tr>
<tr>
<td>BT</td>
<td>96 %</td>
<td>%</td>
<td>%</td>
<td>No antihypertensives</td>
<td>24</td>
<td>58 %</td>
</tr>
<tr>
<td>Cholesterol</td>
<td>57 %</td>
<td>%</td>
<td>%</td>
<td>With antihypertensive</td>
<td>124</td>
<td>37 %</td>
</tr>
<tr>
<td>TG</td>
<td>53 %</td>
<td>%</td>
<td>%</td>
<td>LDL &lt; 2,5</td>
<td>Antal</td>
<td>%</td>
</tr>
<tr>
<td>Mikroalb</td>
<td>55 %</td>
<td>%</td>
<td>%</td>
<td>All tested</td>
<td>36</td>
<td>182</td>
</tr>
<tr>
<td>Retinal exam after 20000101</td>
<td>27 %</td>
<td>%</td>
<td>%</td>
<td>&lt; all tested</td>
<td>36</td>
<td>95</td>
</tr>
<tr>
<td>Waist</td>
<td>7 %</td>
<td>%</td>
<td>%</td>
<td>without lipid lowers</td>
<td>10</td>
<td>61</td>
</tr>
<tr>
<td>Foot exam.</td>
<td>65 %</td>
<td>%</td>
<td>%</td>
<td>without lipid lowers</td>
<td>24</td>
<td>80</td>
</tr>
<tr>
<td>Tobacco</td>
<td>70 %</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>Physical activity</td>
<td>64 %</td>
<td>%</td>
<td>%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### % with complications

| Ischemisk heart. Dis | 16,4 % | % | % |
| Cerbrovaskulær Dis. | 8,2 % | % | % |
| Retinopathi         | 19 %   | | % |
| Loss of vision      | 1 %    | | % |
| Amputation           | 0 %    | | % |

**What happens to our patients?**
Your distribution of cholesterol values

### Patients with cholesterol > 6.0

<table>
<thead>
<tr>
<th></th>
<th>Cholesterol</th>
<th>Lipid lowering drugs</th>
</tr>
</thead>
<tbody>
<tr>
<td>19XXXXXXX-XXX</td>
<td>6.6</td>
<td></td>
</tr>
<tr>
<td>19XXXXXXX-XXX</td>
<td>6.1</td>
<td>x</td>
</tr>
<tr>
<td>19XXXXXXX-XXX</td>
<td>6.7</td>
<td>x</td>
</tr>
<tr>
<td>19XXXXXXX-XXX</td>
<td>6.2</td>
<td>x</td>
</tr>
<tr>
<td>19XXXXXXX-XXX</td>
<td>6.3</td>
<td>x</td>
</tr>
<tr>
<td>19XXXXXXX-XXX</td>
<td>6.8</td>
<td></td>
</tr>
<tr>
<td>19XXXXXXX-XXX</td>
<td>7.2</td>
<td>x</td>
</tr>
<tr>
<td>19XXXXXXX-XXX</td>
<td>6.1</td>
<td></td>
</tr>
<tr>
<td>19XXXXXXX-XXX</td>
<td>6.4</td>
<td>x</td>
</tr>
<tr>
<td>19XXXXXXX-XXX</td>
<td>6.9</td>
<td>x</td>
</tr>
<tr>
<td>19XXXXXXX-XXX</td>
<td>7.8</td>
<td>x</td>
</tr>
<tr>
<td>19XXXXXXX-XXX</td>
<td>6.3</td>
<td></td>
</tr>
<tr>
<td>19XXXXXXX-XXX</td>
<td>6.2</td>
<td></td>
</tr>
</tbody>
</table>
### Which patients need change of care

**What’s to do ?**

<table>
<thead>
<tr>
<th>PERSNR</th>
<th>ALGER</th>
<th>KÖN</th>
<th>HBA1C-ERY</th>
<th>Biguanid</th>
<th>Sulfonylurea</th>
<th>Glitazioner</th>
<th>Insulin</th>
<th>BMI</th>
<th>SYSTOLBT</th>
<th>DIASTBT</th>
<th>Anti HT</th>
<th>KOLESTEROL-P</th>
<th>LDL-KOLESTEROL-P</th>
<th>TG-FP</th>
<th>Lipidaskivskramn</th>
<th>IHD ?</th>
<th>TOBAK</th>
</tr>
</thead>
<tbody>
<tr>
<td>23</td>
<td>Man</td>
<td></td>
<td>5,2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>24,03</td>
<td>120</td>
<td>55</td>
<td>4,2</td>
<td>2,2</td>
<td>0,88</td>
<td></td>
<td></td>
<td>icle-rökare</td>
</tr>
<tr>
<td>31</td>
<td>Kvinna</td>
<td></td>
<td>6,2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>36,3</td>
<td>Ja</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>icle-rökare</td>
</tr>
<tr>
<td>50</td>
<td>Kvinna</td>
<td></td>
<td>4,9</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>28,11</td>
<td>135</td>
<td>85</td>
<td>5,9</td>
<td>4</td>
<td>0,74</td>
<td>Ja</td>
<td></td>
<td>icle-rökare</td>
</tr>
<tr>
<td>51</td>
<td>Man</td>
<td>Ja</td>
<td>11,2</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td></td>
<td>25,68</td>
<td>125</td>
<td>70</td>
<td>5,6</td>
<td>3,7</td>
<td>1,2</td>
<td></td>
<td></td>
<td>Rökkare</td>
</tr>
<tr>
<td>53</td>
<td>Man</td>
<td>Ja</td>
<td>7,9</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td></td>
<td>155</td>
<td>80</td>
<td>Ja</td>
<td>4,6</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Uppgift saknas</td>
</tr>
<tr>
<td>53</td>
<td>Man</td>
<td>Ja</td>
<td>5,7</td>
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<td>115</td>
<td>75</td>
<td></td>
<td></td>
<td>26,47</td>
<td>134</td>
<td>80</td>
<td>5,6</td>
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<td>icle-rökare</td>
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<tr>
<td>54</td>
<td>Kvinna</td>
<td>Ja</td>
<td>6,1</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td></td>
<td>31,24</td>
<td>150</td>
<td>90</td>
<td>5,5</td>
<td>3,4</td>
<td>2,2</td>
<td>Ja</td>
<td></td>
<td>icle-rökare</td>
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<tr>
<td>55</td>
<td>Kvinna</td>
<td>Ja</td>
<td>6,2</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td></td>
<td>31,4</td>
<td>120</td>
<td>70</td>
<td>4,1</td>
<td>2</td>
<td>2,4</td>
<td>Ja</td>
<td>Rökkare</td>
<td></td>
</tr>
<tr>
<td>56</td>
<td>Man</td>
<td>Ja</td>
<td>5,8</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td></td>
<td>35,67</td>
<td>160</td>
<td>90</td>
<td>4,9</td>
<td></td>
<td></td>
<td>Ja</td>
<td>Fd rökare</td>
<td></td>
</tr>
<tr>
<td>57</td>
<td>Kvinna</td>
<td>Ja</td>
<td>7,5</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td></td>
<td>33,21</td>
<td>160</td>
<td>80</td>
<td>4,8</td>
<td>2,4</td>
<td>2,6</td>
<td>Ja</td>
<td>Ja</td>
<td>Uppgift saknas</td>
</tr>
<tr>
<td>57</td>
<td>Kvinna</td>
<td>Ja</td>
<td>6,6</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td></td>
<td>35,14</td>
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<td>85</td>
<td>3,6</td>
<td>1,9</td>
<td>0,59</td>
<td></td>
<td>Rökkare</td>
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<tr>
<td>57</td>
<td>Man</td>
<td>Ja</td>
<td>6,4</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td>Ja</td>
<td></td>
<td>36,07</td>
<td>155</td>
<td>85</td>
<td>5,5</td>
<td></td>
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An idle dream in a country where health care is managed by 21 autonomous counties?