RIKS-STROKE
The Swedish stroke register

- from 1994 onwards
- funded publicly
- voluntary
- all 78 hospitals admitting acute stroke patients
- all ages
- questionnaire follow-ups at 3 months (administered by each hospital) and 12 months (administered centrally)
AIMS OF RIKS-STROKE
The Swedish Stroke Register

- **Primary:** to improve quality of stroke care in all hospitals and after discharge from hospital
  - processes (adherence to evidence-based national guidelines on stroke care)
  - outcome, including patient-reported variables (PROMs)
- **Secondary:** Research
RIKS-STROKE TECHNICALITIES

- Paper protocols → diskettes → Internet-based registrations → pilot studies for direct transfer of data from computerised medical records
- Hospitals have immediate access to own data, using a simple statistical and presentation package
- Annual feedback to individual hospitals (time trends, relative to other hospitals, etc.)
- Open-access website with comparisons between counties and hospitals
COVERAGE

- >=82% in various validation studies

- Less likely to be covered: early deaths, not admitted to a stroke unit, elderly in nursing homes

- Follow-up data at 3 months: 87% of all survivors included in the acute phase
4 YEARS TO INCLUDE ALL HOSPITALS

Per cent of hospitals

5 YEARS TO ACHIEVE NEXT-TO-FULL COVERAGE:
CUMULATED NO. OF EVENTS IN RIKS-STROKE

Approx 25 000 events per year
RIKS-STROKE: MULTIDIMENSIONAL MONITORING OF STROKE CARE QUALITY

Processes

Entire stroke care chain

IoM dimensions of quality and outcome
SIX DIMENSIONS IN QUALITY OF HEALTH CARE

What is done in health care should be …

- based on evidence/knowledge
- safe
- provided in time
- distributed fairly
- patient-orientated
- cost-effective (optimal use of resources)

From: Institute of Medicine, Crossing the Quality Chasm: A New Health System for the Twenty-First Century (Washington: National Academy Press, 2001)
EVIDENCE-BASED?
PROPORTION OF ACUTE STROKE PATIENTS TREATED IN A STROKE UNIT 1994-2006

Stroke unit
General ward
Other

Riks-Stroke
The Swedish Stroke Register
Evidence-based?

PROPORTION TREATED IN A STROKE UNIT BY HOSPITAL 2006

- Stroke unit
- General ward
- Other
THROMBOLYSIS FOR ISCHEMIC STROKE IN SWEDEN 2003-2008

Proportion of patients with ischemic stroke, 18-80 years treated with thrombolysis, %
DISSEMINATION OF STROKE THROMBOLYSIS ACROSS SWEDEN

Proportion of patients treated with thrombolysis

- < 2%
- 2% - 4.9%
- 5% - 9%
- > 9%

Map of Sweden with regions colored according to the proportion of patients treated with thrombolysis in 2008.
Safe?

DISCARDING OF AN UNSAFE THERAPY: HIGH-DOSE HEPARIN FOR ISCHEMIC STROKE

Proportion of patients with ischemic stroke treated with high-dose heparin

- 1999
- 2000
- 2001
- 2002
- 2003
- 2004
- 2005
- 2006
- 2007
- 2008
**In time?**

DELAY FROM ONSET TO ARRIVAL IN HOSPITAL

Hours, median

- 1996
- 1997
- 1998
- 1999
- 2000
- 2001
- 2002
- 2003
- 2004
- 2005
- 2006
- 2007
- 2008

- Median delay from onset to arrival in hospital, hours.
After age adjustment, no differences in …
- admission to a stroke unit
- thrombolysis
- anticoagulation after embolic stroke
- other antithrombotic secondary prevention
- antihypertensives

More men than women treated with statins after stroke
### Patient-oriented?

#### DISSATISFIED WITH ACUTE CARE BY COUNTY

<table>
<thead>
<tr>
<th>County</th>
<th>Proportion dissatisfied, %</th>
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<tbody>
<tr>
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</tbody>
</table>

The Swedish Stroke Register
Cost-effective?
OPTIMAL USE OF RESOURCES

... cost-effectiveness comparisons are in an early development phase
SUMMARY OF KEY QUALITY INDICATORS ON OUTCOME

- Survival
- Primary ADL functions at 3 months
- Institutionalisation at 3 months
- Support from family members and social services
- Smoking cessation
- Low mood
- Self-assessed general health
- Quality of life (EQ-5D)
TO BE DEVELOPED

- Automatic data transfer from electronic medical records
- Improved adjustments for case-mix differences
- Linkage to other registers (e.g., analyses of socioeconomic differences)
- Improved presentations for patients and citizens
- Better use of Riks-Stroke data in implementation and decision-making