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 <u>all</u> 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

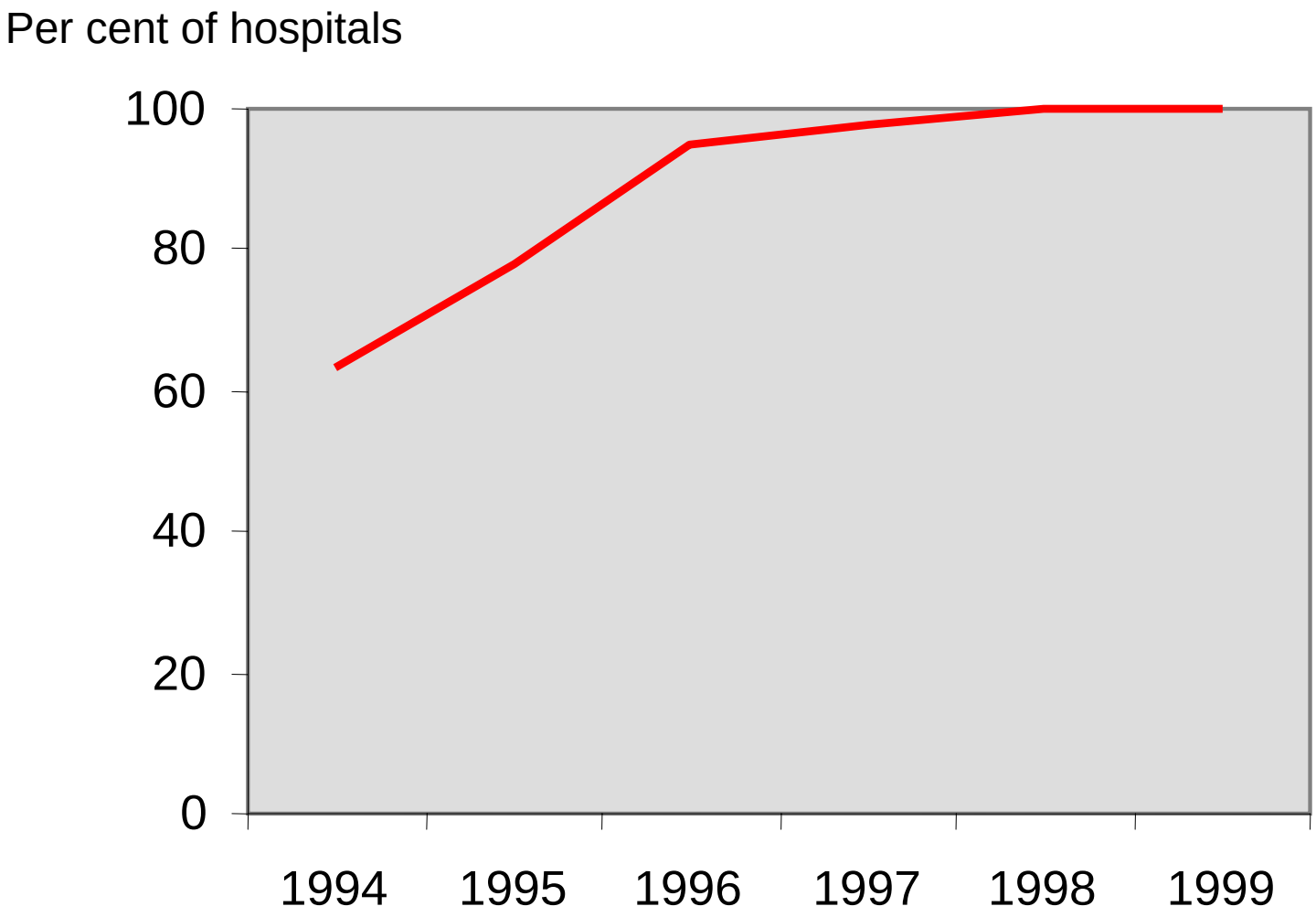
- Paper protocols ➡ diskettes ➡ Internet-based registrations ➡ pilot studies for direct transfer of data from computerised medical records
- Hospitals have immediate access to own data, using a simple statistical and presentation package
- Annual feedback to individual hospitals (time trends, relative 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

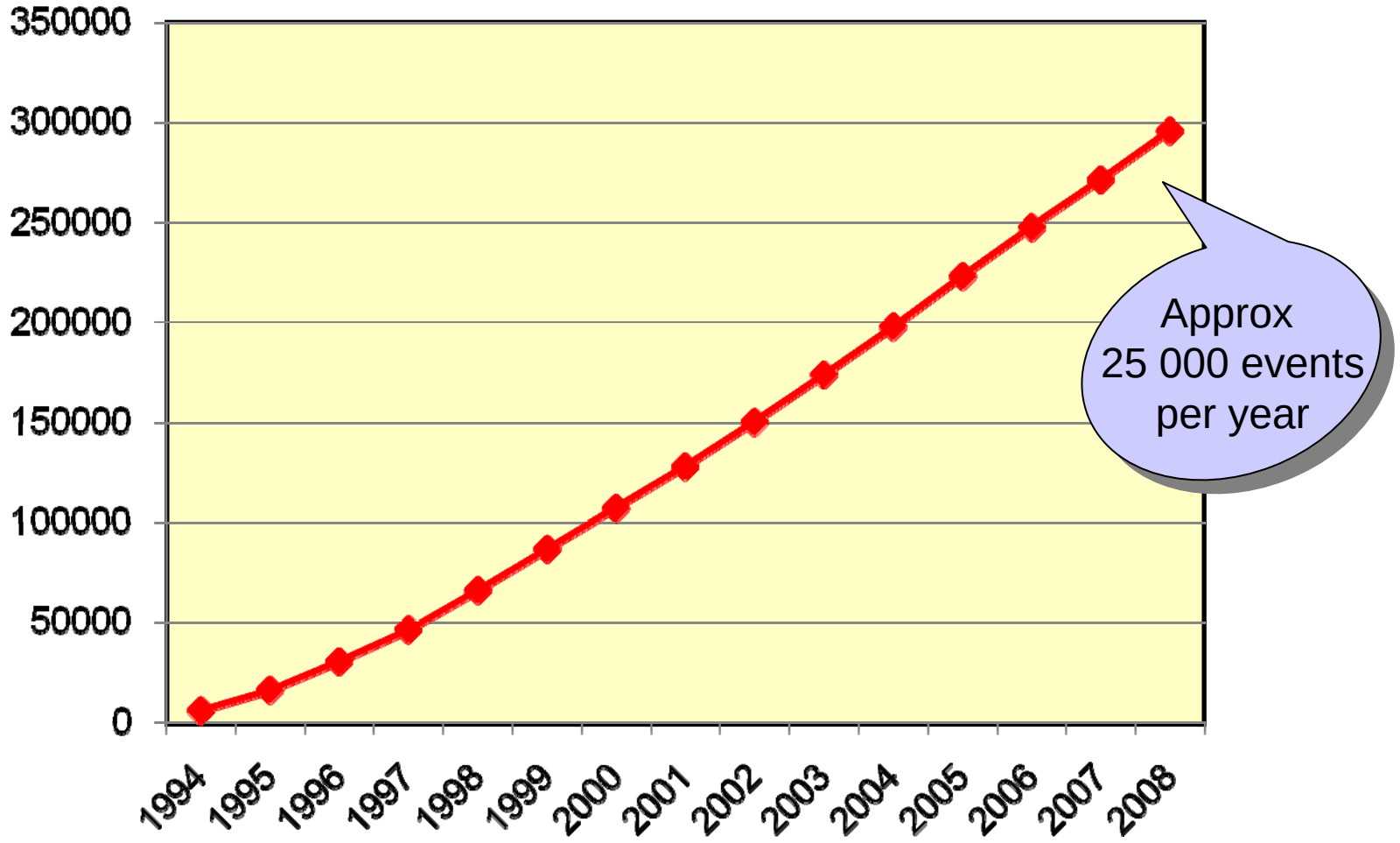
4 YEARS TO INCLUDE ALL HOSPITALS

Riks-Stroke
The Swedish
Stroke Register



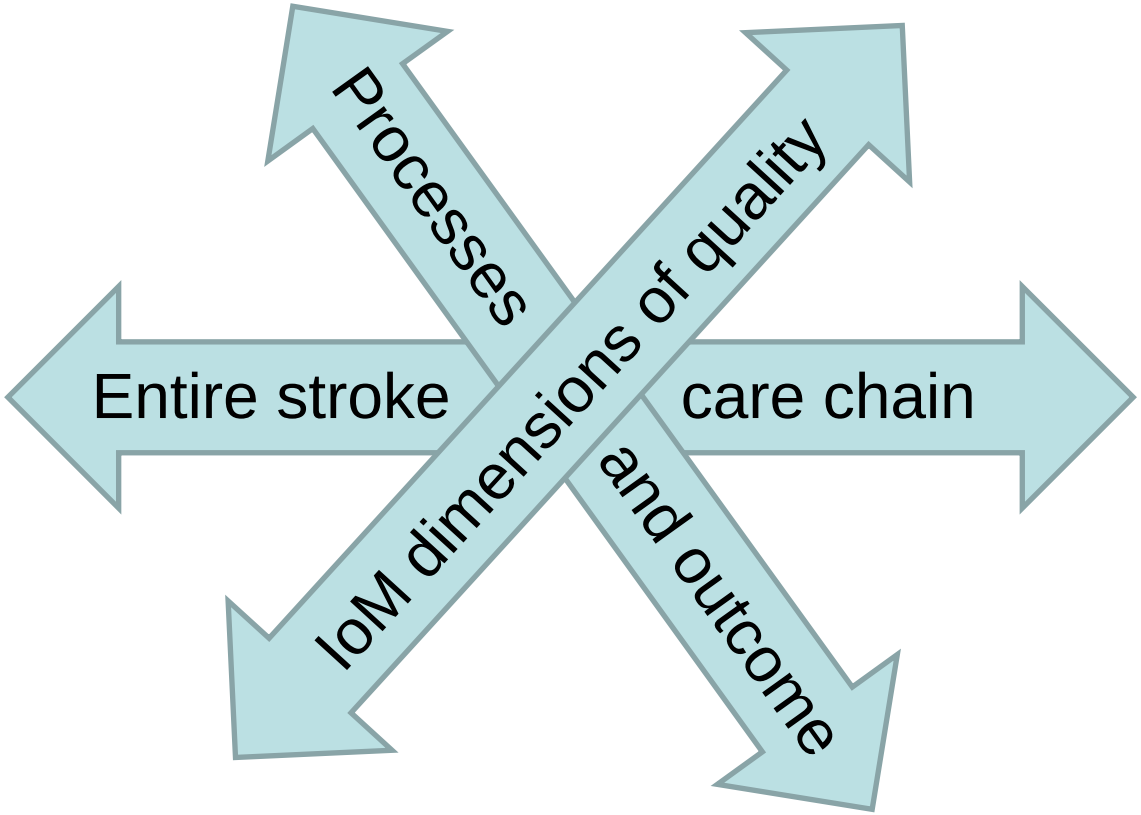
5 YEARS TO ACHIEVE NEXT-TO-FULL COVERAGE:
CUMULATED NO. OF EVENTS IN RIKS-STROKE

Riks-Stroke
The Swedish
Stroke Register



RIKS-STROKE: MULTIDIMENSIONAL MONITORING OF STROKE CARE QUALITY

Riks-Stroke
The Swedish
Stroke Register



SIX DIMENSIONS IN QUALITY OF HEALTH CARE

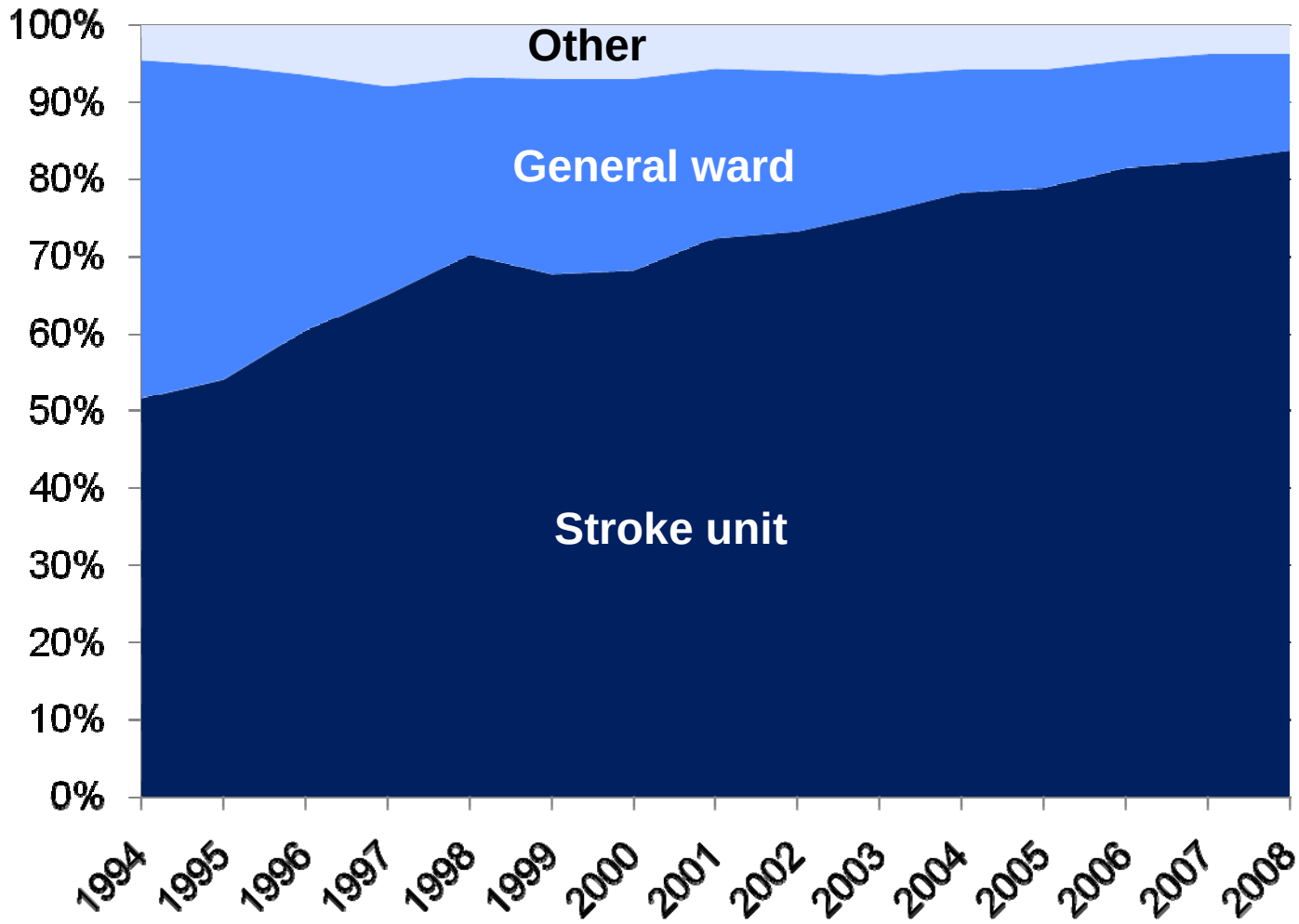
What is done in health care should be …

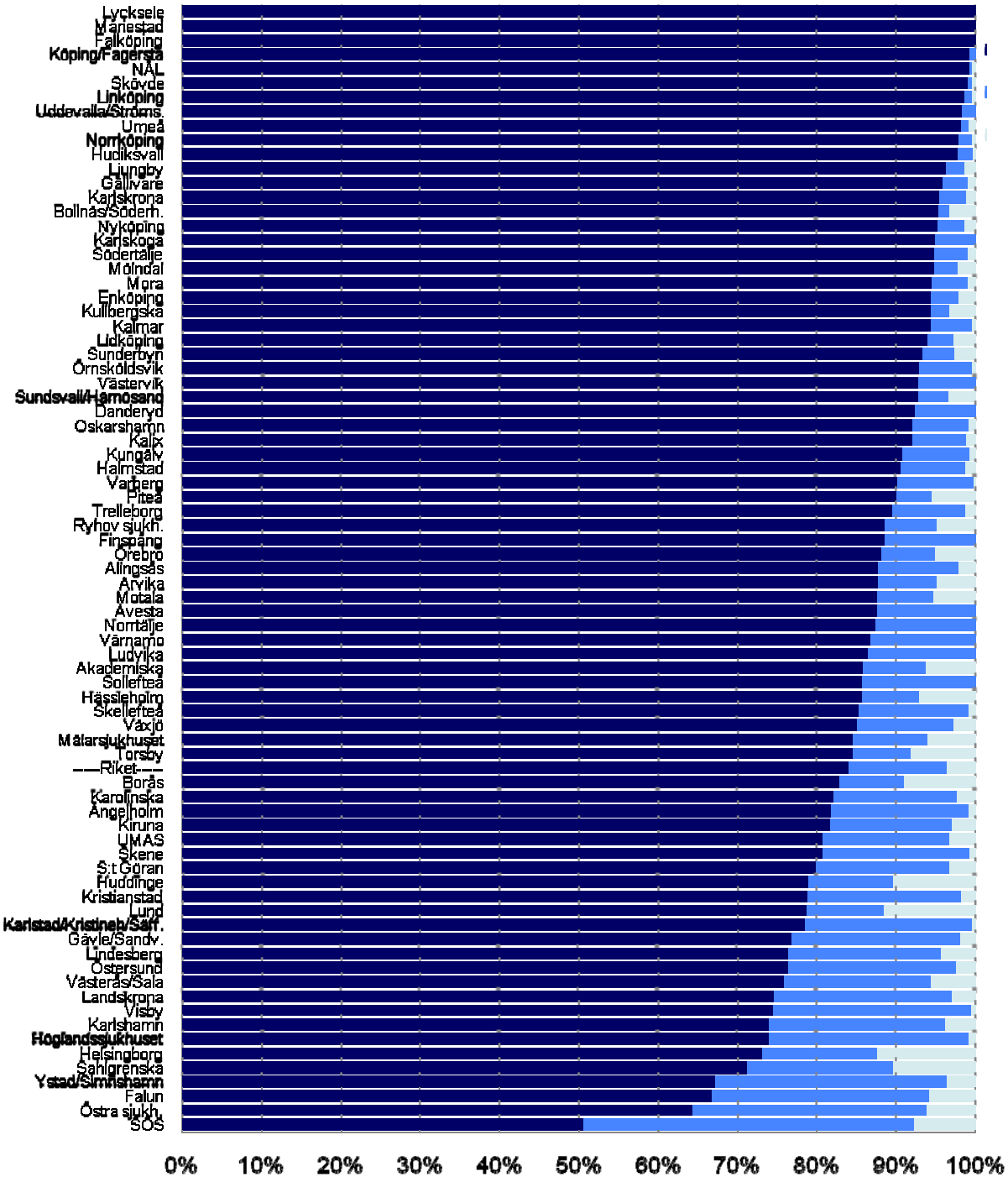
- based on evidence/knowledge
- safe
- provided in time
- distributed fairly
- patient-orientated
- cost-effective (optimal use of resources)

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

Riks-Stroke
The Swedish
Stroke Register





Riks-Stroke
The Swedish
Stroke Register

Evidence-based?

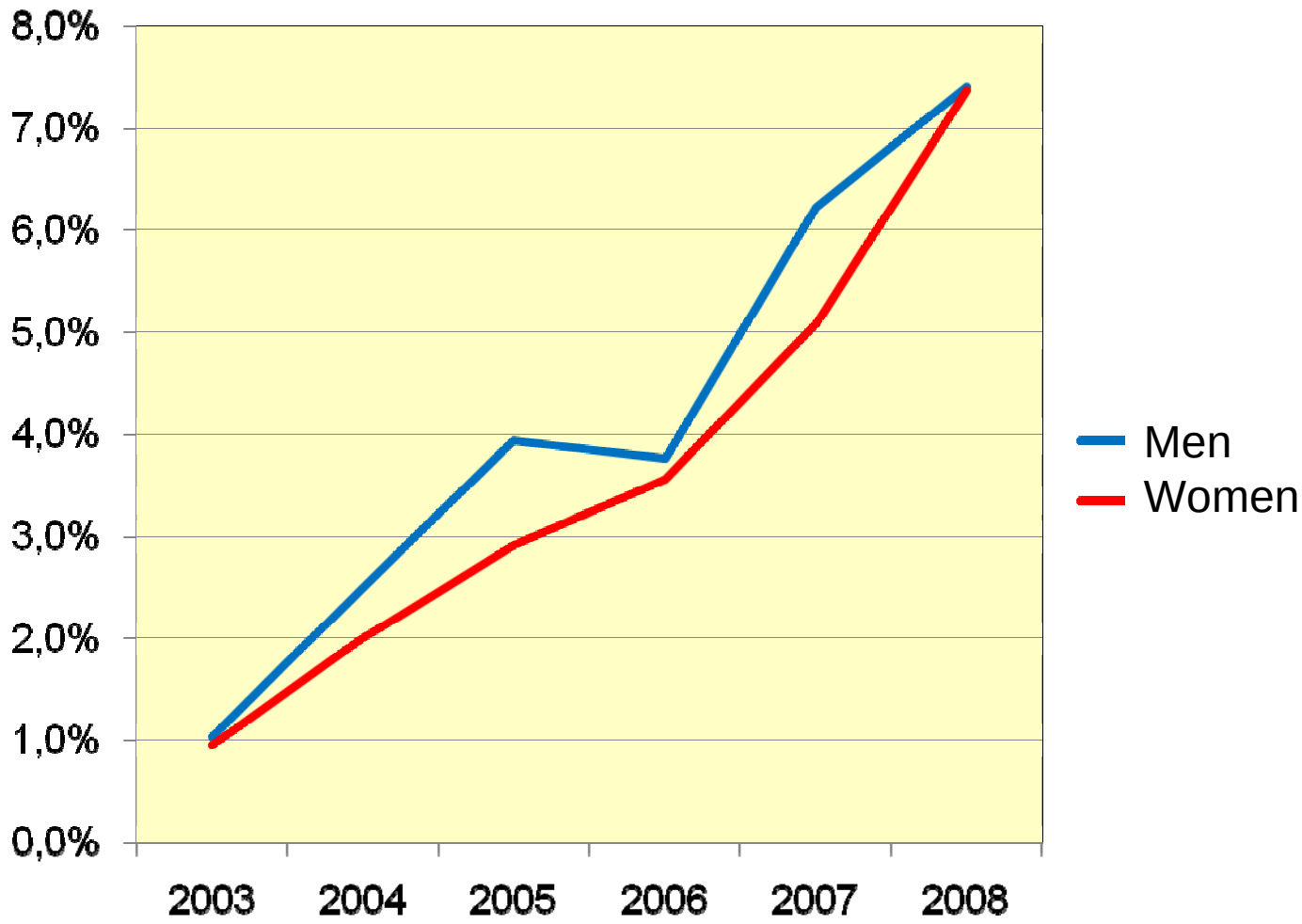
PROPORTION TREATED IN A STROKE UNIT BY HOSPITAL 2006

- Stroke unit
- General ward
- Other

THROMBOLYSIS FOR ISCHEMIC STROKE IN SWEDEN 2003-2008

Riks-Stroke
The Swedish
Stroke Register

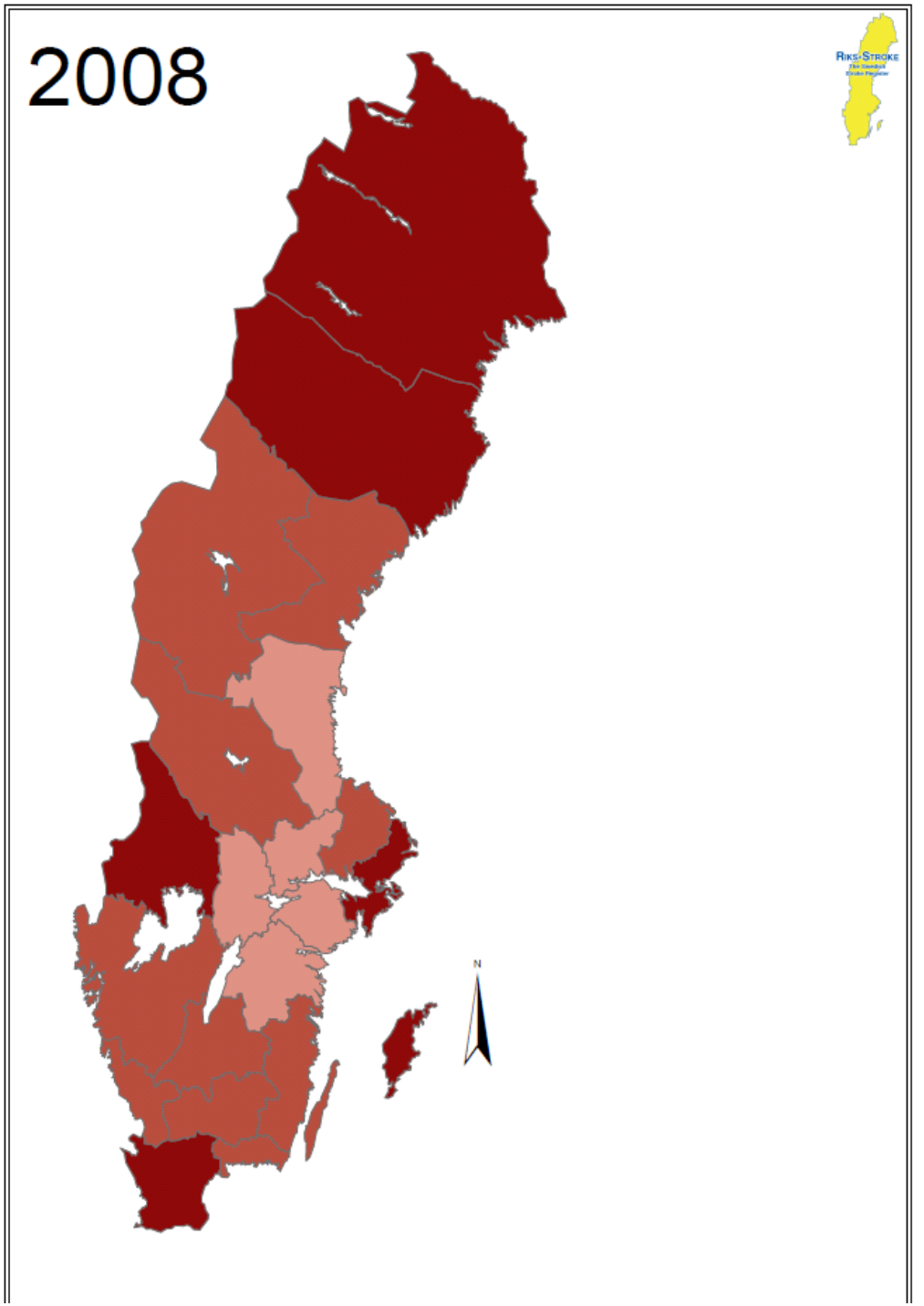
Proportion of patients with ischemic stroke, 18-80 years treated with thrombolysis, %



DISSEMINATION OF STROKE THROMBOLYSIS ACROSS SWEDEN

Proportion of patients treated with thrombolysis

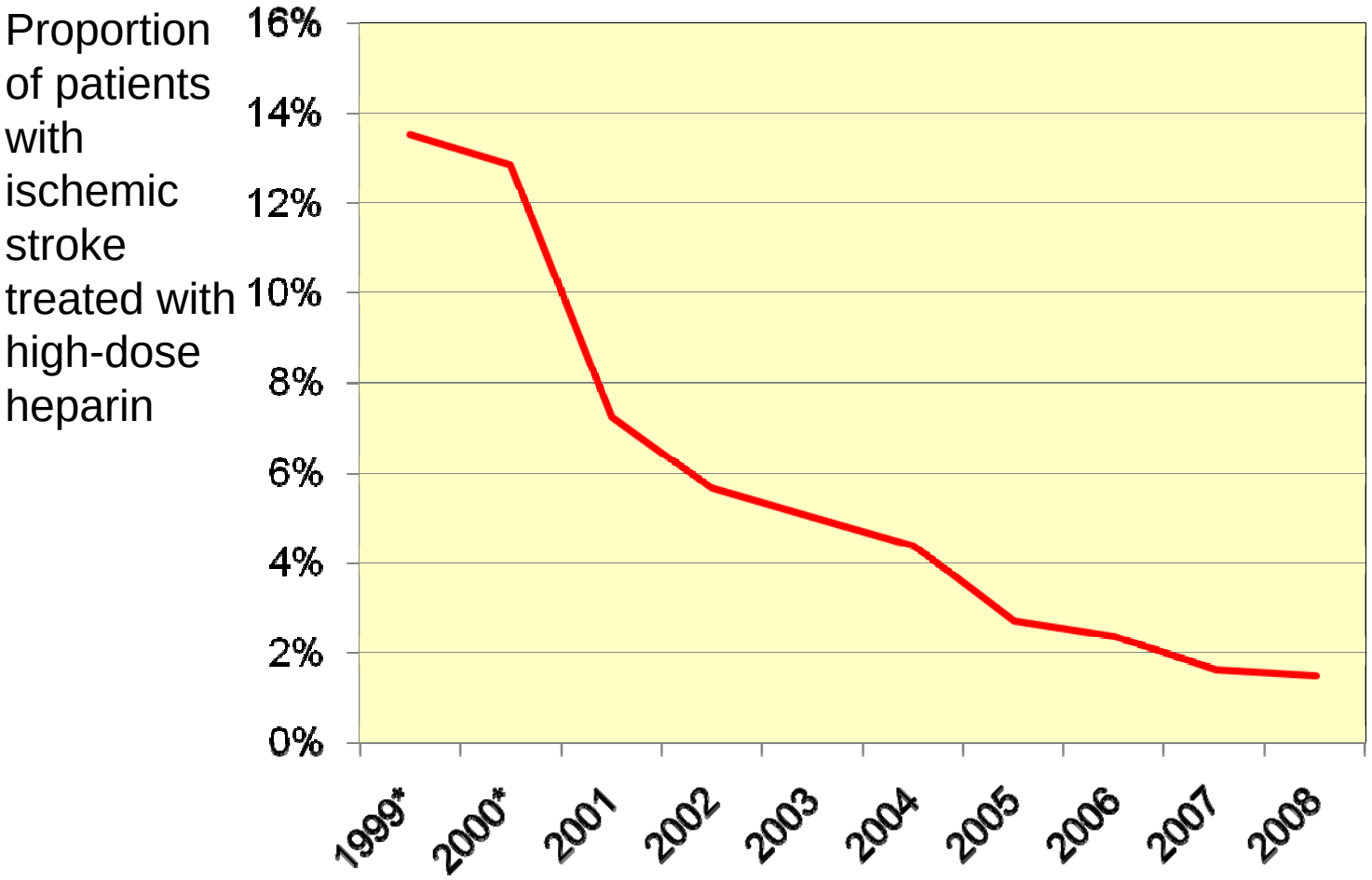
- < 2%
- 2% - 4,9%
- 5% - 9%
- >9%



Safe?

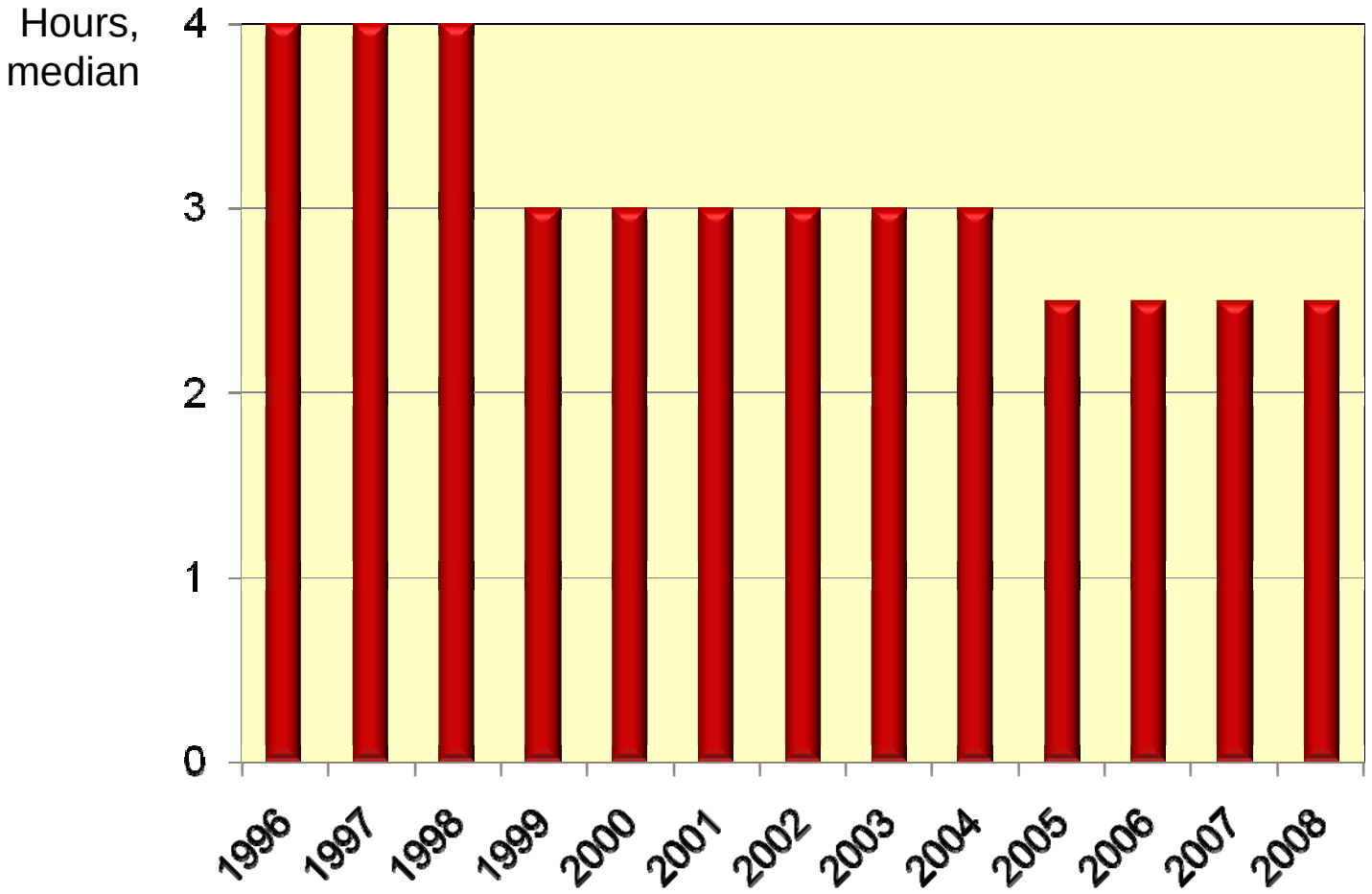
DISCARDING OF AN UNSAFE THERAPY: HIGH-DOSE HEPARIN FOR ISCHEMIC STROKE

Riks-Stroke
The Swedish
Stroke Register



In time?
DELAY FROM ONSET TO ARRIVAL IN HOSPITAL

Riks-Stroke
The Swedish
Stroke Register



Distributed fairly?
SEX DIFFERENCES

Riks-Stroke
The Swedish
Stroke Register

After age adjustment, no differences in …

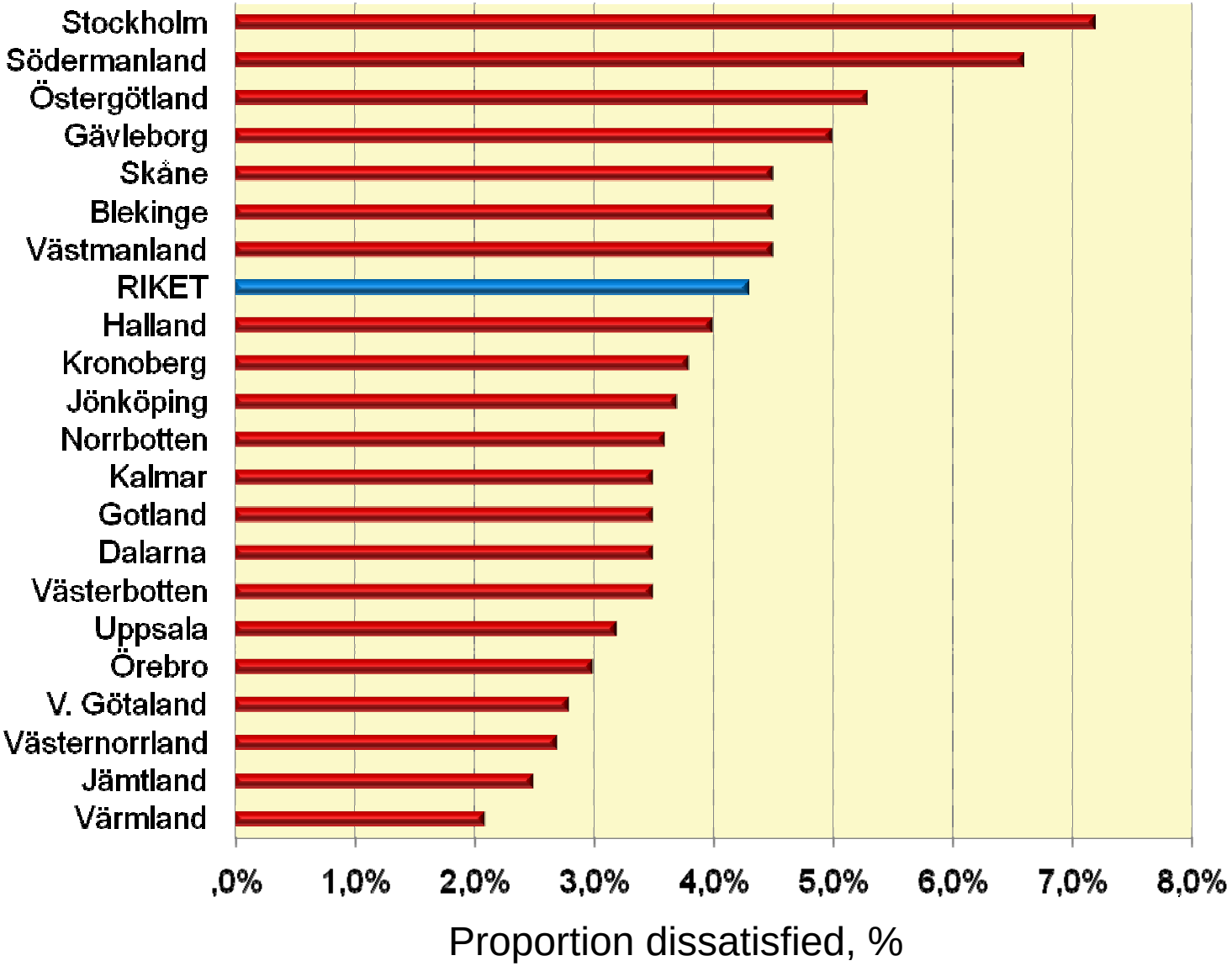
- admission to a stroke unit
- thrombolysis
- anticoagulation after embolic stroke
- other antithrombotic secondary prevention
- antihypertensives

More men than women treated with statins after stroke

Patient-oriented?

DISSATISFIED WITH ACUTE CARE BY COUNTY

Riks-Stroke
The Swedish
Stroke Register



Cost-effective?
OPTIMAL USE OF RESOURCES

Riks-Stroke
The Swedish
Stroke Register

… cost-effectiveness comparisons are in an early development phase

SUMMARY OF KEY QUALITY INDICATORS ON OUTCOME

Riks-Stroke
The Swedish
Stroke Register

- 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