PERFECT Stroke – the Finnish national stroke registry
Atte Meretoja MD, PhD, MSc(Stroke)
Melbourne Brain Centre@RMH&Austin
University of Melbourne
Finland – a few facts

• Pop. 5.4 Million (Australia: 23 M)
• Land mass 0.34 MKm$^2$ (7.3 MKm$^2$)
• GDP $303$ Billion ($1 284$ B)
• GDP/capita $46 000$ ($46 000$)

• Swedish rule 1150 – 1809
• Russian Grand Duchy 1809 – 1917
• Independent democracy for 85 years, since 1917
• Civil war in 1918 between communists and antisocialists (the latter won)
• Defended itself against the Russian red army in 1939-1944
• Olympic games in 1952
• Strong welfare state built in the 1970’s (childcare, primary and university education, health services & social benefits fully tax funded)
Health services in Finland

• Public hospitals form backbone of services
• Hospitals are run by health districts
  – Health districts (n=21) based on geographic areas
  – Owned and managed by communes
  – Funded with tax money
  – Perform acute stroke care and most of rehabilitation
• Private sector is small, has no emergency services and mainly exists due to public sector waiting lists
Cerebrovascular disease
Six subgroups

- Subarachnoid haemorrhage
- Intracerebral haemorrhage
- Ischaemic stroke
- Other cerebrovascular disease
- Transient ischaemic attack
- Sequalae of stroke
Stroke
= SAH + ICH + Ischaemic stroke

Subarachnoid haemorrhage
Intracerebral haemorrhage
Ischaemic stroke

Other cerebrovascular disease
Transient ischaemic attack
Sequalae of stroke
70% of patients living at home one year from stroke. 10% are institutionalized.
Stroke epidemiology - context
Current 5 most common causes of death in Finland, last 40 years

- Coronary heart disease
- Cancer
- Dementia
- Cerebrovascular disease
- Trauma
Helsingborg Declaration 2006 on European Stroke Strategies
T. Kjellström  B. Norrving  A. Shatchkute

• Organisation of stroke services
  – All patients in Europe with stroke will have access to a continuum of care from organized stroke units in the acute phase to appropriate rehabilitation and secondary prevention measures.

• Management of acute stroke
  – More than 85% of stroke patients survive the first month after stroke.
  – All patients with acute stroke who are potentially eligible for acute specific treatment are transferred to hospitals where there is the technical capacity and expertise to administer such treatment.

• Prevention
  – Stroke mortality is reduced by at least 20% from the level of 2005.
  – All countries aim to reduce the major risk factors for stroke in their populations, most importantly hypertension and smoking.
  – All patients who have suffered a TIA or stroke receive appropriate secondary preventive measures.

• Rehabilitation of stroke
  – 3 months after the onset of stroke, over 70% of the surviving patients are independent in their ADL.

• Evaluation of Stroke Outcome and Quality Assessment
  – All countries aim to establish a system for the routine collection of data needed to evaluate the quality of stroke management, including patient safety issues.
<table>
<thead>
<tr>
<th>Country</th>
<th>Registry</th>
<th>Hospitals and institutions</th>
<th>Annual patients registered</th>
<th>Proportion of population-based patients included</th>
<th>3-month follow-up rate</th>
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<tr>
<td>Argentina (2004)</td>
<td>ReNACer</td>
<td>74</td>
<td>1300</td>
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<td>Australia</td>
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<td>19</td>
<td>2500</td>
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<td>90%</td>
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<td>Finland (1999)</td>
<td>PERFECT Stroke</td>
<td>338</td>
<td>15 000</td>
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<td>100%</td>
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<td>Scottish Stroke Care Audit</td>
<td>31</td>
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<td>4100</td>
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<td>Sweden (1994)</td>
<td>RIKS Stroke</td>
<td>79</td>
<td>24 000</td>
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<td>National Sentinel Stroke Audit</td>
<td>224</td>
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<td>USA (2001)</td>
<td>Paul Coverdell National Acute Stroke Registry</td>
<td>195</td>
<td>15 000</td>
<td>15%</td>
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</table>
The aim of the PERFECT Stroke database has been to produce comprehensive data on the Finnish Performance, Effectiveness, and Costs of Treatment episodes in Stroke.

For purposes of Benchmarking, Quality improvement and Cost-effectiveness analyses.
PERFECT Stroke - National register linkages

National Hospital Discharge Register
- Hospital and nursing home stays
- All public and private stays since 1987
- Up to four diagnoses for each stay

Causes of Death Register
- Date of death
- Cause of death

Social Insurance Institution Registries
- Use of prescription medicine
- Long-standing diagnoses
- Sick leaves for >2 weeks
- General pensions
- Use of private medical services

Personal ID number (i.e. 210775-135X)

Center for Pensions Register
- Disability Pensions
Prestroke and Follow-up data retrieved easily

PERFECT Stroke Registry

Personal Identification Number

National database of Medication Purchases

National database of Hospital Discharges

National database of Causes of Death

Coronary heart Initial stroke Rehabilitation Recurrence

TIME
## Reconstructing care episodes

<table>
<thead>
<tr>
<th></th>
<th>I63 Ischaemic stroke</th>
<th>I69 Sequalae of stroke</th>
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<td>A</td>
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<tr>
<td>B</td>
<td>I63 Ischaemic stroke</td>
<td>I69 Sequalae of stroke</td>
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<tr>
<td>C</td>
<td>I61 ICH</td>
<td>I69 Sequalae of stroke</td>
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<tr>
<td></td>
<td>I64 Undefined stroke</td>
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<td>D</td>
<td>I69 Sequalae of stroke</td>
<td>I63 Ischaemic stroke</td>
</tr>
<tr>
<td>E</td>
<td>I25 Myocardial infarction</td>
<td>I63 Ischaemic stroke</td>
</tr>
<tr>
<td>F</td>
<td>I63 Ischaemic stroke</td>
<td>I25 Myocardial infarction</td>
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</tbody>
</table>
Patient recruitment 1999-2008

All cerebrovascular events
n = 227,591

PERFECT Stroke
n = 152,596

Non-incident events (inspected until 1987)
n = 74,995

Ischemic Stroke
n = 82,950
79% of stroke

ICH
n = 14,267
14%

SAH
n = 7,682
7%

Other CVD
n = 14,886

TIA
n = 32,811
Data can be used for classic epidemiology

Incidence of ischaemic stroke, % of population, 1999-2008

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Male 1999</th>
<th>Female 1999</th>
<th>Total 1999</th>
<th>Male 2008</th>
<th>Female 2008</th>
<th>Total 2008</th>
<th>Change</th>
<th>95% CI</th>
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<tr>
<td>0-24</td>
<td>.001</td>
<td>.001</td>
<td>.001</td>
<td>.002</td>
<td>.003</td>
<td>.002</td>
<td>69 %</td>
<td>-5 – 199%</td>
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<tr>
<td>25-34</td>
<td>.005</td>
<td>.003</td>
<td>.004</td>
<td>.008</td>
<td>.007</td>
<td>.008</td>
<td>85 %</td>
<td>16 – 196%</td>
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<tr>
<td>35-44</td>
<td>.02</td>
<td>.01</td>
<td>.02</td>
<td>.03</td>
<td>.02</td>
<td>.02</td>
<td>39 %</td>
<td>9 – 77%</td>
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<tr>
<td>45-54</td>
<td>.09</td>
<td>.04</td>
<td>.07</td>
<td>.08</td>
<td>.04</td>
<td>.06</td>
<td>-7 %</td>
<td>-18 – 6%</td>
</tr>
<tr>
<td>55-64</td>
<td>.3</td>
<td>.1</td>
<td>.2</td>
<td>.2</td>
<td>.1</td>
<td>.2</td>
<td>-13 %</td>
<td>-20 – 5%</td>
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<tr>
<td>65-74</td>
<td>.7</td>
<td>.4</td>
<td>.5</td>
<td>.5</td>
<td>.3</td>
<td>.4</td>
<td>-23 %</td>
<td>-27 – 18%</td>
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<tr>
<td>75-84</td>
<td>1.3</td>
<td>1.1</td>
<td>1.2</td>
<td>1.1</td>
<td>.8</td>
<td>.9</td>
<td>-20 %</td>
<td>-24 – 15%</td>
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<tr>
<td>85-94</td>
<td>1.8</td>
<td>1.8</td>
<td>1.8</td>
<td>1.4</td>
<td>1.5</td>
<td>1.5</td>
<td>-19 %</td>
<td>-25 – 13%</td>
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<tr>
<td>95+</td>
<td>2.9</td>
<td>1.8</td>
<td>2.0</td>
<td>1.5</td>
<td>2.0</td>
<td>1.9</td>
<td>-3 %</td>
<td>-28 – 30%</td>
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<tr>
<td>Total</td>
<td>.16</td>
<td>.17</td>
<td>.16</td>
<td>.16</td>
<td>.16</td>
<td>.16</td>
<td>-3 %</td>
<td>-6 – 0%</td>
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</table>

Population <45 has decreased by 4%, but incident ischaemic strokes in them increased from 166 to 233 (+39%).

Population >65 has increased by 16%, but incident ischaemic strokes in them dropped from 6600 to 6400 (-4%)
## Baseline comorbidities

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<tr>
<td><strong>Ischemic stroke</strong></td>
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<tr>
<td>Hypertension</td>
<td>63 %</td>
<td>68 %</td>
<td>52 %</td>
<td>55 %</td>
<td>30 %</td>
<td>40 %</td>
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<tr>
<td>Coronary heart disease</td>
<td>29 %</td>
<td>26 %</td>
<td>18 %</td>
<td>18 %</td>
<td>8 %</td>
<td>8 %</td>
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<tr>
<td>Atrial fibrillation</td>
<td>15 %</td>
<td>16 %</td>
<td>10 %</td>
<td>11 %</td>
<td>3 %</td>
<td>4 %</td>
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<tr>
<td>Cardiac failure</td>
<td>18 %</td>
<td>11 %</td>
<td>12 %</td>
<td>7 %</td>
<td>3 %</td>
<td>3 %</td>
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<tr>
<td>Periferal artery disease</td>
<td>4 %</td>
<td>4 %</td>
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<tr>
<td>Diabetes</td>
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<td>19 %</td>
<td>11 %</td>
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<td>4 %</td>
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<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>12 %</td>
<td>15 %</td>
<td>11 %</td>
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<tr>
<td>Cancer</td>
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<td>13 %</td>
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<td>Depression</td>
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<td>Alcoholism</td>
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<tr>
<td>Other mental disorder</td>
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<tr>
<td>Parkinsons's disease</td>
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<td>Alcoholism</td>
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</tbody>
</table>
Ischaemic stroke
1-year survival
Case-fatality decreased from 26.2% to 21.6%
Also ICH survival improved
1-year case-fatality decreased from 43.0% to 40.9%
SAH survival more random
1-year case-fatality decreased from 28.2% to 26.3%
Figure 4. Long-term survival after stroke in Finland, 1999 (dotted line) and 2007 (solid line). Cox regression adjusting for age, sex, co-morbidities, medications and living status prior to stroke.
Ischaemic stroke recurrence ↓
1-year rate of recurrence from 14.6% to 11.1%
Some explanations for better survival and fewer recurrences

Proportion of patients treated at specialized stroke centers

Proportion of ischemic stroke patients with guideline secondary preventive medication (effective antithrombotic, statin, and antihypertensive)
Secondary prevention use is of special interest

- Any blood pressure medication
- Statin
- Dipyridamole
- Clopidogrel
- Warfarin
- Either warfarin, dipyridamole, or clopidogrel

1999 - 2008
Costing methods

• In-patient costs evaluated through DRG groups and lengths of stay

• Out-patient care costed through specialty and acuteness

• Prices recalculated annually

• Prescription medication costed with true retail-price
Inpatient care drives cost
Patients of year 2007, mean 1-year cost per patient

Ischemic stroke (IS)
- Prescription medications: 874
- Specialist outpatient care: 1363
- New hospitalizations: 4703
- Nursing home care: 1313
- Post-acute inpatient care: 6366
- First treating hospital: 5501

Intracerebral hemorrhage (ICH)
- Prescription medications: 1168
- Specialist outpatient care: 3199
- New hospitalizations: 1226
- Nursing home care: 11772
- Post-acute inpatient care: 6718
- First treating hospital: 6718

Subarachnoidal hemorrhage (SAH)
- Prescription medications: 418
- Specialist outpatient care: 1566
- New hospitalizations: 3632
- Nursing home care: 449
- Post-acute inpatient care: 9422
- First treating hospital: 13472
Hemorrhagic stroke becoming increasingly expensive

Data valued at 2009 prices with hospital cost index

![Graph showing costs of SAH, ICH, and infarct from 1999 to 2007.][1]

[1]: https://example.com/graph.png
Survival, institutional care & recurrences drive the costs
Ischemic stroke patients of year 2007

- Patients who died within 1 year (n=1783)
- Patients who died within 3 months (n=1263)
- Patients who died within 28 days (n=848)
- Patients on warfarin (n=1091)
- Patients with atrial fibrillation (n=1306)
- Patient with coronary heart disease (n=2280)
- Thrombolytic therapy (n=279)
- Institutional care for 1 year (n=489)
- Discharge home from initial hospital (n=4011)
- Recurrence within one year (n=953)
- All ischemic stroke patients (n=8204)

Thousands

Thousands

Thousands

Thousands

Thousands

Thousands

Thousands
Long-term costs after stroke
5-year annual costs for patients of year 2003

<table>
<thead>
<tr>
<th>Year</th>
<th>Ischemic stroke</th>
<th>ICH</th>
<th>SAH</th>
<th>Total for average stroke patient alive at start of each year</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st year</td>
<td>20 000 €</td>
<td>25 000 €</td>
<td>30 000 €</td>
<td>10 000 €</td>
</tr>
<tr>
<td>2nd year</td>
<td>15 000 €</td>
<td>20 000 €</td>
<td>25 000 €</td>
<td>7 500 €</td>
</tr>
<tr>
<td>3rd year</td>
<td>10 000 €</td>
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Previous year
1st year
2nd year
3rd year
4th year
5th year
Hospital benchmarking

- Hospitals (healthcare providers) and health districts (geographic areas) compared in annual reports
  - Demographics
  - Days spent at different levels of care
  - Procedures and medications
  - Costs
  - Outcome: case-fatality, recurrence, and need of institutional care

- Data presented as crude and adjusted (age, sex, comorb)

- All of the data published on-line for clinicians, politicians, and citizens to scrutinize
Carotid endarterectomy

Proportion of ischaemic stroke patients operated on in 2007, by hospital
Hospital comparison
1-year case fatality/recurrence
Ischemic stroke benchmarking data for 5 university hospitals, adjusted for age, sex, comorbidities, and prior medications.
Resource use
Lenght-of-stay for total inpatient chain of recovery, adjusted
Cost can be compared
Ischemic stroke patients, cost of first hospital care

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Hospitals can be compared
Ischemic stroke patients, cost of first year

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</table>

- Prescription medications
- Specialist outpatient care
- New hospitalizations
- Nursing home care
- Post-acute inpatient care
- First treating hospital

Ischemic stroke (IS)
Intracerebral hemorrhage (ICH)
Subarachnoidal hemorrhage (SAH)
Hospitals can be compared
Ischemic stroke patients, cost of first year
Adjusted for age, sex, comorbidities, prior medications
Helsingborg Goals are for 2015
How is Finland doing now?

Organisation of stroke services
- All patients in Europe with stroke will have access to a continuum of care from organized stroke units in the acute phase to appropriate rehabilitation and secondary prevention measures.

Management of acute stroke
- More than 85% of stroke patients survive the first month after stroke.
- All patients with acute stroke who are potentially eligible for acute specific treatment are transferred to hospitals where there is the technical capacity and expertise to administer such treatment.

Prevention
- Stroke mortality is reduced by at least 20% from the level of 2005.
- All countries aim to reduce the major risk factors for stroke in their populations, most importantly hypertension and smoking.
- All patients who have suffered a TIA or stroke receive appropriate secondary preventive measures.

Rehabilitation of stroke
- 3 months after the onset of stroke, over 70% of the surviving patients are independent in their ADL.

Evaluation of Stroke Outcome and Quality Assessment
- All countries aim to establish a system for the routine collection of data needed to evaluate the quality of stroke management, including patient safety issues.
PERFECT Stroke

Strengths

– Full nationwide coverage
– No selection bias
– 100 % follow-up data for death, recurrence, institutional care, costs, and medication use for years
– Cheap to maintain (annual total cost around 50 000 €)

Weaknesses

– Lack of detailed clinical data on baseline stroke severity
– Lack of detailed in-hospital data
– Functional outcome unknown, independence?
– Patients treated outside hospitals (3% of all stroke) not included
EUROHOPE
European Healthcare Outcomes Performance and Efficiency

• EU-funded project in 6 European countries
  • Finland
  • Hungary
  • Italy
  • Netherlands
  • Scotland
  • Sweden

• Testing transferability of PERFECT methodology
CONCLUSIONS

1. Existing data sources can be linked if there are
   - Comprehensive reliable registries available
   - A common identifier
   - No legal obstacles

2. This approach depicts the whole chain of recovery
   - Long term follow-up in 100 % of patients
   - Health care use and medications before and after stroke
   - Extensive data on in-hospital processes lacking

3. When combined with conventional stroke registries, we approach a “perfect” dataset, if selection bias can be minimized
Thank you – the Finnish PERFECT stroke team

Helsinki University Central Hospital
National Institute for Health and Wellfare (THL)
Turku University Hospital
Jyväskylä Central Hospital
Kuopio University Hospital
Oulu University Hospital
Tampere University Hospital


