STEPS Stroke
Standardized Tools for Stroke Surveillance

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for the STEPS Stroke International Steering Committee
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Status of Stroke Data

- Fragmented surveys; once-off, *ad hoc*, outdated
- Can’t track population changes over time
- Comparison often not possible
- Duplication of efforts and inefficient use of resources
The 3 Steps in STEPS Stroke

- Incidence & CF
- Mortality
- Hospital data

STEPS Stroke Manual:
www.who.int/stroke
Step 1
(Hospital based)

Hospital

- First-time or recurrent event
- Socio-economic status
- Type of event
- Place of treatment
- Medication
- Survival (10 & 28 days)
- MRS (pre- and post-stroke)
Step 2
(Fatal Events in the Community)

- Date of stroke
- First-time or recurrent event
- Type of stroke
- Date of death
- Vital status at days 10 and 28
- ICD-10 classification
Step 3
(Non-fatal Events in the Community)

- Date of stroke
- First-time or recurrent event
- Survival at 28 days (follow-up)
STEPS Stroke: What it offers

- Study Protocol and Instrument
- Data Entry Tool
- International Comparisons
STEPS Stroke Manual (Summary)

- Purpose and background
- Definitions
- Roles and responsibilities
- Application form
- The STEPS Stroke Instrument
Guide to Completing the Instrument: Events Admitted to Hospital (Step 1), Continued

Living situation S1.3 (Core)

<table>
<thead>
<tr>
<th>Option</th>
<th>Refers to patients living</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independent at home</td>
<td>Without depending on any assistance from relatives or professionals</td>
</tr>
<tr>
<td>Dependent at home</td>
<td>Depending on assistance from relatives or professionals</td>
</tr>
<tr>
<td>Community facility</td>
<td>In nursing or residential homes, serviced flat or other long term care facility</td>
</tr>
</tbody>
</table>

Modified Rankin scale S1.4 (Expanded)

If possible, the Modified Rankin scale prior to acute stroke event should be assessed retrospectively based on the information provided by patient and/or close relatives. The number corresponding to the patient’s functional level is to be entered. The scale is divided into 6 levels (from level 0 to level 5) as described in the table below.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No symptoms, No symptoms at all</td>
</tr>
<tr>
<td>1</td>
<td>No significant disability, No significant disability despite symptoms, i.e. can do all usual activities</td>
</tr>
<tr>
<td>2</td>
<td>Slight disability, Unable to do all previous activities, but able to look after own affairs without assistance</td>
</tr>
<tr>
<td>3</td>
<td>Moderate disability, Able to walk without assistance, Requiring some help but able to walk without assistance</td>
</tr>
<tr>
<td>4</td>
<td>Moderate disability, Unable to walk without assistance, Unable to walk without assistance, and unable to attend to own bodily needs without assistance</td>
</tr>
<tr>
<td>5</td>
<td>Severe disability, Bedridden, incontinent, and requiring constant nursing care and attention</td>
</tr>
</tbody>
</table>

Note: The modified Rankin Scale measures independence rather than performance of specific tasks. Mental as well as physical adaptations to the neurological deficits are incorporated, and the score gives an impression of whether the patients can look after themselves in daily life.

Continued on next page
### WHO STEPS STROKE INSTRUMENT

**<INSERT COUNTRY/SITE NAME>**

#### All Stroke Events

For further guidance on All Stroke Events, see Section 5, page 5-15

### Patient Identification and Patient Characteristics

1. **Stroke Surveillance Site Code**
   - Insert 8 digits of automatically generated code from DEIT

2. **Interviewer Code**
   - Insert code provided by the ICU

3. **Date of completion of the instrument**
   - d d m m y y y y

### Patient individual records

4. **Patient’s family name**
   - Use CAPITALS, include all names

5. **Patient’s first name**
   - Use CAPITALS, include all names

6. **Contact phone number**
   - Insert area codes (optional)

7. **Contact address**
   - For follow-up questionnaires (optional)

8. **Unique identification number where available**
   - Number, ID etc. (optional)

### Contact person of patient

9. **Contact person’s family name**

10. **Contact person’s first name**

11. **Contact person’s phone number**

12. **Contact person’s address**

13. **Relationship of contact person to the patient**

### Demographic characteristics

14. **Date of birth**
   - If date of birth is unknown, enter age

15. **Sex**
   - [select one]
   - Male (1)
   - Female (2)

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2006-05-09 STEPS Stroke Instrument (V2.1)
The STEPS Stroke Data Entry Tool

- Developed according to the STEPS Stroke Instrument
- Data storage
- Includes basic features for data presentation & analyses
- Includes an export function for further analyses
- Possibility for adaption to meet local needs
The STEPS Stroke Data Entry Tool
STEPS Stroke Feasibility Study

• **Aim**
  - Test the utility of the instrument in geographically diverse locations

• **Measures**
  - Hospital-based data from different low- and middle-income countries
  - Data collection by adherence to the same protocol
  - Standardized data analyses
• Data from 5,557 patients

• Data collection from 3 to 21 months

• Central analyses of selected variables

Table 1: Demographic and stroke data, by selected surveillance sites
• Mean age 64.2 years
• 19% had a history of stroke
• 2/3 had ischemic stroke
• Half were admitted to hospital the same day
• Compared with men, women were less likely to have diagnostic examination of stroke type
**STEPS Stroke**
Feasibility Study

*Barriers to implementation*

- Funds
- Staff training
- Data management
- Consecutive event registration

*Minimum resources needed (Step 1)*

- 2 trained persons for data collection
- Access to computers
- Team leader with background in stroke epidemiology
- 12-month registration period
- Possible to use the STEPS Stroke instrument in different settings
- Future studies should attempt to move from hospital-based (Step 1) registries to population-based registries (Steps 1–3)
- Linkage with data on the source population

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Total (n=5486)</th>
<th>Women* (n=2484)</th>
<th>Men* (n=2981)</th>
<th>p value†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>64.2 (14.6)</td>
<td>66.1 (14.7)</td>
<td>62.56 (14.4)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>66 (55-75)</td>
<td>69 (58-76)</td>
<td>65 (64-73)</td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td>15-105</td>
<td>15-105</td>
<td>15-103</td>
<td></td>
</tr>
<tr>
<td>Median per centre (range)</td>
<td>50-70</td>
<td>58-74</td>
<td>53-70</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age-groups (n [%], years)</th>
<th>Total (n=5486)</th>
<th>Women* (n=2484)</th>
<th>Men* (n=2981)</th>
<th>p value†</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;45</td>
<td>549 (10)</td>
<td>214 (9)</td>
<td>335 (11)</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>45-54</td>
<td>726 (13)</td>
<td>261 (11)</td>
<td>465 (16)</td>
<td></td>
</tr>
<tr>
<td>55-64</td>
<td>1107 (20)</td>
<td>448 (18)</td>
<td>659 (22)</td>
<td></td>
</tr>
<tr>
<td>65-74</td>
<td>1636 (30)</td>
<td>789 (32)</td>
<td>847 (28)</td>
<td></td>
</tr>
<tr>
<td>75-84</td>
<td>1187 (22)</td>
<td>614 (25)</td>
<td>572 (19)</td>
<td></td>
</tr>
<tr>
<td>≥85</td>
<td>261 (5)</td>
<td>101 (6)</td>
<td>163 (5)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Previous stroke (n [%])</th>
<th>Total (n=5486)</th>
<th>Women* (n=2484)</th>
<th>Men* (n=2981)</th>
<th>p value†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>1044 (19)</td>
<td>488 (20)</td>
<td>555 (19)</td>
<td>0.0176†</td>
</tr>
<tr>
<td>No</td>
<td>2795 (51)</td>
<td>1367 (55)</td>
<td>1428 (48)</td>
<td></td>
</tr>
<tr>
<td>Insufficient data</td>
<td>345 (6)</td>
<td>188 (8)</td>
<td>157 (5)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>1282 (23)</td>
<td>441 (18)</td>
<td>841 (28)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stroke subtype (n [%])</th>
<th>Total (n=5486)</th>
<th>Women* (n=2484)</th>
<th>Men* (n=2981)</th>
<th>p value†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ischaemic stroke</td>
<td>3648 (67)</td>
<td>1673 (67)</td>
<td>1974 (66)</td>
<td>0.1660‡</td>
</tr>
<tr>
<td>Intracerebral haemorrhage</td>
<td>1004 (20)</td>
<td>468 (16)</td>
<td>536 (21)</td>
<td></td>
</tr>
<tr>
<td>Subarachnoid haemorrhage</td>
<td>102 (2)</td>
<td>52 (2)</td>
<td>50 (2)</td>
<td></td>
</tr>
<tr>
<td>Unspecified type or unknown</td>
<td>504 (9)</td>
<td>232 (9)</td>
<td>272 (9)</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>118 (2)</td>
<td>59 (2)</td>
<td>59 (2)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Verification of stroke subtype (n [%])</th>
<th>Total (n=5486)</th>
<th>Women* (n=2484)</th>
<th>Men* (n=2981)</th>
<th>p value†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical diagnosis alone</td>
<td>395 (7)</td>
<td>219 (9)</td>
<td>176 (6)</td>
<td>0.0006§</td>
</tr>
</tbody>
</table>
## STEPS Stroke in Latin America

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Name</th>
<th>Place, Country</th>
<th>No. of inhabitants</th>
<th>STEPS</th>
<th>IP</th>
<th>$</th>
</tr>
</thead>
<tbody>
<tr>
<td>EMMA</td>
<td>Estudio de Mortalidade e Morbidade do Acidente Vascular Cerebral</td>
<td>São Paulo, Brazil</td>
<td>10 million</td>
<td>1-2-3</td>
<td>P.A. Lotufo</td>
<td>CNPq</td>
</tr>
<tr>
<td>STROQUE</td>
<td>Registro de Accidentes Cerebrovasculares del municipio de Querétaro, Mexico</td>
<td>City of Querétaro, Mexico</td>
<td>72,500</td>
<td>1-2-3?</td>
<td>F. Barrinagarr ementería</td>
<td>CONCYTEQ, CONACYT?</td>
</tr>
<tr>
<td>TAURUSs</td>
<td>Estudio urbano y rural de accidentes cerebrovasculares de Talca</td>
<td>Province of Talca, Chile</td>
<td>390,000</td>
<td>1-2-3</td>
<td>P.M. Lavados</td>
<td>CONICYT?</td>
</tr>
</tbody>
</table>
Conclusions

• It’s time to move towards epidemiological “surveillance” of cerebrovascular diseases.

• We have to adjust the levels of complexity to the available resources.

• We should use standardized, easy-to-use, and modern tools and methodologies.

• STEPS Stroke meets with these requirements.