STEPS Stroke

Standardized Tools for Stroke Surveillance

PAHO/WHO

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for the STEPS Stroke International Steering Committee
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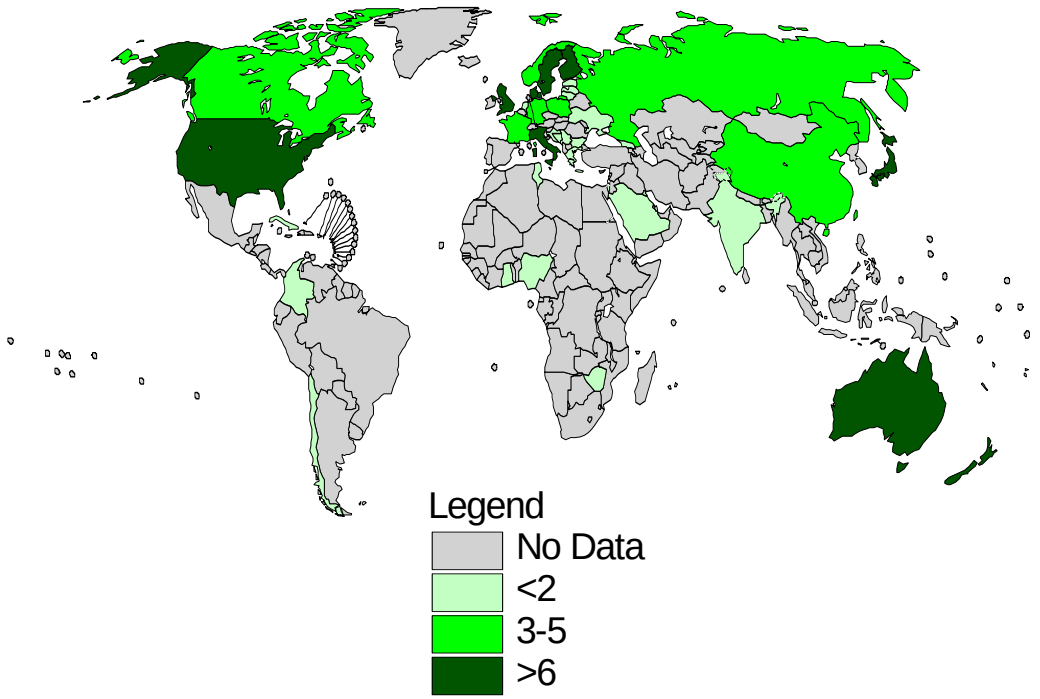
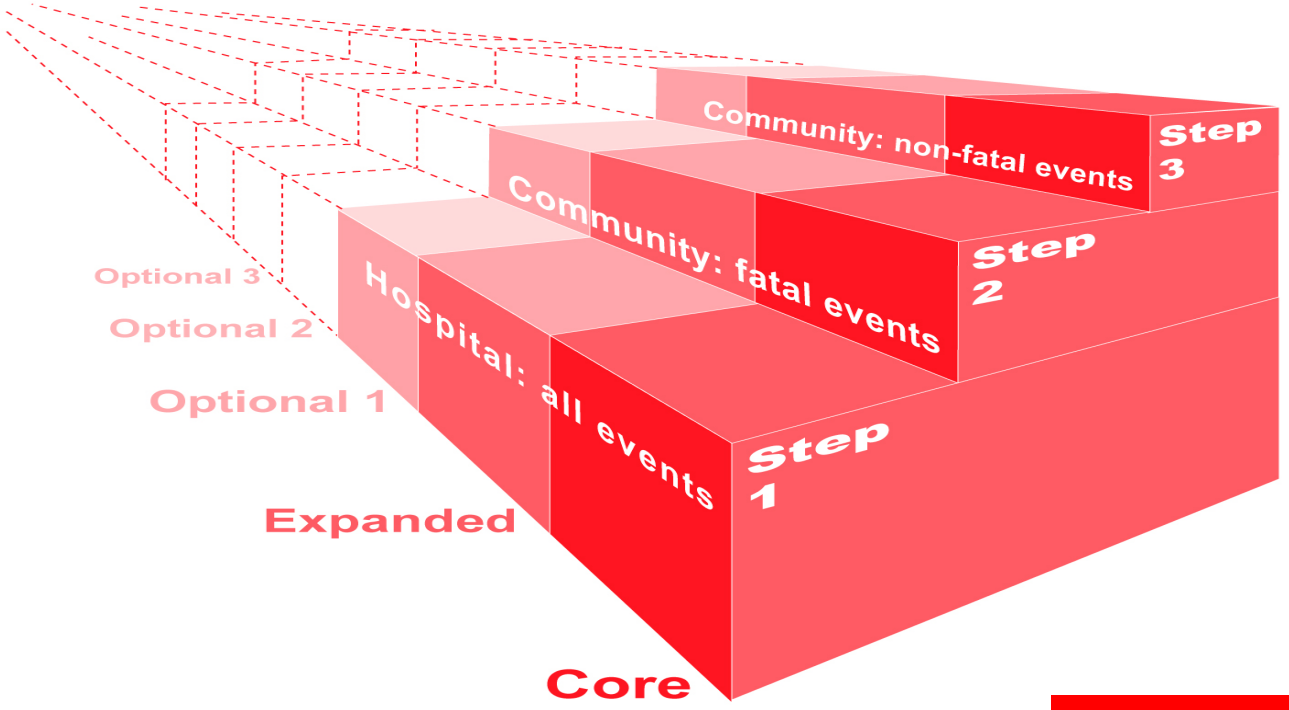
Status of Stroke Data

- Fragmented surveys; once-off, *ad hoc*, outdated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

Stroke Incidence
Publications, 1993–2004



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

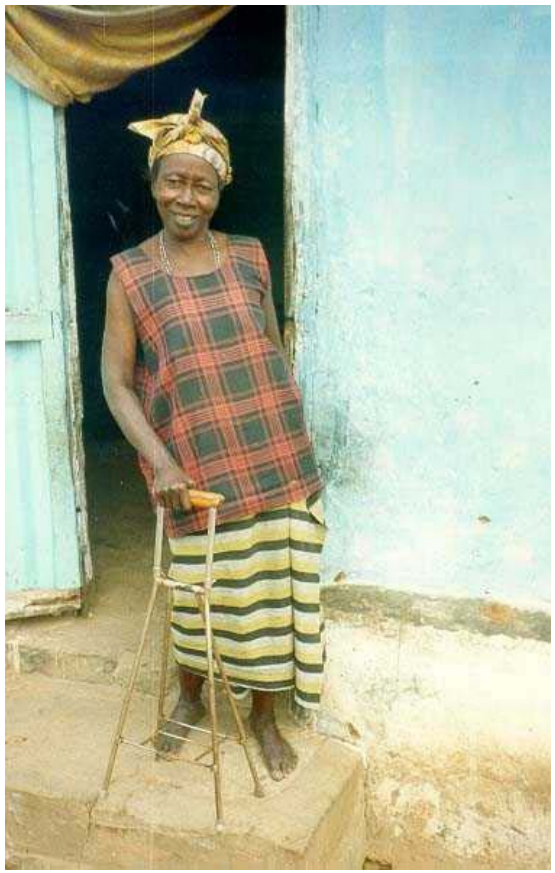
(Fatal Events in the Community)

or

VERBAL AUTOPSY

- 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)

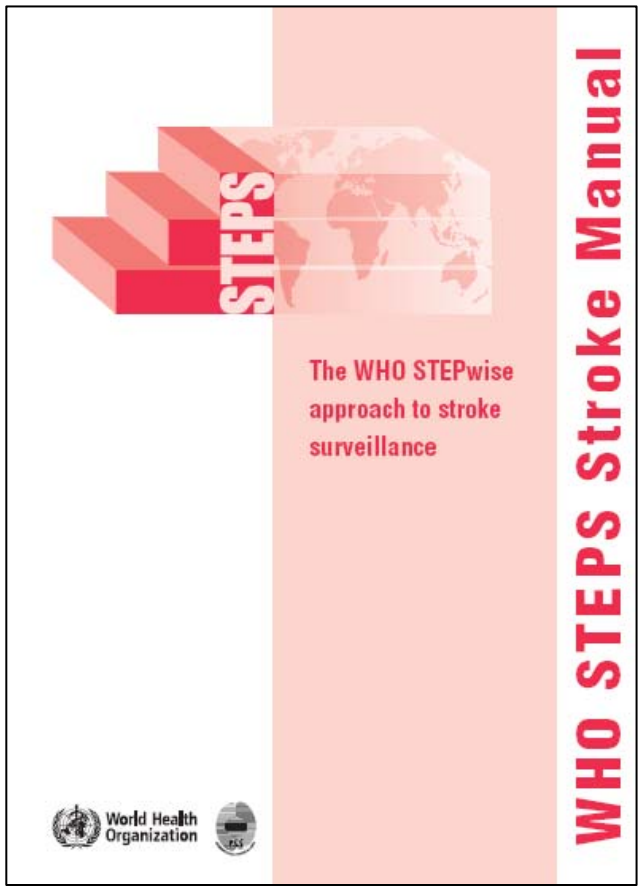
STEPS Stroke: What it offers

- 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



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Guide to Completing the Instrument: Events Admitted to Hospital (Step 1), Continued

Living situation S1 3 (Core)

Living condition options are explained in the table below.

Option	Refers to patients living
Independent at home	Without depending on any assistance from relatives or professionals
Dependent at home	Depending on assistance from relatives or professionals
Community facility	In nursing or residential homes, serviced flat or other long term care facility.

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.

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

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

IDENTIFICATION NUMBER [ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ][ ]

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

(I 1)	Stroke Surveillance Site Code *Insert 1st 5 digits of automatically generated code from DET*	[ ][ ][ ][ ][ ]
(I 2)	Interviewer Code *Insert code provided by the ICU*	[ ][ ][ ]
(I 3)	Date of completion of the instrument	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] d d m m y y y y

Patient individual records

(I 4)	Patient's family name *Use CAPITALS, include all names*	[_____]
(I 5)	Patient's first name *Use CAPITALS, include all names*	[_____]
(I 6)	Contact phone number *Include area codes (optional)*	[_____]
(I 7)	Contact address *For follow-up questionnaires (optional)*	[_____] [_____]
(I 8)	Unique identification number where available *number, PID etc (optional)*	[_____]

Contact person of patient

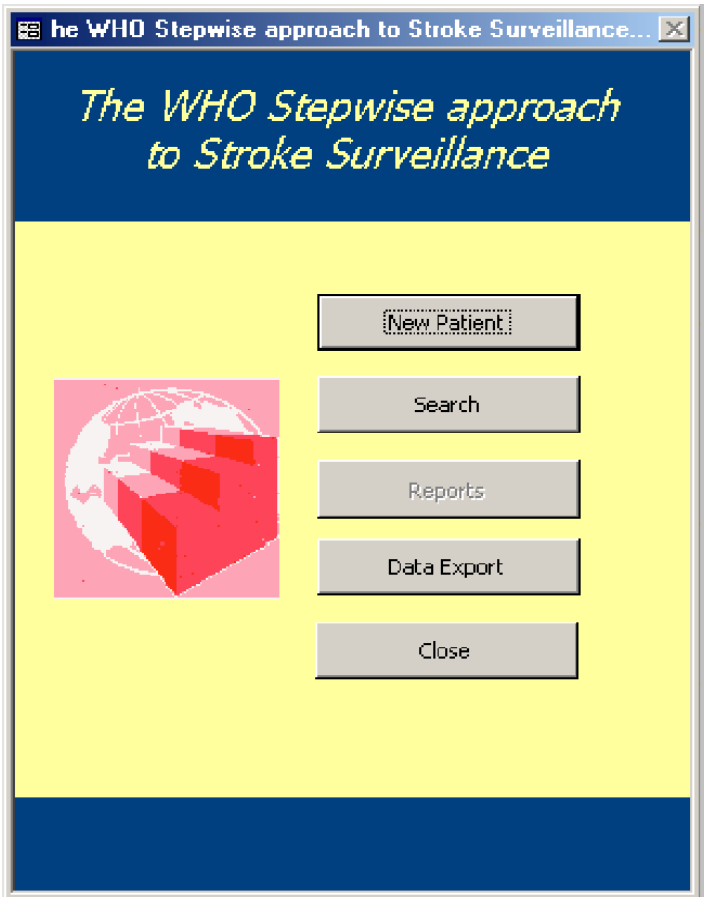
Include contact person who can confirm the living situation of the patient

(I 9)	Contact person's family name	[_____]
(I 10)	Contact person's first name	[_____]
(I 11)	Contact person's phone number	[_____]
(I 12)	Contact person's address	[_____] [_____]
(I 13)	Relationship of contact person to the patient	[_____]

Demographic characteristics

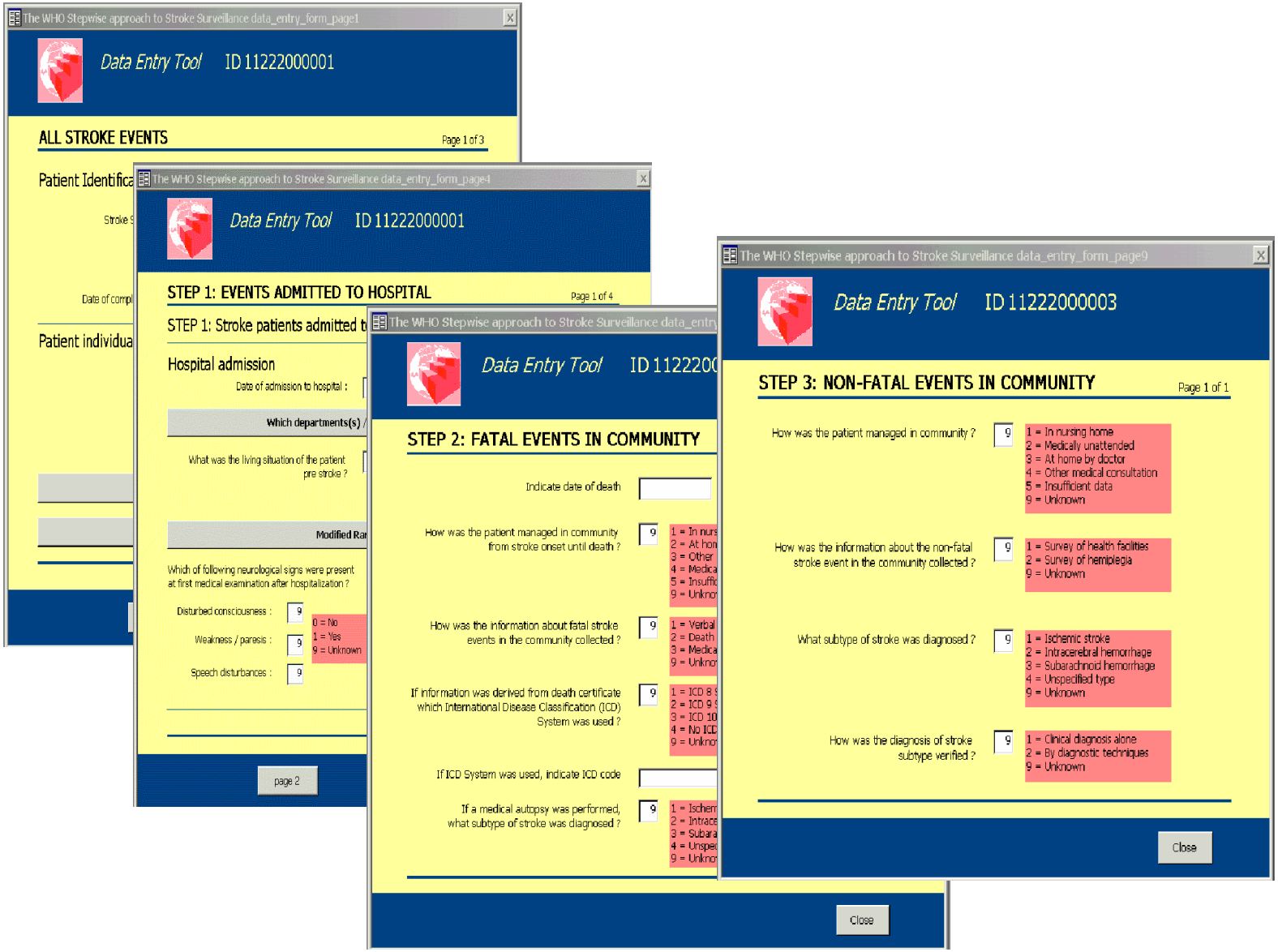
(I 14)	Date of birth *If date of birth is unknown, enter age* [ ][ ][ ]	[ ][ ]/[ ][ ]/[ ][ ][ ][ ] d d m m y y y y
(I 15)	Sex *[select one]*	Male (1) [ ] Female (2)

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

STEPS Stroke
Feasibility Study

- Data from 5,557 patients
- Data collection from 3 to 21 months
- Central analyses of selected variables

	Patients enrolled with acute stroke event (n)	Duration of registration (months)	Male participants (n [%])	Mean (SD) age (years)
India (Bangalore)	1174	8	782 (67)	54·8 (16·6)
India (Chennai)	402	11	265 (66)	61·6 (13·4)
India (Mumbai)	136	12	73 (54)	65·3 (10·4)
India (Trivandrum)	477	7	236 (49)	65·7 (12·1)
Iran (Isfahan)	2585	21	1292 (50)	68·1 (13·1)
Mozambique (Maputo)	119	3	65 (55)	57·6 (12·6)
Nigeria (Ibadan)	169	15	84 (50)	60·5 (13·1)
Russia (Moscow 1)	95	7	48 (51)	64·4 (14·1)
Russia (Moscow 2)	400	12	174 (44)	68·4 (12·2)

Table 1: Demographic and stroke data, by selected surveillance sites

STEPS Stroke

Feasibility Study (combined data)

- 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

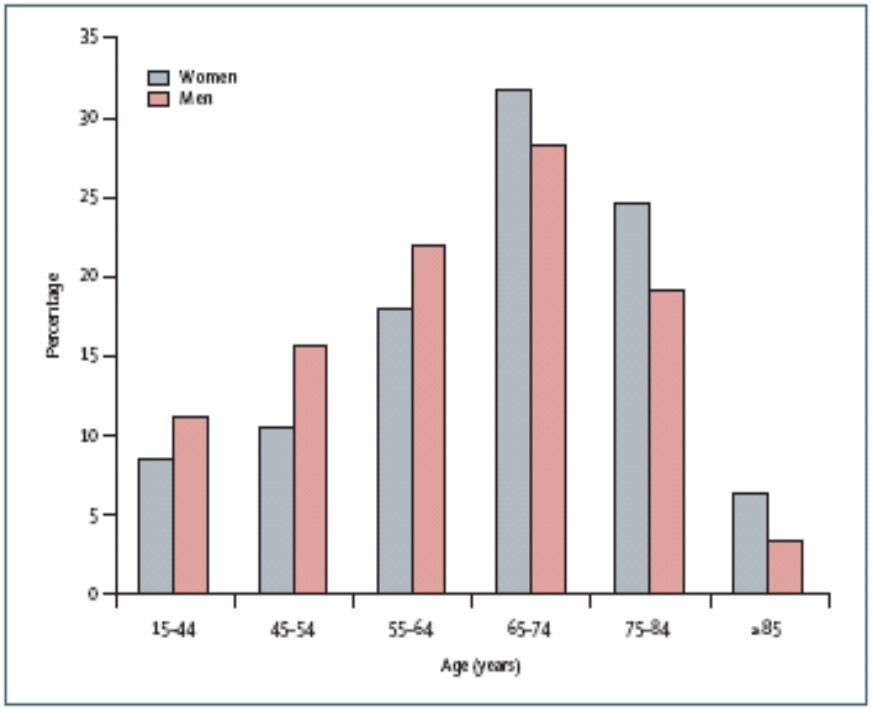


Figure: Age distribution of stroke patients

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

STEPS Stroke

Conclusions from the Feasibility Study

- 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

	Total (n=5466)	Women* (n=2484)	Men* (n=2981)	pvalue†
Age (years)				
Mean (SD)	64·2 (14·6)	66·1 (14·7)	62·56 (14·4)	<0·0001
Median (IQR)	66 (55–75)	69 (58–76)	65 (54–73)	
Range	15–105	15–105	15–103	
Median per centre (range)	56–70	58–74	53–70	
Age-groups (n [%], years)				<0·0001
<45	549 (10)	214 (9)	335 (11)	
45–54	726 (13)	261 (11)	465 (16)	
55–64	1107 (20)	448 (18)	659 (22)	
65–74	1636 (30)	789 (32)	847 (28)	
75–84	1187 (22)	614 (25)	572 (19)	
≥85	261 (5)	158 (6)	103 (3)	
Previous stroke (n [%])§				0·0176‡
Yes	1044 (19)	488 (20)	555 (19)	
No	2795 (51)	1367 (55)	1428 (48)	
Insuffident data	345 (6)	188 (8)	157 (5)	
Missing	1282 (23)	441 (18)	841 (28)	
Stroke subtype (n [%])				0·1660‡
Ischaemic stroke	3648 (67)	1673 (67)	1974 (66)	
Intracerebral haemorrhage	1094 (20)	468 (19)	626 (21)	
Subarachnoid haemorrhage	102 (2)	52 (2)	50 (2)	
Unspecified type or unknown	504 (9)	232 (9)	272 (9)	
Missing	118 (2)	59 (2)	59 (2)	
Verification of stroke subtype (n [%])				0·0006‡
Clinical diagnosis alone	395 (7)	219 (9)	176 (6)	

STEPS Stroke in Latin America

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

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.

www.who.int/chp/steps/stroke