

Section 5: Data Collection Guidelines

Overview

Introduction This section provides generic guidelines for data collection staff.

Intended audience This section is designed for use by those fulfilling the following roles:

- Interviewers
- Stroke principal investigator

In this section This section covers the following topics:

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Case Finding Methods

Introduction

The main case finding methods used to identify stroke cases are:

- Hot pursuit (active, ongoing recruitment)
 - Cold pursuit (retrospective record review)
 - Combination of hot and cold pursuit.
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Hot pursuit

Hot pursuit refers to ongoing 'active' identification of all stroke events as they occur. The main purpose is to confirm that the criteria for stroke is met and ensure complete identification of all events including mild stroke events.

Hot pursuit involves regularly checking the following:

- Daily hospital admissions,
 - Hospital separations or discharges
 - Emergency room registers
 - Wards or units
 - Death certificates.
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Cold pursuit

Cold pursuit refers to retrospective identification of stroke events, for example, based on information from hospital discharge records, or death certificates.

This identification method relies on diagnoses made by several doctors of varying neurological experience who are not working to a protocol. It requires a team identifying and validating stroke events when it is convenient, based on information from routine data sources. Direct examination of the patient is often not possible, and the diagnosis is based on data from records.

Combined approach

Many studies use a combined approach with a mix of hot and cold pursuit to ensure the most complete identification of stroke events (so called overlapping identification sources or overlapping sources of information).

Some of the patients must have been identified as soon as possible after symptoms onset with the possibility of direct examination, while the remaining events are based on routine data.

For example, the researchers have done direct examinations after hospital admission but to ensure the completeness of the data, hospital discharge records, death certificates etc. are checked, physicians are asked to report non-hospitalized stroke events.

Identifying Stroke Patients in Hospitals (Step 1)

Introduction Surveillance of stroke managed in hospitals should be limited to patients who:

- Are admitted to any unit, ward, division or department of the hospital with a provisional diagnosis of having experienced the onset of a new stroke.
- In-hospital patients who suffer a stroke due to the treatment of another disease.

Identifying stroke patients Stroke patients may be identified through the following hospital systems and channels:

- Emergency room daybook (or register)
- Admissions book (or register)
- Outpatient clinics
- Radiology departments
- Specialist physicians or neurologists
- Physiotherapists, speech or occupational therapists
- Discharge records
- Death certificates

Note: It is necessary to devise systems in each hospital to detect patients who suffer from an in-hospital stroke, whether intra-operatively or at some other time, and whether in acute or on long-stay wards.

Difficult cases While many cases are straightforward, stroke has a long differential diagnosis. Resolving the difficult cases requires that the patient be assessed by an experienced medical practitioner and preferably by an internal physician or a specialist neurologist.

Re-assessment of the patient at least 24 hours after the initial presentation may be vital to differentiate stroke from TIA and other neurological or medical diseases such as hemiplegic migraine and epilepsy.

Death following stroke In order to assess trends in case fatality, a system for accessing details on all deaths occurring in stroke patients registered in the study is necessary. Date of death should be registered in the Instrument, together with details of cause of death. Vital status of all patients should be known at 28 days after the onset of stroke. This length of follow up is not always feasible. A minimum follow up is 7 days.

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Identifying Stroke Patients in Hospitals (Step 1) Continued

Diagnostic criteria

Each registered stroke event must meet the standard WHO clinical definition of stroke (see p1-4). Key features of the clinical definition are as follows:

- Sudden onset
- Neurological deficit
- Lasting 24 hours or longer
- Of presumed vascular origin.

The table below provides an example of some of the diagnoses that should be considered for STEPS stroke registration.

Stroke specific	Focal and global signs that could be caused by stroke
<ul style="list-style-type: none"> • (Acute) stroke <i>or</i> (acute) cerebrovascular episode • Cerebral <i>or</i> cerebellar embolus, thrombosis <i>or</i> infarction • Occlusion, thrombosis <i>or</i> embolus of carotid, (pre) cerebral <i>or</i> vertebral artery • Lacunar hemorrhage <i>or</i> stroke • Subarachnoid, (primary) intracerebral, cerebellar <i>or</i> pontine hemorrhage <i>or</i> stroke • Ruptured berry aneurysm • Transient (cerebral) ischemic attack 	<ul style="list-style-type: none"> • (Acute) hemiplegia <i>or</i> (acute) hemiparesis • Faint, fit, funny turn, (acute) confusional state • Loss of consciousness • (Acute) dysphasia, dysarthria, dyspraxia • Homonymous hemianopia • Amaurosis fugax • Acute monocular blindness

Note: Further details on symptoms for the three major stroke types can be found in section 1, About Stroke.

Residency criteria

If a population based study, the stroke case, to be eligible, must be resident in the defined population at the time of the onset of the stroke.

Identifying Fatal Stroke Patients in the Community (Step 2)

Introduction

The three main methods for identifying and estimating the number of stroke patients that die from a stroke, but who do not reach hospital facilities:

- Death certificates
 - Verbal autopsies
 - Medical autopsy.
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Death certificates

Communities that have routine medical certification of cause of death can provide direct data on deaths due to stroke. Note that delays in processing death registrations and certificates may occur and also a wide variety of terms may be used to describe fatal stroke. When in doubt, verification or follow up is essential. Methods for searching death registrations may include:

- Electronic keyword search
 - Manual record search by visual sighting.
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Verbal autopsies

Verbal autopsies (VAs) are increasingly being used to monitor the distribution of deaths by cause in places where medical certification of cause of death is uncommon. This technique is based on the assumption that most causes of death have distinct symptom complexes, and that these can be recognized, remembered and reported by health professionals or lay respondents.

Official WHO verbal autopsy for adult deaths is currently being developed. A provisional form for assisting with the process of verifying deaths which may possibly have been due to stroke is available on request from the ICC for those SSS planning population based registers.

Follow up with this modified VA is essential where cause of death is cited in such vague terms as:

- Ill defined
- Unknown
- "old age"
- Senility.

Sensitivity in obtaining this information must be adhered to at all times.

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Identifying Fatal Stroke Patients in the Community (Step 2), Continued

Verbal verification

When interviewing health professionals or family members about the signs and symptoms associated with a possible stroke event, the following questions provide a structure to the interview:

- Was the deceased ill prior to death?
- Did s/he have weakness on one side of the body prior to death?
- Did that weakness develop suddenly?
- Did it last more than 24 hours?
- Was it a sudden death (died within 24 hours)?
- Was there a history of severe headache just prior to death?
- How many days was the patient ill before death?
- Was the patient seen by a medical or health professional?
- Was the patient admitted to hospital or a clinic? How many nights?

A detailed description of the previous illnesses, treatment, and events leading to death should be prepared and used in the decision by the study coordinator as to whether the criteria for stroke have been met.

Validation of codes and diagnosis

Both the codes used and diagnosis of stroke as the immediate or underlying cause of death should be validated as indicated in the table below.

Validation of	Based on
Codes	<ul style="list-style-type: none">• Medical and medico-legal records (within 28 days of death).• Interview with decedent's next-of-kin or other informant (verbal autopsy).
Diagnosis	<ul style="list-style-type: none">• Clinical signs according to the stroke definition• Neuro imaging or autopsies.

Medical autopsies

Since medical autopsy rates are declining in many countries autopsies are unlikely to provide a substantial coverage of fatal strokes. However, records of post mortem examinations are an accessible way of getting information for the surveillance system. They provide a valid diagnosis, and contribute to a more complete understanding of the stroke occurrence in the study population.

Estimating Non-Fatal Stroke Events in the Community (Step 3)

Introduction The main methods for estimating numbers of non-fatal events in the community include:

- Tracking local medical practices and health facilities by survey
 - Hemiplegia/ hemiparesis survey (prevalence survey)
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Primary health care facilities Where general practitioners are widely used at primary health care facilities, these should be included as part of the case finding methods.

In some countries there are only a few general practitioners or only a proportion of stroke patients who ever have contact with them. In these sites, local healers may be the primary contact person and it is important to consider their potential for collaboration.

General practitioners You will need to use different survey techniques depending on the size of the study population to determine the number of general practitioners to include, as indicated in the table below:

If the study population is	Then..
Small (limited size)	Include all the general practitioners and local health facilities in the study (eg. public health care centres, nursing homes, rehabilitation centres etc).
Large (entire population)	Survey a representative sample of medical practitioners to assess the number of cases that they have managed over a defined, preceding period.

Local healers Given instructions on stroke symptoms, local informal healers may be able to provide a contact to the patient, who then can be examined for stroke symptoms.

Note: This procedure is likely to underestimate the true rate as mild cases are unlikely to be detected, but the overall effect on the estimates is likely to be minor.

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Estimating Non-Fatal Stroke Events in the Community (Step 3), Continued

Sampling community based facilities

Informing the community about the purposes of a stroke surveillance system is crucial in enlisting assistance in case finding for the hard to reach people who are not listed with a registered facility or hospital.

Identification of these patients involves the collaboration and cooperation of general practitioners and other health care providers in the community, but their identification is vital for the accurate determination of stroke incidence.

These strokes are a combination of milder and more severe strokes than those that present to hospital, and consequently their inclusion influences case fatality ratios. One approach is to notify all general practitioners (or equivalent) of the study. They should be provided with information kits and memory aids to focus their attention on the study and to alert the team to any cases in their practice who have a stroke- especially if not admitted to a hospital.

In addition to general practitioners (or equivalent), the study team will need to maintain close liaison with community health nurses and village elders/church leaders to ensure ongoing support and referral of potentially eligible cases to the study.

Prevalence of stroke

One way of estimating the proportion of non fatal stroke events is to obtain an estimate from the prevalence of survivors. In most communities the causes of adult-onset hemiplegia or hemiparesis are limited to stroke and head injury and can be distinguished from patient history.

Hemiplegia/ hemiparesis survey

If the incidence of residual hemiplegia following stroke and the survival time are constant within a given community, trends in the prevalence of hemiplegia will reflect trends in the incidence of stroke.

This could be useful for stroke surveillance because hemiplegia is recognisable and identifying cases does not require self diagnosis. The prevalence of hemiplegia can therefore be identified by questionnaire based population surveys or interviews with a representative from selected households. The problem, however, is that even prevalence of stroke is relatively rare.

If such a survey has already been undertaken, check to see if information was obtained on the proportion who said they had never been admitted to a hospital facility. This could act as a proxy measure of the non fatal community based group.

Notes: The linkage between prevalence of hemiplegia/ hemiparesis and incidence of stroke has not been validated in a study so far.

Interview Skills

Introduction Although much of the data that needs to be collected can be obtained from records, some contact with patients or next of kin may be required.

Participation The patient (or person being interviewed) needs to feel comfortable about the interview and can refuse to be interviewed as participation is voluntary. The interview should therefore be as natural as possible and conducted politely, like a normal conversation.

Behaviour and tact The table below provides guidelines on appropriate behaviour during an interview:

Behaviour	Guidelines
Respect confidentiality	Maintain the confidentiality of all information you collect.
Respect patient's time	You are asking patients for their time so be polite and prepared to explain.
Tact	If you feel that a person is not ready to assist you, do not force them but offer to come back later.
Friendly disposition	Act as though you expect to receive friendly co-operation and behave accordingly.
Body language	Maintain good eye contact and adopt appropriate body language.
Pace of interview	Don't rush the interview. Allow the patient enough time to understand and answer a question. If pressured, a patient may answer with anything that crosses their mind.
Patience	Be patient and polite at all times during the interview and ensure you have set aside enough time for patients with aphasic disturbances.
Appreciation	Thank them for their help and cooperation.

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Interview Skills, Continued

Handling refusals

Be prepared to obtain co-operation from a patient who does not want to be interviewed. In general, be pleasant, good-natured, and professional and most patients will co-operate.

If...	Then...
The patient becomes defensive	<ul style="list-style-type: none">• Show patience and understanding• Provide token agreement and understanding of his/her viewpoint, that is, saying something like, 'I can understand that' or 'You certainly have the right to feel that way.'• Convey the importance of the study to the patient and that all stroke patients are being registered.
You may have visited at a bad time.	Try again later.
The patient may have misunderstood the purpose of the visit.	Try to explain the purpose again.
You think you may get a 'no'	Try to leave and suggest coming back later before you get a partial or an absolute 'no'.

Patient consent

Each patient (or family member) should provide verbal and/or written consent in accordance with local standards before taking part in the Study.

A sample patient consent form is discussed in section 3-14.

Recording Responses for Registration

Introduction All results that are recorded on the STEPS instrument must be written as clearly as possible to avoid ambiguity and confusion when checking and entering the results.

Requirements Some general requirements for recording survey information are as follows:

- Record the patient identification number on every page of each instrument.
- Do not erase any notes made.
- If a question has been skipped by mistake, correct it.
- If a patient changes his/her mind on one of the options, record the new answer.
- Record only answers that are relevant to the study.
- Record comments or explanations in brackets in the Instrument next to the corresponding question.
- Do not get too absorbed recording. Keep the patient's interest by saying the patient's response aloud as you write it down.
- Standard agreement on how to write numbers.

Handling issues Use the table below to help with some common issues you may encounter.

If..	Then..
You are uncertain about a response	Repeat the question and record the answer exactly. Do not paraphrase a response.
A question doesn't apply or the patient doesn't know and these options are not available on the Instrument	For "don't know" record: 9, 99 or 999 etc.
You have missed a question	Go back and ask the question, making a note that the question was asked out of sequence.

Checking and editing At the end of each interview check the Instrument and make sure that:

- All the questions have been answered.
 - The information recorded is clear and legible for others to read.
 - Probing comments are indicated.
 - Check that all the information has been completed including the ID number on every page.
 - Review the Instrument to check it is complete and that every question has been answered.
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Guide to Completing the Instrument: All Stroke Events

Introduction	Guidelines on how to complete some questions in the All Stroke Events section of the Instrument are given below, with further guidance given in the Question by Question Guide in section 7.
Identification number	The patient identification number is to be written in the boxes at the top of each page of the Instrument and all patient specific documents at the time the completed Instrument is being entered into the register.
Patient identification and patient characteristics I 1 - I 3 (Core)	<p>Accurate core participation and patient characteristic information is essential for analysing and reporting on the overall results of the STEPS Stroke surveillance.</p> <p>Patient identification and patient characteristics should be completed for every patient documented in Step 1, Step 2 and Step 3. If the age and sex of a patient has been missed out, the Instrument cannot be used in the analysis, as most analyses are grouped by these criteria.</p>
Contact name and address I 9 - I 13	An acute stroke event often results in dramatic consequences for the patient after discharge from hospital. This may mean the patient goes to live with relatives or a nursing home for long term care. The contact person, phone number and address should therefore be for someone who knows about the actual living situation of the patient. Children or other close relatives could serve as contact persons for the patient. The relationship of the contact person to the patient should also be documented.
Dates of birth and age I 14 (Core)	In some countries exact dates of birth and/or age are not known. In these situations age has to be estimated. To estimate someone's age, you will need to ask them how old, or at what stage in life they were at the time that a number of widely known major local events occurred.
Information on acute stroke event I 20 - I 22 (Core)	<p>If the exact onset of stroke symptoms is unknown (e.g. stroke occurred during sleeping), ask the patient or another person when the first symptoms of stroke were noticed and enter that date.</p> <p>To differentiate between a first-time event and a recurrent event it is important to obtain information about possible previous strokes. Please note that that the following are not counted as a stroke:</p> <ul style="list-style-type: none">• previous TIA• silent strokes (ie detected by scanning but did not result in a neurological deficit longer than 24 hours).

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Completing the Stroke Instrument Continued

Expanded items Expanded questions are shown in the shaded boxes. Some of these questions may have been adapted so the terms and phrases make sense to patients in your environment. Some of the adaptations may include relevant:

- Ethnic, racial and or cultural groups
 - Highest level of education
 - Categories of work
 - Income level.
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Choosing expanded items Each site coordinator should choose which of the expanded items will be included in the final Instrument. It is a question of balance between obtaining the minimum data (core items) and what can reasonably added without additional effort and cost.

Choosing expanded questions depends on local circumstances and the use to which the information will be put. As with core questions, expanded questions should not be altered.

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

Introduction This section is to be completed for all eligible stroke patients admitted to hospital. Information collected includes:

- Hospital admission
- Stroke classification
- Vascular risk factors
- Medical treatment
- Secondary prevention
- In-hospital management
- Follow up of the patients

Note: Each of these is explained in more detail below.

**Hospital admission
S1 1 (Core)**

Stroke patients admitted to hospital must have survived until hospitalization, and must have been able to get to the hospital either:

- by themselves
- with the help from relatives/care givers, or
- using any kind of emergency medical service.

Note: Despite differences between countries and changes in admission practices over time, data based on hospitalized events gives valuable information for local health authorities, and constitutes the first step to a better understanding of stroke in the population.

**Hospital departments
S1 2(Expanded)**

There are seven possible answers for indicating in which departments or units the patient was treated. The available options are explained in the table below.

Department/unit	Refers to patients managed at..
Intensive care	An intensive care unit, including any type of acute medical unit.
Medical	A general medical ward, including a geriatric unit.
Neurological	A general neurological ward.
Neurosurgical	A general neurosurgical ward.
Rehabilitation	A specialized rehabilitation unit, except a rehabilitation stroke unit.
Stroke	Acute and rehabilitation stroke units.
Other	Other units, e.g. outliers or patients on surgical wards.

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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.

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

Neurological signs S 1 5 (Core)

Neurological deficits, for example, disturbances of consciousness, are an important predictor of stroke severity. Neurological deficits present at the first medical examination after hospitalization should be documented to adjust potential differences in outcome and disability for stroke severity. The different levels of deficit are explained in the table below.

Neurological deficit type	Refers to
Disturbed consciousness	Disturbances of consciousness, including semi consciousness, e.g. not fully aroused, and coma, either response to pain only or no response at all
Weakness/paresis	Motor deficits of the upper or lower limbs.
Speech disturbances	Speech disturbances present on admission, like aphasia or dysarthria.

Stroke classification S1 6 (Core)

Stroke events can be classified into either

- ischemic stroke
- intracerebral haemorrhage
- subarachnoid haemorrhage, or
- unspecified.

It is recommended that stroke types are classified as a result of neuro-imaging.

Whether an event is haemorrhagic versus ischemic is also of importance from a clinical perspective in terms of treatment and early secondary prevention, as aspirin should not be given to patients with haemorrhagic stroke and anticoagulation as well as thrombolysis is obviously contraindicated in hemorrhagic strokes.

Where no diagnostic examination was done to verify the subtype of stroke, choose the option *Unspecified*.

Note: For further details on stroke classification, see section 1, About Stroke.

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

Subtype diagnosis S1 7 (Core)

Diagnosis of stroke subtype, refers to patients where the subtype classification was verified from one of two methods as follows:

Diagnosis by	Explanation
Clinical diagnosis alone	Clinical diagnosis alone and was not verified by brain imaging (or in subarachnoid hemorrhage on lumbar puncture) in non-fatal cases or also by medical autopsy in fatal cases; please indicate also clinical diagnosis alone if any scoring system not based on brain imaging or medical autopsy was used
Diagnostic techniques	In non-fatal cases to patients where the subtype of stroke was verified by brain imaging; subtype verification of subarachnoidal hemorrhage might also be based on lumbar puncture alone; in fatal cases verification of stroke subtype might also be based on medical autopsy.

Risk factors S1 10 (Expanded)

The main modifiable risk factors that are present pre-stroke are listed and defined in the table below.

Risk factor	Defined as a patient who pre-stroke..
Atrial fibrillation	Has atrial fibrillation in ECG prior to stroke (records seen) or during hospitalization.
Current tobacco use	<ul style="list-style-type: none"> • Is a current tobacco user (smoking and other forms of tobacco), or • Was a recent tobacco user but stopped less than 3 months before acute stroke event.
Diabetes mellitus	<ul style="list-style-type: none"> • Has been diagnosed with or has self reported diabetes mellitus, and • Uses antidiabetic drugs
Hypercholesterolemia	<ul style="list-style-type: none"> • Has reported elevated plasma total or LDL cholesterol level, or • Uses lipid-lowering medication
Raised blood pressure	<ul style="list-style-type: none"> • Has diagnosed or self reported raised blood pressure, or • Uses antihypertensive drugs.

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

Pharmaceutical treatment
S1 11 S1 12
(Core)

Pharmaceutical treatment means continuous medication. The only exception is for thrombolysis, which is only given one time. The table below lists the categories of drug type and drugs used in each category.

Drug type	Including
Anticoagulant	<ul style="list-style-type: none"> • Warfarin • Heparin
Anti diabetic	<ul style="list-style-type: none"> • Antidiabetic medications • Insulin injections
Antiplatelet	<ul style="list-style-type: none"> • Aspirin • Clopidogrel • Dipyramidol
Cholesterol lowering	<ul style="list-style-type: none"> • Statins
Blood pressure lowering	<ul style="list-style-type: none"> • Thiazides • Angio-tensin targeting agents • Beta-blockers • Calcium channel blockers

In hospital assessment
S1 13 - 14
(Expanded)

The in-hospital assessment questions refer to assessments of the listed disorders during hospitalization, irrespective of whether the patient was treated or not after the first visit.

Patient discharge
S1 15 - 18 Core)

If the patient is alive at discharge (S1 18), there are three possible destinations. These are explained in the table below.

Option		Refers to patients discharged to
1	Home	Private address (either the same or a new address)
2	Other hospital	<ul style="list-style-type: none"> • Another hospital • Rehabilitation unit • Rehabilitation hospital • Long-stay hospital
3	Community facility	Facilities with access to service and staff eg: <ul style="list-style-type: none"> • Nursing or residential homes • Long term care facilities for psychiatric disorders • Serviced flat, or • Assisted living

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

Modified Rankin scale S1 9 (Expanded)

If the patient is alive at discharge, the Modified Rankin scale should be assessed just before discharge from hospital. The number corresponding to the patient's functional level is to be entered. The scale is described on page 5-16.

Follow up at day 28 F1 - F7 (Optional)

Follow up on day 28 (from onset of stroke) provides valuable information about the long-term burden of stroke. These optional questions may be difficult to obtain for all registered patients. If a patient or contact person could not be contacted on day 28, try to get all necessary information as soon as possible, and within the next few days.

Some possible ways to follow up with patients after discharge from hospital include:

- Direct examination, e.g. during a home visit, outpatient department or in hospital.
- Medical record review, if the patient is still in the hospital at day 28.
- Telephone interview with the patient or close relative.
- Questionnaire posted to the patient.

Note: Confidentiality, ethical issues and other legal aspects in terms of performing a follow up should be clarified before starting data collection.

Guide to Completing the Instrument: Fatal Community Events (Step 2)

Introduction Step 2 covers identifying and registering every fatal stroke event treated in community and not admitted to hospital.

How information is collected S2 3 (Core) There are three main methods for collecting information about fatal stroke events in the community. These include:

- verbal autopsy
- death certificates
- medical autopsy.

For further information on each of these methods see page 5-5.

International classification of diseases (ICD) S2 4 - 5 (Core) The International Classification of Diseases (ICD) system is commonly used to record the cause of death on death certificates. There are three versions of the ICD codes and a range of eight or nine coded diseases that may relate to stroke as the cause of death. Some of these disease will not meet the definition of stroke, but should be included in all broad searches for stroke events.

The ICD versions and codes are as follows:

Version	Codes	Disease
ICD 8 ICD 9	430	Subarachnoid haemorrhage
	431	Intracerebral haemorrhage
	432	Other and unspecified intracranial haemorrhage
	433	Occlusion and stenosis of precerebral arteries
	434	Occlusion of cerebral arteries
	435	Transient cerebral ischemia
	436	Acute but ill-defined cerebrovascular disease
	437	Other Ill-defined cerebrovascular disease
	438	Late effects of cerebrovascular disease
ICD 10	I60	Subarachnoid haemorrhage
	I61	Intracerebral haemorrhage
	I62	Other non-traumatic intracranial haemorrhage
	I63	Cerebral infarction
	I64	Stroke, not specified as haemorrhage or infarction
	I65	Occlusion and stenosis of precerebral arteries, not resulting from cerebral infarction
	I65	Occlusion and stenosis of cerebral arteries, not resulting from cerebral infarction
	I67	Other cerebrovascular diseases
	I68	Cerebrovascular disorders in diseases classified elsewhere
	I69	Sequelae of cerebrovascular disease

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Guide to Completing the Instrument: Fatal Community Events (Step 2), Continued

Verbal autopsies (Optional)

The purpose of Verbal autopsies (VA) is to describe cause of mortality at a community or population level where no better alternative resources exist. Verbal Autopsies are based on interviews with friends and relatives of a deceased person. After an interview has been conducted, the following takes place:

- A panel of physicians reviews the forms and assigns a probable cause of death.
- Medical records coders trained in ICD rules select and code the underlying cause of death, according to a code score.
- Mortality results are tabulated using a standard list capable of generating comparable mortality statistics.

Unfortunately, the tools and methods employed are often imperfect and require rigorous validation and continuous quality assurance.

Guide to Completing the Instrument: Non-Fatal Community Events (Step 3)

Introduction

Step 3 covers identifying and estimating the non-fatal stroke events treated in community and not admitted to hospital. This is the most difficult component of case finding, and efforts at estimating the number of people who would otherwise be missed by a focus only on patients admitted to hospital are essential to show the true incidence of stroke.

How information is collected S3

There are two main methods for estimating non-fatal stroke events in the community. These include:

- Tracking medical practices (health facilities) by survey, and
- Prevalence or Hemiplegia/ hemiparesis survey.

For further information on each of these methods see page 5-7.

Other methods such as capture/re-capture using multiple overlapping sources are available. Please discuss approaches relevant in your setting with the ICC.
