The WHO STEPwise approach to stroke surveillance
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The proposed WHO stepwise approach to stroke surveillance
1. Foreword

In many parts of the world, the proportion of the population surviving until their 50s and 60s is increasing. This trend will have immense effects on the demographic structure of societies in the near future. The global population aged over 65 years is increasing by 9 million a year, and by year 2025 there will be more than 800 million people over 65 years of age in the world. Two-thirds of them will be living in developing countries. For example, in China alone, there will be more than 180 million people over the age of 65. Increases of up to 300% of the older population are expected in many developing countries within the next 30 years, especially in Latin America and Asia. One of the biggest challenges for many nations will be to prevent and postpone disease and disability and to maintain the health, independence and mobility of an ageing population. Many of the chronic conditions of old age, including stroke, can be successfully detected, prevented and treated, but intervention and prevention must start now if epidemics are to be avoided.

Globally stroke is the second leading cause of death. It is a disease that predominantly occurs in adults and the elderly. In 2001 it was estimated that cerebrovascular diseases (stroke) accounted for 5.5 million deaths world wide, equivalent to 9.6% of all deaths. Two-thirds of these deaths occurred in people living in developing countries and 40% of the subjects were aged less than 70 years. Thus, while many of these countries are struggling with the consequences and problems of communicable diseases, noncommunicable diseases are on the rise. In addition to being a major cause of death, many surviving stroke patients are disabled and need help in activities of daily living, which must be provided by family members, the health system, or other social institutions.

In response to this situation, the World Health Organization (WHO) has intensified its efforts to support member countries in their activities to address the problems related to an ageing population, with emphasis on the surveillance of the major NCDs. This will enable countries and their communities to assess the magnitude and profile of the burden of these diseases, and to facilitate the design of appropriate interventions and to monitor their effectiveness.

To facilitate this process, WHO has commissioned the production of a manual with basic tools for establishing a stroke surveillance system that is pertinent to the needs and relevant to their environment, especially cognisant of the availability of resources.

The manual guides the reader through the process of designing a stroke surveillance system, providing core and optional data elements, with standard definitions and categories, thus permitting various levels of detail as may be accommodated by the environment. Sample forms and output reports are also provided. The stroke system provides a mechanism by which data may be compared across different localities and time periods to provide a more accurate description of the problem internationally. Such a system will effectively direct and coordinate the international effort to address the problem.

Every attempt has been made to make this manual as easy to use as possible. Users are strongly urged to read the manual at least twice before applying its precepts, since the
sequence of topics is an imposed one for the sake of convenience. Many of the activities occur concurrently, interactively and/or iteratively.
2. Introduction to the WHO Stroke Surveillance System

The WHO stroke surveillance system consists of 6 modules arranged on three different steps according to which stroke patient category is included, Figure 1. The three steps represent the possible initial outcomes for stroke patients: events in hospital, fatal events in community, and non-fatal events in community. The stroke surveillance system begins with cases admitted to hospital, as this group is the one most easily identified, and follow these patients until discharge or death. The second level of complexity involves identifying and validating the diagnoses for fatal instances of stroke where the patient is not admitted to a hospital, i.e., the fatal events in the community. The third step represents non-fatal non-hospitalised events.

The optimal stroke surveillance system requires collection of data from all three steps. However, costs and complexity increase when more details are wanted and it may not be feasible to obtain all levels of the stroke surveillance system especially in countries with limited resources, or where health services are poorly established. Therefore, a requirement is that the surveillance system should be flexible and able to function in different settings, and still yield data that can allow comparisons between populations and time periods. The WHO surveillance system seeks a balance between feasibility and practicality at the same time as being sufficiently attractive to ensure participation of both less developed countries and more developed countries.

2.1 STEP 1: Events in hospital (health facilities)
Module 1 represents the core data such as age, gender, identification of whether it is a first-time or recurrent stroke, and vital status (dead or alive) at discharge from hospital. This module represents data, which should be possible to collect in all countries. The two other modules in step 1 of the stroke surveillance system (module 2 and 3) are optional and can be adopted according to local needs. Module 2 includes measures of functional level, and medical treatment received during the stay in hospital and prescribed at discharge. Until this point access to technological facilities is not required. Classification of the stroke as either ischemic or hemorrhagic requires advanced technical equipment, and constitutes the most comprehensive level of data collection in hospitalised stroke patients, module 3.

2.2 STEP 2: Fatal events in the community
Reports from both developed and developing countries indicate that a large proportion of fatal stroke events occur without admission to health facilities. Fatal events that occur in the community constitute the next level in the hierarchical approach to surveillance of stroke. The first component is to get information from death certificates or by using verbal autopsies, module 4. Identification of stroke events using death certificates are only possible in communities with a stable and continuing certification of causes of death. However, in many countries death certificates are either not routinely issued or their validity is doubtful. Verbal autopsies, based on interviews with close relatives or care-takers, are increasingly being used to monitor the distribution of death by cause in places where medical certification of cause of death is uncommon. A standardized verbal autopsy questionnaire is being developed but not ready and therefore not included in the present document.
Data from autopsies represent the next level of complexity, module 5. There is variation between countries regarding the proportion of deaths undergoing autopsy, and often this proportion only includes a minority of all fatal stroke events. Nevertheless, it provides an opportunity to classify the stroke according to type, and to obtain knowledge about causes for the stroke symptoms other than vascular disease.

2.3 **STEP 3: Non fatal non hospitalised events**

Patients with stroke who are cared for entirely within the community are difficult to identify but may constitute a large proportion of the total number of stroke patients. Thus advancing to include this group of stroke patients represents the most complex level (module 6). Self-reports of acute symptoms compatible with stroke are an inadequate basis on which to make this diagnosis. The aim, therefore, should be to estimate the number of non-fatal events that are recognized medically as cases of stroke but where the patient is not managed in hospital. Two different methods are described, which may be used for estimating the number of subjects in this group.

In summary, the WHO STEP-wise approach to stroke surveillance provides a flexible system and an opportunity for all countries to contribute data on stroke. The level of complexity will depend on development of health services and resources, and each participating country may collect precisely the amount of data that it finds is feasible.

2.4 **Source population**

Each of the three steps contributes with a proportion of all the stroke events that occur within the population and for the results to be meaningful it is essential that the source population be well defined. This means that the total number of men and women in the different age groups should be known. The registration of stroke events in hospital will then be an estimate of the admission rate for stroke (Step 1), the stroke mortality rates (Step 2), and the incidence and case fatality (Step 3), with additional details according to level of complexity. Commencement of the WHO STEPS Stroke system is encouraged only in countries/areas where it is possible to provide an accurate estimate of the source population (further information in section 10 p. 30). Step 1 can be undertaken without knowledge of the reference population but will in this case not provide the admission rate.
3. Surveillance

Data generated by surveillance systems are used to assess the magnitude of a disease, describe populations at risk, identify associated risk factors, and monitoring trends over time. Such data provide the basis for designing and implementing interventions, and monitoring and evaluating their effectiveness.

Surveillance is the ongoing systematic collection, analysis, interpretation and dissemination of health information. The primary purpose of establishing and maintaining a system of surveillance is to provide health workers and policy makers with a reliable tool to plan cost-effective strategies to meet the demands for health care and prevention in the population. Furthermore, it enables researchers to monitor trends of the disease in the population at different times, and helps to evaluate the success of prevention and treatment strategies.

Surveillance differs from health information systems, for example registration of births and deaths, in that these latter systems are not necessarily set up to provide information to be used for public health issues. Surveillance also differs from surveys, which are usually designed to give a picture of the situation at one moment in time. Measures of diseases at only one period of time yield data of limited interest since the estimates could be an expression of random variation. Furthermore, only by comparison with other population groups, and by following the trends within the population, does a meaningful picture emerge of the burden of the disease and the potential gains from prevention and intervention.

3.1 Why we need a stroke surveillance system

World-wide cancer, heart disease, and stroke are serious NCDs that have huge consequences in terms of lost productivity, premature death, and long term disability. Thus, surveillance systems for heart disease and cancer are just as warranted as for stroke. However, unlike stroke, heart disease and cancer rely on access to laboratories, and medical specialists, whereas stroke is a clinically defined disease, which makes it possible to follow trends in many different countries irrespective of access to technological equipment.

Several clinical trials and numerous epidemiological studies have shown that stroke to a large extent is preventable. Two of the major risk factors for stroke are level of blood pressure and tobacco smoking. However, public actions to lower the prevalence of exposure to risk factors are unlikely to be taken, if a problem (disease) is not identified. A well-conducted stroke surveillance system provides the necessary information to ensure appropriate allocation of health resources. As stroke is a costly disease because of the large numbers of premature deaths as well as ongoing disability in many survivors, the results would be of interest to health planners and hospital authorities.

3.2 Stroke surveillance in developed and developing countries

Countries with existing data collection systems may be able to incorporate several elements of the WHO stepwise approach to stroke surveillance at relatively low costs. Conversely, in countries without such systems it may represent a major challenge to establish all the necessary parts of a surveillance system. It is therefore emphasized that the most important issue is to start the surveillance program, for example by inclusion
of one or more sentinel sites, and then gradually progress towards a national sample. The basis for the core data in the WHO STEPS Stroke project presented in Module 1, is that establishment of a system to collect these data represents the corner stone from which the variety of more elaborated data can develop.

Starting the collection of hospital data will provide data that can be used to evaluate the treatment, complications, and prevention of stroke. Furthermore, it will provide an opportunity for the training of people who will be involved with the study. When sufficient knowledge has been obtained, inclusion of stroke deaths will require only the additional detection of deaths in the population, and finally the non-fatal non-hospitalised events can be included. Thus, it is advised to start with a study population that can be handled, learn from the experience, and then move on to the next steps in the surveillance system.
4. Stroke

The recommended standard WHO stroke definition is “a focal (or at times global) neurological impairment of sudden onset, and lasting more than 24 hours (or leading to death) and of presumed vascular origin”.

This definition has been employed for decades in many different settings, and has proven to be a valuable tool that may be used irrespectively of access to technologic equipment. Although many countries already have invested in diagnostic tools such as neuro imaging, enabling sub typing and more detailed descriptions, the clinical definition remains the standard and is suitable for future studies of stroke. The definition excludes transient ischemic attack (TIA), which is defined as focal neurologic symptoms but lasting less than 24 hours. Subdural hemorrhage, epidural hemorrhage, poisoning, and symptoms caused by trauma are also excluded.

Occasionally, a focal brain lesion compatible with a previous stroke is randomly found in patients undergoing neuro imaging for other reason than stroke. However, if there is no history of corresponding symptoms the diagnosis of stroke is not met. Thus, it is emphasised that stroke is a clinical diagnosis and not based on radiological findings.

4.1 Types of stroke

There are three major stroke sub groups; ischemic stroke, intracerebral hemorrhage, and subarachnoid hemorrhage. Each of the types can produce clinical symptoms that fulfill the definition of stroke, however, they differ with respect to survival and long-term disability.

Ischemic stroke is caused by a sudden occlusion of arteries supplying the brain. The occlusion may either be due to a thrombus formed directly at the site of occlusion (thrombotic ischemic stroke), or be a thrombus formed in another part of the circulation, which follows the blood stream until it obstructs arteries in the brain (embolic ischemic stroke). The diagnosis of ischemic stroke is usually based on neuro imaging recordings, but it may not be possible to decide clinically or radiological whether it is a thrombotic or embolic ischemic stroke.

Intracerebral hemorrhage is a bleeding from one of the brain’s arteries into the brain tissue. The lesion causes symptoms that mimic those seen for ischemic stroke. A diagnosis of intracerebral hemorrhage depends on access to neuroimaging where it can be differentiated from ischemic stroke. Spontaneous intracerebral hemorrhage may be more prevalent in developing countries than in developed countries. The reasons for such differences remain unclear but variations in diet, physical activity, treatment of hypertension, and genetic predisposition may be responsible.

Subarachnoid hemorrhage is characterised by arterial bleeding in the space between the two meninges pia mater and arachnoidea. Typical symptoms are sudden onset of very severe headache and usually impaired consciousness. Symptoms that mimic stroke may occur but are often rare. The diagnosis can be established either by neuro imaging or lumbar puncture.

Criteria for how to classify type of stroke are given in section 7.3.
4.2 Causes of stroke

Stroke is a multi factorial disease where many determinants have been described. These determinants, or risk factors, can be divided into modifiable and non-modifiable. Age and sex are examples of two well-known risk factors for stroke; high age and male sex are in many populations associated with an increased risk. Although they are of major importance in predicting the occurrence of stroke in the community, they cannot be modified. In contrast, reduction in the exposure to modifiable risk factors may lead to a lower occurrence of stroke such as tobacco smoking, physical activity, diet, or factors in the environment such as passive smoking, and access to medical treatment. The combination of these risk factors, which do not all have to be present, will over time influence the subject’s likelihood of suffering a stroke.

Figure:

- Individual characteristics
- Stroke
- Risk factor(s)

Previous stroke and TIA are well-known risk factors for a new cerebrovascular event. Stroke survivors are a group of patients who are known to have an increased risk of suffering a new stroke, as compared with the background population. This may be due to damages of the cerebral blood vessels, or other co-morbidities, some of them eminable to intervention. Attention should therefore be directed to the opportunity to lower the person’s risk by pharmaceutical intervention (for example lowering the blood pressure) and changes in life style (smoking cessation, increased physical activity, change in diet), while in contact with the health care system.

Assessment of risk factors is not included in the present version of the WHO STEPS-Stroke manual, but can be added as optional.

4.3 How to prevent stroke?

Prevention can be divided into three groups: primary, secondary, and tertiary prevention. Primary prevention is aimed at reducing the occurrence of stroke in the first place. This could be through population wide initiatives to increase physical activity or legislation to control tobacco smoking. Secondary prevention is aimed to reduce the risk of stroke occurrence in people who already are at a greater risk of stroke, for example, hypertensive people, smokers, and diabetics. Tertiary prevention is aimed to reduce the consequences and damages in stroke patient, for example, through treatment of infections in the acute stage, management of co-morbidities, and improved rehabilitation.
However, efficient prevention relies on access to good data on stroke. The more modules that are included the better data for public health advice and patient treatment are provided.

4.4 Other causes of stroke symptoms

According to the definition of stroke the symptoms should be of “presumed vascular origin”. This is important as the link between the results from stroke surveillance to public health actions relies on this and the majority of the stroke events due to vascular disease are related to the exposure to factors such as hypertension, smoking, a sedentary lifestyle, and obesity. However, a broad range of other diseases may cause similar symptoms, for example the following:

- Syphilis
- HIV/AIDS
- Tuberculosis
- Intracerebral cancer

These diseases are known to be able to cause focal neurologic disturbances and thereby mimic a stroke. Attention to the progression of diseases is therefore important to avoid other diseases being misinterpreted as vascular disease, and leading to ineffective preventive strategies.
5. The WHO Stroke Surveillance System

This section provides a detailed description of the WHO STEPS Stroke project. The first section is general for all levels in the system and includes the definition of stroke and clinical stroke symptoms. Thereafter, the questionnaires relating to each of the 6 modules will be presented together with detailed examples on how to complete them.

5.1 Definition of first-time stroke, recurrent stroke, fatal and non-fatal stroke

The recommended WHO stroke definition is “a focal (or at times global) neurological impairment of sudden onset, and lasting more than 24 hours (or leading to death) and of presumed vascular origin” \(^5\).

A first-ever stroke means a stroke that occurs in a person who never has had a stroke before. Previous TIA is not considered a stroke as these events last less than 24 hours. Careful review of the patient’s history may be required to differentiate between a previous stroke and previous TIA as the two episodes may be mistaken. A recurrent stroke is defined as a person with a history of a previous stroke, and who is being registered with a new stroke event. Survival and disability rates are different between first-ever stroke and recurrent stroke and it is therefore of interest to distinguish between the two types.

A patient with a non-fatal event is one who survives at least 28 days after the onset of the stroke, while a fatal event denotes a stroke that resulted in death of the patient within 28 days, both are calculated by subtraction of dates. However, patients may experience a new and entirely unrelated stroke in the territory of another of the four major cerebral arteries during that time due to any of haemorrhage, thrombosis or embolism. Thus, for a new episode of symptoms to be counted as a new ‘case’ the general criteria of the definition of stroke must be met and either the previous event in the same arterial distribution must have occurred 29 or more days previously (by subtraction of dates) or the new event is unequivocally in a different arterial territory from a earlier one occurring 28 or fewer days previously. If a patient experience further acute symptoms suggestive of stroke within 28 days of the onset of a first episode and in the same carotid or vertebral artery territory, this second episode is not counted as a new ‘case’.

5.2 Stroke symptoms

The definition of stroke includes reference to focal or global disturbance of the cerebral function. One or more of the following definite focal signs must be present to make a diagnosis of stroke.

**Definite focal signs**

Definite focal signs are clinical presentations, which can be accepted as indicative of a stroke. It must be remembered that the time dimension (lasting more than 24 hours or leading to death) must be met and the signs must have developed of a presumed vascular origin.

- **Unilateral or bilateral motor impairment (including uncoordination)**
- **Unilateral or bilateral sensory impairment**
- **Aphasia/dysphasia (non-fluent speech)**
- **Hemianopia (half-sided impairment of visual fields)**
• Diplopia
• Forced gaze (conjugate deviation)
• Apraxia of acute onset
• Ataxia of acute onset
• Perception deficit of acute onset

Unspecific focal or global signs
These clinical presentations are not adequate for a diagnosis of stroke, as they often occur as a result of other diseases or abnormalities (for example dehydration, cardiac failure, infections, dementia, and malnutrition). Even if they develop sudden and lasts for more than 24 hours additional evidence must be obtained. This could be definite focal neurologic impairment, or evidence of intracerebral ischemia or hemorrhage, or subarachnoid hemorrhage.

• Dizziness, vertigo
• Localized headache
• Blurred vision of both eyes
• Dysarthria (slurred speech)
• Impaired cognitive function (including confusion)
• Impaired consciousness
• Seizures
• Dysphagia

The term “global” refers to patients with subarachnoid hemorrhage or deep coma but excluding coma of systemic vascular origin such as shock, Stokes-Adams syndrome or hypertensive encephalopathy.
6. Unique identification of the patient – all modules

The questionnaires (see appendix A) for each of the 6 modules are presented separately for clarity but should be combined into one when used.

The first part identifies the patient and must ensure that each is uniquely identified.

(I 1 through 5) Country, center, and interviewer codes. Will be provided when a centre is applying for joining the WHO STEPS Stroke Project.

(I 6) Patient’s family name: Write the patients family name with capital letters. In case there are several names should all be included and the most common used should be underlined.

(I 7) Patient’s first name: Write the patients first name with capital letters. In case there are several names all should be included and the most common used should be underlined.

(I 8) Sex: Record sex as observed entering either 1 for male or 2 for female.

(I 9) Date of birth: The variable consists of 8 digits for day, month and year for example 02041954 for the second of April 1954. It should be noted that all dates in the questionnaire are written in the same format as this example. If the patient’s date of birth is unknown the approximate age of the person can be used as an alternative (I 10). However, this is a less certain identification and should be avoided whenever possible.

Stroke occurrence is highly dependent on age, and rates are often higher for men than for women. In many populations more women than men reach high age, which may explain why there may be an absolute higher number of women than men getting a stroke. Knowing the age of patients admitted to hospital with stroke forms the basic of projections of the need of medical care in the future.

(I 11) Contact telephone number: The contact telephone number can be any telephone number, which enables an easy contact to the patient. Thus, it is not necessarily the telephone number of the patient. It is advised to enter area codes and that these should be easy identified being shown in brackets ()..

This information is optional as not all patients may wish to give their address, and/or telephone number. However, it is a good way to further identify the patient and facilitates contacting the patient for further examinations.

(I 12) Specify whose phone: For later references please indicate who will be contacted when using the telephone number.

(I 13) Unique identification number: In some countries centrally allocated unique identification numbers are used (for example social security number, personal identification number, etc) and may provide the best way to identify the study subjects. It is optional, applicable where possible and feasible.
7. **STEP 1: Stroke patients admitted to hospital**

Stroke patients admitted to hospital constitute a selected group of stroke patients. They must have survived until hospitalisation, and must have been able to get to the hospital either by themselves or with the help from relatives/care givers. There are substantial differences between countries regarding the proportion of stroke patients who are admitted to hospital, and many stroke patients in developing countries are not admitted to hospital\(^6\). Furthermore, admission practices may change over time and these differences limit comparison of rates within and between populations. Nevertheless, data based on hospitalised events give valuable information for local health authorities, and will constitute the first step to a better understanding of stroke in the population.

**Identifying the stroke patients**

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 differentiating stroke from TIA and from other conditions such as hemiplegic migraine and epilepsy. If the patient can reach hospital, major strokes are likely to be admitted but more minor ones may be assessed in the Emergency Room or Outpatient Department and sent home again.

**Setting priorities for stroke surveillance**

In order to avoid the challenges of follow-up of minor cases in the community, the surveillance for stroke managed in hospital should be limited to patients who are admitted with a provisional diagnosis of having experienced the onset of a new stroke. However, it should also include patients who suffer a stroke while in hospital and those who present to the Emergency Room in a moribund state following an episode suggestive of stroke and who die soon afterwards. The criteria for ascertainment and registration need to be generous in order that all unusual presentations of stroke are identified.

**Examples of admission diagnoses that should be considered for registration include:**

- (acute) stroke or (acute) cerebrovascular episode
- transient (cerebral) ischemic attack
- cerebral or cerebellar embolus, thrombosis or infarction
- lacunar hemorrhage or stroke
- (acute) hemiplegia or (acute) hemiparesis
- faint, fit, funny turn, (acute) confusional state or loss of consciousness – for investigation
- subarachnoid, (primary) intracerebral, cerebellar or pontine hemorrhage or stroke
- ruptured berry aneurysm
- occlusion, thrombosis or embolus of carotid, (pre) cerebral or vertebral artery
- (acute) dysphasia, dysarthria, dyspraxia or homonymous hemianopia – for investigation
- extradural or subdural hemorrhage
- amaurosis fugax
- acute monocular blindness
General approaches to hospital based event ascertainment

Ascertainment would normally begin with the Emergency Room daybook and admissions book. However, cases of stroke may also be admitted from outpatient clinics and via radiology departments to which they have been referred for assessment or investigation. It is necessary also to devise systems in each hospital to detect patients who suffer a stroke while in hospital, whether intra-operatively or at some other time, and whether in acute or on long-stay wards. For example, patients in this group may be found by monitoring requests to specialist physicians or neurologists to provide a consultant opinion, or to physiotherapists, speech or occupational therapists for assessment and assistance in management. A further group of patients that should be registered are those who present in a moribund condition and die in the Emergency Room after apparently suffering a stroke. Discharge diagnoses may also be reviewed in order that possible strokes are not missed.

7.1 Module 1: Core data

- **Date of stroke symptoms onset**
- **Vital status day 10**

(M1-1) *Date of stroke*: Enter the date for stroke symptoms onset.

(M1-2) *Definite stroke*: The questionnaires relating to modules 1, 4, 5 and 6 in the Stroke Surveillance System include fields to enter whether the event was a definite stroke (1), not a stroke (2), or if there were insufficient data (3) to provide a conclusive diagnosis. This question is answered by inserting the corresponding number. The number of events designated to have insufficient data (3) should be kept as low as possible.

The questionnaires for modules 2 and 3 do not include this question, as they will be preceded by completion of module 1.

(M1-3) *Has the patient had a previous stroke*: In order to differentiate between a first-time event and a recurrent event it is important to obtain information about possible previous strokes. It is emphasised that a TIA is not counted as a stroke.

There five different answers: Yes, records seen (1), yes, records not seen (2), no, records seen (3), no, records not seen (4), insufficient data (5). This question is answered by inserting the corresponding number. The amount of events designated to have insufficient data (5) should be kept as low as possible.

(M1-4) *Vital status day 10*: There are four categories: patient alive (1), death directly related to stroke (2), death unrelated to stroke (3), and death, unknown cause (4).

Follow-up of hospitalised stroke patients until day 10 covers most fatal complications directly related to the stroke such as herniation. It also falls within the average length-of-
stay in hospital for uncomplicated stroke. It provides the 10-day case-fatality of hospitalised patients, and comparison of this measure between and within populations is of importance in order to improve treatment of stroke itself and its complications.

Death directly related to stroke includes expansion of the stroke, incarceration, respiratory distress occurring in direct association with the stroke (pneumonia), and embolus to the lungs. Death unrelated to stroke is for example myocardial infarction, diabetes, cancer, poisoning, surgical complications, and accidents. Finally, death of unknown relationship to stroke should only be used on the rare occasions where thorough examination of the patient’s file is inconclusive.

This question is answered by inserting the corresponding number. The amount of events designated to have unknown relationship to stroke (5) should be kept as low as possible.

(M1-5) Race: The risk of stroke and type of stroke differs between races. Please indicate the race of the patient as judged at the examination.

There are 4 possible answers: Asian (1), Black (2), White (3), and Others (4).

(M1-6) If patient dead at day 10 indicate date of death. Insert the date of death.

(M1-7) Vital status at 28 days from stroke onset: This question is optional, as it will include follow-up of a substantial proportion of stroke patients who have been discharged from hospital.

There are four categories: patient alive (1), death directly related to stroke (2), death unrelated to stroke (3), and death, unknown cause (4).

How to code is similar as for vital status at day 10 (please see M1-4).

(M1-8) If patient dead at day 28 indicate day of death: Insert the data of death.

7.2 Module 2: Treatment and disability

- Admission to hospital departments
- Pharmaceutical treatment
- Vital status at 28 days
- Modified Rankin scale
- The National Health Institute Stroke Scale

Note: Module 2 should always be accompanied by the Module 1 questionnaire.
(M2-1) Which department was the patient treated in? There are 7 possible answers: acute stroke unit (1), neurology ward (2), rehabilitation stroke unit (3), neuro surgery (4), acute medical unit (5), geriatric unit (6), and other (9). As a patient may be treated in several different departments multiple answers are allowed. The question is answered by inserting the relevant numbers in the data entry column.

Studies from developed countries have shown that stroke patients admitted to a hospital department with a specialised stroke team have a better outcome than patients admitted to departments without such teams, measured in terms of long term reduction of death, and of dependency and institutionalisation. The beneficial effects are independent of the patient’s age, sex, or stroke severity. The length of stay in hospital or institution is significantly reduced compared with conventional care. Monitoring the departments in which the stroke patient is treated allows local health officers and health decision-makers to see how the hospital services are being used, and if there is adequate provision.

Stroke patients may be treated in several different departments for example in the medical unit, a stroke unit, and finally in a rehabilitation unit. To get a complete overview of the use of all departments local researchers must extend the section of the questionnaire to include data of admission and discharge from each unit.

(M2-2), (M2-3), and (M2-4) Pharmaceutical treatment: In the questionnaire there are three main categories: drug treatment before stroke (M2-2), drug treatment in hospital (M2-3), and drug treatment at discharge (M2-4). Each category is sub-divided into six or seven categories: tablets for high blood pressure (1), aspirin (2), warfarin (3), dipyridamole (4), clopidogrel (5), cholesterol lowering drugs (6), and thrombolysis (7). If the patient’s pharmaceutical treatment is unknown this is indicated by inserting a (9) for “unknown”. By treatment is meant a continuous medication (i.e., that will be sustained also when the patient is discharged), following a predetermined set of standards. The only exception is for thrombolysis, which is only given one time.

The question is answered by inserting the relevant numbers in the data entry column and multiple answers are possible.

The different medications have all been shown to reduce risk of stroke or stroke severity in selected groups of patients in predominantly developed countries. Both new and old anti-hypertensive drugs are effective lowering the blood pressure and substantial reductions in stroke occurrence can be achieved through an efficient effort to control blood pressure in the population. Anti-coagulant therapy is used primarily in patients with chronic atrial fibrillation, and for preventing deep vein thrombosis and pulmonary emboli in patients. Aspirin given to patients with transient ischaemic attack and ischaemic stroke is an inexpensive and highly effective way of reducing subsequent cardio-vascular disease. It is perhaps the only feasible strategy in many countries. However, aspirin may also increase the risk of hemorrhagic stroke. It remains unclear whether low-dose aspirin should be administered to stroke patients in developing countries without access to CT scans. If the proportion of hemorrhagic stroke is large, the beneficial and adverse effects of anti platelet treatment may no longer favour aspirin administration. In order to get these data, follow-up of the pharmaceutical treatment of stroke patients is desirable. However, this is beyond the scope of the WHO STEPS Stroke system but could be added as optional.
(M2-5) Vital status at 28 days from stroke onset: Follows the same instructions as for vital status at day 10 as described for Module 1 (please see M1-4 to M1-7).

(M2-6) If patient dead at day 28 indicate day of death: Insert the date of death.

(M2-7) Measure of neurological deficit: The National Institutes of Health Stroke Scale (NIHSS) is one of the most frequently used stroke scales and it is a quantitative measure of stroke related neurological deficit including level of consciousness, language function, neglect, visual fields, eye movements, facial symmetry, motor strength, sensation, and co-ordination. It is a test that has been used in several clinical stroke trials, can be performed in 5 to 8 minutes, and can be reliably administered after short training. The NIHSS is available online at [http://www.stroke-site.org/stroke_scales/stroke_scales.html](http://www.stroke-site.org/stroke_scales/stroke_scales.html) including questionnaire, definitions, and associated materials. The NIHSS should be administered at admission or within the first 48 hours.

(M2-8) Modified Rankin scale: The scale is divided into 6 levels (from level 0 to level 5), where 0 is no impairment at all and 5 is severe disability. The Modified Rankin scale should be used 28 days after stroke, a time where most stroke patients have reached a stable state. The number corresponding to the patient’s functional level is to be entered. For patients dying before day 28 please insert (9) for unknown.

Both telephone interview and physical examination are acceptable methods to evaluate the functional status of the patient.

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.

(M2-9) Follow-up for Modified Rankin Scale: The method used for measuring the Modified Rankin Scale in subjects surviving until day 28 is indicated for each patient. If physical examination was used insert (1), and telephone interview is indicated by (2). Use “does not apply” (3) for patients who died within the first 28 days. If other means of contacting the patient was used other than physical examination or telephone interview this is indicated inserting “other” (4), and if it is not possible to contact the patient, or survival status is unknown use “unknown” (9).
7.3  Module 3: Stroke subtypes

- **Subtype classification**
- **Investigations**
- **Timing between scan and stroke**

*Note: Module 3 should always be accompanied by the Module 1 questionnaire.*

Classification of the stroke events into ischemic or hemorrhagic subtypes relies on access to laboratories and imaging technology. The benefit from using neuro-imaging is that some misclassification will occur if clinical assessment alone is used. For example cancer in the brain may mimic a stroke. Whether an event is hemorrhagic versus ischemic is also of importance from a clinical perspective as aspirin should not be given to patients with hemorrhagic stroke.

Studies that include CT scans in their surveillance system should register days between onset and investigation of the stroke. Preferably the scan should be conducted within the first 2 weeks as minor bleedings otherwise may have been absorbed leading to incorrect classification of the event as ischemic stroke 15.

**Type of stroke (adapted from the MONICA protocol)**

**Subarachnoid Hemorrhage**

Symptoms: Abrupt onset of severe headache or unconsciousness or both. Signs of meningeal irritation (stiff neck, Kernig and Brudzinski signs). Focal neurological deficits are usually not present.

Findings:

At least one of the following must be present in addition to typical symptoms:

1. Necropsy – evidence of recent subarachnoid hemorrhage and an aneurysm or arteriovenous malformation;
2. CT – evidence of blood in the Fissura Sylvii or between the frontal lobes or in the basal cistern or in cerebral ventricles;
3. Blood stained cerebrospinal fluid (>2 000 red blood cells per mm³) and an aneurysm or an arteriovenous malformation found on angiography;
4. Blood stained cerebrospinal fluid (>2 000 red blood cells per mm³) that is also xanithochromic and intra-cerebral haemorrhage excluded by necropsy or CT-examination
Intracerebral hemorrhage

Symptoms: Usually sudden onset during activities. Often rapidly developing coma, but a small haemorrhage can present with no disturbance of consciousness.

Findings: Cerebrospinal fluid often, but not always, bloody or xanthochromic. Often severe hypertension is present. Intracerebral hemorrhage must be confirmed by necropsy or by CT-examination.

Brain infarction due to cerebral thrombosis/embolism

Symptoms: No severe headache, if one at all. Onset acute, sometimes during sleep. Often gradual progression of focal neurologic deficits. Usually, no, or only slight, disturbance of consciousness. TIA can often be detected in history. Often other symptoms of atherosclerosis (CHD, peripheral arterial disease) or underlying diseases (hypertension, diabetes) are also present.

Findings: Brain infarction in the necropsy or in the CT-examination and no evidence for an embolic origin

OR

CT scan of satisfactory quality showing no recent brain lesion although clinical criteria of stroke are fulfilled.

Insufficient data: If the special investigations are inconclusive this field should be used.

Investigations

Most studies that classify strokes into sub categories are likely to use brain imaging. As brain scans remain a costly procedure it is of interest to estimate differences between study populations in their use of this diagnostic tool.

(M3-1) Which diagnostic techniques were used: There are seven possible answers: CT scanning (1), MR scanning (2), angiography (3), lumbar puncture (4), other (5), does not apply (7), and unknown (9). The corresponding number must be inserted in the data entry boxes and there is a maximum of 5 entries allowed. Does not apply should be used for patients not being scanned.

(M3-2) Timing of the first scan after onset of stroke symptoms: The timing of the first scan after onset of stroke is an important issue as delays beyond 2 weeks may lead to re-absorption of small hemorrhagic stroke, causing the event to be misclassified as an ischemic stroke.

There are 6 possible answers: within 24 hours (1), between 24 hours and 7 days (2), between 8 to 14 days (3), more than 14 days (4), does not apply (7), and unknown (9). The relevant number should be entered in the data entry column. Please use the does not apply option for patients who were not scanned.
(M3-3) *What type of stroke was diagnosed?* Please insert the number corresponding to the type of stroke the patient had: ischemic stroke (1), intracerebral hemorrhage (2), subarachnoid hemorrhage (3), or unknown type (9).

For patients where no diagnostic examination was done the unknown type option should be used. Patients with hemorrhagic transformation of an ischemic stroke are included as a patient with ischemic stroke.
8. **STEP 2: Fatal community events**

The characteristics of stroke patients who die out of hospital are likely to differ substantially between and within countries according to the availability and accessibility of health care services in the community. Economic factors might keep people with low income from using health facilities, and local differences in the severity of strokes may be a natural cause of a high proportion of fatal events not being admitted to hospital. The development of infrastructure, and the overall accessibility of health facilities are factors that are likely to differ across time and space.

The main argument for proceeding to this level in the stroke surveillance system is to enable an estimation of the stroke mortality in the study population, and to estimate the years lost prematurely due to stroke.

**General approaches to event ascertainment**

The objective is to identify and document every fatal episode that might have been due to stroke. This includes deaths following onset of symptoms suggestive of stroke where the patient either did not seek medical help or there was a delay in obtaining medical help and sudden unexpected deaths in individuals who had previously appeared well. Events where the death is not observed present a particular challenge, especially if the body is not discovered for some time.

8.1 **Module 4:**

- **Verbal autopsies**
- **Death certificates**
- **Vital status at day 10 or 28**

Expanding the surveillance of stroke to include either verbal autopsies or death certificates constitute the second step in the Stroke Surveillance System.

**Verbal autopsies**

An official WHO verbal autopsy for adult deaths is currently being developed. The method is therefore not ready to be implemented and will only be briefly presented.

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. So far, VAs have predominantly been used to assess causes of childhood and maternal deaths, and adult deaths in only few studies. The VA technique is based on the assumption that most causes of death have distinct symptom complexes, and that these can be recognised, remembered and reported by health professionals or lay respondents. It also assumes that it is possible to classify deaths, based on the reported information, into useful categories of cause of death.

At the present time there is no generally accepted way of using VAs to assess the proportion of deaths in a community due to stroke. A key feature is to have a validation
study so the specificity, sensitivity, and predictive positive value can be determined. This should ideally include both hospitalised and non-hospitalised stroke events. However, in recognition of the very challenging task of conducting validation studies for events out of hospital, it is recommended to restrict it to patients who died in hospital. The main issue is to ensure a high specificity (few false positive events), even if that decreases the sensitivity (proportion of false negative events), but issues such as disease prevalence in the population also has an important impact on the generated results.

We recommend that researchers who wish to undertake VA in their stroke studies get in contact with researchers who previously have had experience with this new epidemiological tool. If VA is used for module 4 of the STEPS-Stroke project please indicate that on the “study information sheet”, appendix C.

Death certificates
Communities that have universal medical certification of cause of death provide a direct information source to obtain data on deaths due to stroke. However, delays in processing death registrations and certificates may occur, hampering follow-up enquiries because either the person who completed the certificate or the family of the patient has moved. There may be no alternative to searching completed death registration entries by hand, but, with the spread of electronic systems, it will increasingly become possible to search the full text of death certificates for keywords. Both hand searchers and those writing electronic search algorithms need to be aware of the wide variety of terms that may be used in the target population as synonyms for fatal stroke.

Death certificate codes with stroke as immediate or underlying causes of death should be identified and validated. Validation is based on any available medical and medico-legal records and, if necessary, interview of the decedent’s next-of-kin or another informant. Medical records for the period within a minimum of 28 days of death should also be examined for information that may elucidate the circumstances leading to death.

For studies using death certificates, the diagnosis of stroke must be based on information that clearly indicating that the patient had clinical signs fulfilling the definition of a stroke, or that other procedures such as neuro imaging or autopsies have been performed showing that it was a stroke the patient died from.

The International Classification of Diseases (ICD) is commonly used for death registration. The following codes should be used in the search for possible stroke events:

ICD  8 : 430 to 438
ICD  9 : 430 to 438
ICD 10 : I60 to I69

The questionnaire
(M4-1) Date of stroke: Enter the date for stroke symptoms onset.

(M4-2) Definite stroke: Indicate whether the event was a definite stroke (1), not a stroke (2), or if there were insufficient data (3) to provide a conclusive diagnosis. This question is answered by insertion of the corresponding number. The number of events designated to have insufficient data (3) should be kept as low as possible.
(M4-3) *Has the patient had a previous stroke:* In order to differentiate between a first-time event and a recurrent event it is important to obtain information about possible previous strokes. It is emphasised that a TIA is *not* counted as a stroke.

There five different answers: *Yes, records seen* (1), *yes, records not seen* (2), *no, records seen* (3), *no, records not seen* (4), *insufficient data* (5). This question is answered by insertion of the corresponding number. The amount of events designated to have insufficient data (5) should be kept as low as possible.

(M4-4) *Date of death:* Insert the date the patient died.

(M4-5) *Vital status day 10:* There are four categories: patient alive (1), death directly related to stroke (2), death unrelated to stroke (3), and death, unknown cause (4).

(M4-6) *Vital status at 28 days from stroke onset:* There are four categories: patient alive (1), death directly related to stroke (2), death unrelated to stroke (3), and death, unknown cause (4).

(M4-7) *International Disease Classification (ICD) system used:* Please indicate which ICD system was used for identifying the event by encircling the relevant revision.

### 8.2 Module 5: Medical autopsy
- **Type of stroke**
- **Vital status at day 10 or 28**

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.

(M5-1) *Date of stroke:* Enter the date for stroke symptoms onset.

(M5-2) *Definite stroke:* Indicate whether the event was *a definite stroke* (1), *not a stroke* (2), or if there were *insufficient data* (3) to provide a conclusive diagnosis. This question is answered by insertion of the corresponding number. The number of events designated to have insufficient data (3) should be kept as low as possible.

The questionnaires for modules 2 and 3 do not include this question as they will be preceded by completion of module 1.
(M5-3) *Has the patient had a previous stroke:* In order to differentiate between a first-time event and a recurrent event it is important to obtain information about possible previous strokes. It is emphasised that a TIA is *not* counted as a stroke.

There five different answers: *Yes, records seen (1), yes, records not seen (2), no, records seen (3), no, records not seen (4), insufficient data (5).* This question is answered by insertion of the corresponding number. The amount of events designated to have insufficient data (5) should be kept as low as possible.

(M5-4) *Date of death:* Insert the date the patient died.

(M5-5) *Vital status day 10:* There are five different categories: patient alive (1), death directly related to stroke (2), death unrelated to stroke (3), and death, unknown cause (4).

(M5-6) *Vital status at 28 days from stroke onset:* There are five different categories: patient alive (1), death directly related to stroke (2), death unrelated to stroke (3), and death, unknown cause (4).
9. **STEP 3: Non-fatal community events**

Extending data collection also to include subjects who get a non-fatal stroke and who are not admitted to a health facility constitutes the third step in the WHO STEPS Stroke Project.

9.1 **Module 6: Non-fatal community events**

- Surveillance by medical practice
- Surveillance by surveys

Non-fatal non-hospitalised events are usually the stroke patients with the less severe strokes and it is often the most challenging proportion of the stroke patients to identify.

Continuous surveillance of communities for non-fatal cerebrovascular events managed out of hospital is impractical. Moreover, self-reports of acute symptoms compatible with stroke are an inadequate basis on which to make this diagnosis. Rather the aim should be to estimate numbers of non-fatal events that are recognised medically as cases of stroke but where the patient is not managed in hospital. Two methods are suggested as ways in which such an estimate can be made.

**Tracking of medical practice (health facilities) by survey**

In areas where the locals often use general practitioners, efforts should be directed to include them in the surveillance activities. If the study population is of limited size it is often possible to include all the general practitioners in the area. Instead of only including general practitioners all local health facilities may be included (nursing homes, rehabilitation centres etc).

If the study population is large (for example the entire population in a country) it may not be possible to include all general practitioners. Alternatively, one method of monitoring the extent of out-of-hospital management of non-fatal stroke is to survey a representative sample of medical practitioners to assess the number of cases that they have managed over a defined, preceding period. In many communities, this survey can be conducted quickly and easily by post rather than by personal contact. After allowance is made for the sampling and response fractions, one can derive a numerical factor by which numbers of non-fatal events managed in hospital should be adjusted to obtain the overall count of such events in the target population. For example, suppose that a 5% sample survey of 800 doctors achieved a 75% response and indicated that, between them, over the preceding two years, the 30 doctors who responded had managed 60 non-fatal cases of stroke without admitting the patient to hospital. In addition, if an average of 600 non-fatal events per annum had been registered through surveillance in hospitals during the same period, then the estimated total number of non-fatal stroke events annually in that population is:
In some countries there are only few general practitioners or only a proportion of stroke patients who ever have contact to them. Instead, local healers may be the primary contact person and it is important to consider the potential for collaboration. Given instructions on stroke symptoms they may be able to provide a contact to the patient, which then can be examined for stroke symptoms. 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.

**Surveys of hemiplegia / hemiparesis**

In most communities the causes of adult-onset hemiplegia or hemiparesis are limited to stroke and head injury and these can be distinguished from the history. Thus, if the incidence of residual hemiplegia following stroke and the time course of survival of affected patients are constant within a given community, trends in the prevalence of hemiplegia will reflect trends in the incidence of stroke. This could be of critical usefulness to surveillance of stroke because hemiplegia is so readily recognisable and ascertaining cases does not require that the affected individual know his or her own diagnosis. Thus, the prevalence of hemiplegia could be ascertained in the course of door-to-door population surveys or even where census data are collected by interview with a representative of each household. Studies from Bolivia and India serve as examples of places where surveys of hemiplegia have been done.

*The linkage between prevalence of hemiplegia/hemiparesis and incidence of stroke has not been validated in a study.*

The same questionnaire is used for both methods.

*(M6-1) Date of stroke:* Enter the date for stroke symptoms onset.

*(M6-2) Definite stroke:* Indicate whether the event was *a definite stroke* (1), *not a stroke* (2), or if there were *insufficient data* (3) to provide a conclusive diagnosis. This question is answered by insertion of the corresponding number. The number of events designated to have insufficient data (3) should be kept as low as possible.

*(M6-3) Has the patient had a previous stroke:* In order to differentiate between a first-time event and a recurrent event it is important to obtain information about possible previous strokes. It is emphasised that a TIA is *not* counted as a stroke.

There five different answers: *Yes, records seen* (1), *yes, records not seen* (2), *no, records seen* (3), *no, records not seen* (4), *insufficient data* (5). This question is answered by insertion of the corresponding number. The amount of events designated to have insufficient data (5) should be kept as low as possible.

*(M6-4) Vital status at 28 days from stroke onset:* There are four different categories: *patient alive* (1), *death directly related to stroke* (2), *death unrelated to stroke* (3), and *death, unknown cause* (4).
10. Source population

Calculation of epidemiologic rates is based on the number of events occurring in the source population. One of the first steps in setting up surveillance studies is therefore to specify and describe the population in which the study is going to take place.

The selection of study population is of paramount importance, as the data, and interpretation of the results, will depend on what part of the population is included. To provide a reliable estimate of the stroke occurrence, community based programs are recommended. Inclusion of the entire population in a country is usually not possible, and it may therefore be better to identify different regions in the country for the survey. Often there are differences between urban and rural districts with respect to exposure to risk factors, treatment of predisposing diseases, for example hypertension, and access to health authorities and facilities. An ideal surveillance program therefore should include a random, representative part of the population, from both urban and rural districts. Furthermore, it should not be restricted for example to private hospitals, people how are employed, or only men or women.

Calculation of rates and proportions, and identifying statistical significantly differences depend on size of the population, and the number of events. Expenses of the study are correlated to the size of the source population in which the surveillance is going to take place. It is therefore often feasible to restrict the program to age groups where stroke starts to occur. Although there may be regional variation it is likely that most strokes will happen in people aged more than 45 years, why this may be set as the lower age limit. Elderly people often have multiple co-morbidities, which increase the uncertainty of assigning one specific disease as the primary cause of death. It may therefore be feasible to set the upper age limit to 85 years.

Strokes rates are often higher in men than in women, but the differences is not as marked as for other diseases. The sampling ratio for men and women should therefore be 1:1.

10.1 Defining the source population

When starting a WHO STEPS Stroke study the population scheme should be filled out and a copy sent to the regional WHO office, appendix B.

The data provided are to be the best available estimates of the mid-year population size and structure.

The form can be completed either be typewriter, hand, or electronically. In either case, the recorded information should be examined carefully for both correctness and legibility. Since it may be necessary to photocopy typewritten hand-written forms, it is essential that the recorded information be clear and dark. Hence, a dark ribbon should be used for typewriters or a dark ball-point pen if the form is completed by hand.

Correcting mistakes: If a mistake is made in entering information for this item, please draw a single line through the erroneous entry and provide the correct information immediately to the right. Even if only one digit of the code is incorrect, please draw a
single line through the entire number and re-write the correct number immediately to the
right as is indicated in item 1. This is valid for all items.

Completing the reference population scheme

Item 1:

The WHO SSS Collaborating centre name: 0 0 5 0 1 4

The official WHO SSS Collaborating Centre name and code are to be entered in the
spaces provided. Be sure to use all 3 spaces for the code, thus if yours centres code for
example is 14, then 014 should be written (see example – with correction).

Item 2:

Calendar year for which information is being provided: 2 0 0 1

Type the calendar year (1 January through 31 December) for which data are being
provided. Include all 4 digits of the year as described in the example above. If a one-year
study period covers two calendar years, please indicate the months in the space before
entering the calendar year, and enter the first calendar year only.

Item 3:

Complete the following table (do not include population groups which are excluded from
the survey or event registration).

Print the official counts of the indicated age and sex groups for the study population in
the reporting unit. If the reporting unit does not include all age groups then NA should
be typed in each box and the total be computed for the age groups reported.

If you have decided to exclude some people living in the reporting unit area (e.g. those
who are not citizens of the country) from the survey sample and event registration, such
population groups are excluded from the study population and must not be counted here.

If a mistake is made in entering information for this item, please draw a single line
through the erroneous entry and write and circle a capital letter in the cell of the
erroneous entry. In the right side of the table, print and circle the same letter followed by
the correct number. Remember to use different letters for different corrections.

A properly completed table, with an example of an error correction, is shown below. This
example if for a WHO reporting unit including subjects aged 45 to 84 years.

Item 4:
4. Total number of inhabitants in the WHO STEPS Stroke Reporting Unit, including all ages and sexes without any exclusions

Print the total population size, including all ages and sexes for the official WHO SSS reporting unit in the space provided. Here is requested the **count of all inhabitants without any exclusions**. If this is not available, write “Not available” in the space and explain in item 8. **Do not leave blank!**

**Item 5:**

5. If you recorded the numbers in item 4 by hand, please write above each number printed to the right the numbers as used for item 4

This item is added as an attempt to help read hand-written entries that may appear elsewhere on this form. If you are entering data on writer, leave this item blank. If you are completing the form by hand, please write, in your handwriting, each number above the digits as shown in the example below. Then compare the entries in the table and elsewhere on the form with those as written for this item and change those that may be confusing or unclear.

**Item 6:**

6. Source of information: (enter correct code in box to the right)
   a. Direct census count
   b. Intercensal estimate
   c. Population register
   d. Other (please explain):

Print the appropriate letter in the box for the code letter. If the source of the information is not the same as reported for the previous year, please indicate the reason for the change in item 8. It is not necessary to note the change from a direct census count to an intercensal estimate or vice-versa.

Also, please describe clearly in item 8 the source of information if “other” is coded for this item.

**Item 7:**

7. Person providing information: ___________________________  Date: __________

   (Please type or print)   (Signature)

Type the name of the person completing this form and the date completed in the spaces provided. Note that this form is to be completed by the Principal Investigator.
Item 8:

Comments or reservations about data provided. Type any reservations or comments about the data that may be helpful using the data or preparing summary reports. Note especially the instructions for items 2, 4, and 6. Attach additional sheets if necessary.
11. Getting started

Before the study is initiated attention should be directed to the selection and training of the interviewers. Also, a pilot study may be a valuable way to make adjustments in detection practices, and data handling and can reduce the amount of problems that may otherwise occur later in the process.

11.1 The interviewers

It is essential that the persons who are collecting the information have been trained specifically to do this kind of work. As surveillance takes time the staff should ideally be hired and available for a longer period of time, in order to avoid spending time and funds on training new people. It is of paramount importance that they are committed to the work and efforts should be made to reinforce a good working spirit on every level.

The medical background for example as nurse or doctor is not a necessity. Lay people may be just as good, but they must be educated before starting the project. The following is a list of key elements an interviewer should master before starting:

- Have a good basic knowledge of what kind of clinical symptoms that should be recognised as stroke;
- Have an excellent understanding of the stroke definition and the questionnaire
- Be thorough;
- Have a good, natural and relaxed attitude when interviewing patients and relatives, and
- Must be good to know how to contact with people how are in a stressed situation or are recalling a sad moment in life.

In order to protect the interviewer, and the patients, it is recommended that the interviewer is not a member of the community being surveyed.

11.2 Pilot study

Before the surveillance program is initiated we strongly recommend that a pilot study is conducted first. That gives an opportunity to make sure that the way the surveillance staff get information, validate, and report is satisfying. A pilot study provides the opportunity to make adjustments before the real study begins and can save many working hours and disappointments. A crude estimate of the number of events in the population can also be calculated which will indicate the number of people that is necessary survey in order to get sufficient statistical power. Thus, a pilot study is especially warranted in places where it is uncertain how many events will be identified during the follow-up.

It is not possible to give general guidelines for duration of the pilot study as that depends on the local structure, and on how many problems that needs to be tackled.

11.3 The Study Summary sheet

When all the preparations for the study have been ended and the registration procedure is about to begin, a brief summary of the study should be filled out, appendix C.
The summary provides an easy overlook of the basic component of the local stroke surveillance project. The information will, if accepted by the study research group, be up-loaded on the WHO Stroke Surveillance web site.

The following components are included in the Study Summary sheet.

**Identification of stroke events:**

“Hot pursuit” refers to ongoing identification of stroke events as they occur, i.e., a prospective collection of data. Ideally a research team is constantly registering the strokes as they occur. The main purpose is to ensure a complete identification of all events in a defined population to determine the incidence rates; hot pursuit is more likely to include mild strokes.

“Cold pursuit” refers to retrospective identification of stroke events, for example based on information from hospital discharge records, and death certificates. This identification method relies on diagnoses made by several doctors of varying neurological experience who are not working to a protocol.

Many studies use a mix of hot and cold pursuit to ensure the most complete identification of stroke events (overlapping identification sources). The following definitions may be useful:

“hot pursuit” = a specific team identifying new non-fatal stroke events as soon as possible after symptoms onset. There may be a possibility for direct examination of the patient. For fatal events, the events may be identified using death certificates but this should be on an on-going basis via direct contact with coroners, local statistical offices, etc.

“cold pursuit” = a team identifying 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.

“mixed pursuit” = a mix of hot and cold pursuit. 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

**Autopsy method:**

Please include if it is medical or verbal autopsy which is used.

**Start of study:**

Insert the date when the study starts.

**End of study:**

Insert the date when the study ends.

**Expected number of stroke events included per year:**
Based on previous experience or results from a pilot study the expected number of stroke events is entered.

*Expected number of stroke events included in total:*
Insert the expected number of stroke events that will be included in total during the study period.

*STEPS Stroke modules:*
Please indicate how many of the modules of the WHO STEPS Stroke Project is being included in the local study.

*Additional data collected:*
As emphasised throughout this document, more data may be collected according to local needs. We would like to know which additional information is collected for future updates of the STEPS Stroke manual. In addition, as this information may be accessible on the official WHO web site for stroke surveillance, it may encourage other researchers in the region to consider including similar data registration forms.
12. Technical advice

The WHO STEPS-Stroke manual and all schemes can be down-loaded at the following web site:

http://www.who.int/noncommunicable-diseases/main.cfm?p=0000000381

The presented questionnaire is a draft and can be modified to meet local needs, as long as the questions remain the same.

The statistical software Epi Info can be down-loaded at the following web site:

http://www.cdc.gov/epiinfo

The WHO does not provide assistance installing and running the programme. The WHO is not responsible for errors related to the programme or any use of it.

12.1 The data

It is essential to check the correctness of the entered data. The electronic data sheets have been created so as to reduce the amount of possible mistakes. However, incorrect entries may still occur, why it is advised to checks the correctness of the entered data. This may be done by daily checks, or as random checking procedures, and it is advised that one person is responsible for this.

When the data have been checked each participating center is invited to send a copy to the WHO of the results obtained according to sex and age. This collection of data will enable international comparisons and calculations which will be used for international initiatives for prevention.

12.2 Sample size

The larger the sample size the more accurate information is collected. What matter is the annual number of events, more than the population size. In areas with high stroke occurrence smaller populations can be studied whereas areas with a low occurrence would need larger populations to be included.

Populations generating less than 200 stroke end-points (that is either for mortality, case-fatality or incidence analyses) in both men and women, are likely to have difficulties in establishing data on trends with confidence.

In a study where the stroke mortality is expected to be approximately 1 % each year for both men and women, the source population must consist of approximately 40 000 individuals (men and women combined).

If using the hospital-based part of the surveillance system, there is no requirement for sample size.

It should be noted that the quality of the surveillance would be a more critical issue than the size of the population. The better quality, the more benefit will there be from having
a large population. In contrast, if the achieved quality of data is low, a large number of events is useless for the accuracy of the results.

12.3 Standard population

When rates are compared they are often presented as crude rates, including the number of events and the total number of observed person years, and as standardized rates.

There is no conceptual justification for choosing one standard over another, thus the choice is arbitrary. In general, choosing a standard population with higher proportions of the younger age groups tends to weight events at these ages disproportionately. Similarly, choosing an older standard does the opposite.

Rather than selecting a standard to match the current age-structure of some populations, the WHO has developed a standard, based on the average age-structure of those populations to be compared over the likely period of time that a new standard will be used, using the latest UN assessment for 1998 (UN Population Division, 1998). From these estimates, an average world population age-structure was constructed for the period 2000-2025. The WHO World Standard population has fewer children and notably more adults aged 70 and above than the world standard and is also younger than the European standard.

The new WHO World Standard Population

<table>
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<tr>
<th>Age group (years)</th>
<th>World</th>
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<tbody>
<tr>
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</tr>
<tr>
<td>1-4</td>
<td>7 000</td>
</tr>
<tr>
<td>5-9</td>
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<td>20-24</td>
<td>8 200</td>
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<td>25-29</td>
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<td>3 700</td>
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<td>65-69</td>
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<td>80-84</td>
<td>900</td>
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<tr>
<td>85+</td>
<td>600</td>
</tr>
<tr>
<td>Total/total</td>
<td>100 000</td>
</tr>
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13. Ownership of the data
The local centre that provides the data owns them and can publish results based on these data.

The stroke component of the WHO NCD InfoBase offers storage of data from all participating centres (counts according to sex and age in an anonymous form). For the purpose of making international comparisons, the WHO will request permission to use aggregate data for comparable studies of incidence, mortality, and case-fatality between populations.

Forms for reporting aggregate data are available upon request from the WHO CCS/NMH stroke coordinator.
14. Glossary of terms
The following list refers to terms used in the previous chapters of this document.

More detailed descriptions can be found in medical text books.

- Amaurosis fugax: Periodical blindness of an eye due to embolic occlusion of the artery supplying the retina.
- Apraxia: The inability to execute a planned motor act in the absence of paralysis of the muscles normally used in the performance of the act.
- Ataxia: Co-ordination disturbances.
- Bilateral: Includes both sides of the body.
- Case-fatality: The proportion of events that are fatal within a given period of time.
- Contra-lateral: Refers to the opposite side of the body.
- Demography: The composition of the population.
- Diplopia: Double vision.
- Dysarthria: A defect in the articulation of the speech.
- Dysphagia: Impaired ability to swallow.
- Dysphasia: Difficulty with comprehension or production of the language despite intact articulation and phonation.
- Hemiplegia: Weakness of the arm and leg on one side of the body.
- Homonymous hemianopia: Loss of vision in one half of the visual field. Lesions of the optic nerve behind the chiasm produces contra-lateral visual field deficits.
- Incidence: A rate of how many events that occurs per person years.
- Intracerebral hemorrhage: Bleeding from intracerebral arteries and may cause stroke symptoms.
• Ischemic stroke: Stroke symptoms known to origin from an occlusion of cerebral arteries.

• Modified Rankin Scale: A scale that indicates the level of handicap in a person.

• Morbidity: A rate of how many people get sick per person years.

• Mortality: A rate of how many people die per person years.

• Stroke: A clinical diagnosis based on recognisable clinical symptoms indicating a vascular cause of sudden onset of neurologic deficits. For definition please see item 4 (p.9).

• Subarachnoid hemorrhage: A bleeding from intra cranial arteries leading to blood between two membranes than surround the brain.

• Surveillance: Ongoing, continuous collection of epidemiologic data in a population.

• Transient Ischemic Attack (TIA): Sudden neurologic deficits that lasts less than 24 hours, and with full recovery.

• Unilateral: Restricted to one side of the body.

• Vertigo: A false sense of rotary movement of self or surrounding objects. May be associated with nausea and vomiting.
Reference List


Appendix A: The Questionnaires

STEPS-Stroke Questionnaire (Version 1.2)

The WHO STEPwise approach to stroke surveillance

Noncommunicable Diseases and Mental Health World Health Organization
20 Avenue Appia, 1211 Geneva 27, Switzerland
Fax: +41 22 791 4769; Email: ncd_surveillance@who.int
Identification Information:
This is a draft cover page. The cover page will contain personal identifying information. The exact details to be collected in each STEPS-Stroke centre will vary depending on the design and implementation procedures. Regardless of how many modules are included in the study a process by which all identifying information is stored should be carefully designed and must meet recommended ethical standards.

<p>| | |</p>
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<td>Country</td>
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<tr>
<td>I2</td>
<td>Center (name):</td>
</tr>
<tr>
<td>I3</td>
<td>Centre (code):</td>
</tr>
<tr>
<td>I4</td>
<td>Interviewer code and initials</td>
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<tr>
<td>I5</td>
<td>Date of completion of the questionnaire</td>
</tr>
<tr>
<td>I6</td>
<td>Patients family Name</td>
</tr>
<tr>
<td>I7</td>
<td>Patients first Name</td>
</tr>
<tr>
<td>I8</td>
<td>Sex (Record sex as observed)</td>
</tr>
<tr>
<td>I9</td>
<td>Date of birth</td>
</tr>
<tr>
<td>I10</td>
<td>Age</td>
</tr>
<tr>
<td>I11</td>
<td>Contact phone number where possible</td>
</tr>
<tr>
<td>I12</td>
<td>Specify whose phone</td>
</tr>
<tr>
<td>I13</td>
<td>Unique identification number where possible</td>
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<td>Module 1</td>
<td>Core data</td>
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<tr>
<td>----------</td>
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<tr>
<td><strong>M1-1</strong></td>
<td>Date of stroke</td>
</tr>
<tr>
<td><strong>M1-2</strong></td>
<td>Definite stroke</td>
</tr>
<tr>
<td><strong>M1-3</strong></td>
<td>If Yes, Has the patient had a previous stroke?</td>
</tr>
<tr>
<td><strong>M1-4</strong></td>
<td>What is vital status at day 10?</td>
</tr>
<tr>
<td><strong>M1-5</strong></td>
<td>Race</td>
</tr>
<tr>
<td><strong>M1-6</strong></td>
<td>If patient death at day 10 indicate date of death</td>
</tr>
<tr>
<td><strong>M1-7</strong></td>
<td>What is vital status at day 28? (Optional see also M2-5)</td>
</tr>
<tr>
<td><strong>M1-8</strong></td>
<td>If patient death at day 28 indicate day of death (optional see also M2-6)</td>
</tr>
<tr>
<td>Module 2</td>
<td>Treatment and disability questions</td>
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<tr>
<td>----------</td>
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<tr>
<td><strong>M2-1</strong></td>
<td>Which department was the patient treated in?</td>
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<td>(Multiple answers possible)</td>
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<td></td>
<td>Response</td>
</tr>
<tr>
<td></td>
<td>Data Entry</td>
</tr>
<tr>
<td></td>
<td>Acute stroke unit</td>
</tr>
<tr>
<td></td>
<td>Neurology ward</td>
</tr>
<tr>
<td></td>
<td>Rehabilitation stroke unit</td>
</tr>
<tr>
<td></td>
<td>Neuro surgery</td>
</tr>
<tr>
<td></td>
<td>Acute medical unit</td>
</tr>
<tr>
<td></td>
<td>Geriatric unit</td>
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<tr>
<td></td>
<td>Other</td>
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<tr>
<td><strong>M2-2</strong></td>
<td>Did the patient receive one or more of the following medications prior to stroke?</td>
</tr>
<tr>
<td></td>
<td>(Multiple answers possible)</td>
</tr>
<tr>
<td></td>
<td>Response</td>
</tr>
<tr>
<td></td>
<td>Data Entry</td>
</tr>
<tr>
<td></td>
<td>Not taking any drug</td>
</tr>
<tr>
<td></td>
<td>Tablets for high blood pressure</td>
</tr>
<tr>
<td></td>
<td>Antiplatelet agents</td>
</tr>
<tr>
<td></td>
<td>(aspirin, clopidogrel, etc)</td>
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<tr>
<td></td>
<td>Anticoagulant drugs</td>
</tr>
<tr>
<td></td>
<td>(Heparin, Warfarin, etc)</td>
</tr>
<tr>
<td></td>
<td>Antidiabetic drugs</td>
</tr>
<tr>
<td></td>
<td>Cholesterol lowering drugs</td>
</tr>
<tr>
<td></td>
<td>Others</td>
</tr>
<tr>
<td></td>
<td>Unknown</td>
</tr>
<tr>
<td><strong>M2-3</strong></td>
<td>Did the patient receive one or more of the following medications while in hospital?</td>
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<tr>
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<td>Tablets for high blood pressure</td>
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<tr>
<td></td>
<td>Antiplatelet agents</td>
</tr>
<tr>
<td></td>
<td>(aspirin, clopidogrel, etc)</td>
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<tr>
<td></td>
<td>Anticoagulant drugs</td>
</tr>
<tr>
<td></td>
<td>(Heparin, Warfarin, etc)</td>
</tr>
<tr>
<td></td>
<td>Antidiabetic drugs</td>
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<td></td>
<td>Cholesterol lowering drugs</td>
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<td>Thrombolysis</td>
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<td></td>
<td>Others</td>
</tr>
<tr>
<td></td>
<td>Unknown</td>
</tr>
<tr>
<td><strong>M2-4</strong></td>
<td>Did the patient receive one or more of the following medications at discharge from hospital?</td>
</tr>
<tr>
<td></td>
<td>(Multiple answers possible)</td>
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<tr>
<td></td>
<td>Response</td>
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<tr>
<td></td>
<td>Data Entry</td>
</tr>
<tr>
<td></td>
<td>Not taking any drug</td>
</tr>
<tr>
<td></td>
<td>Tablets for high blood pressure</td>
</tr>
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<td></td>
<td>Antiplatelet agents</td>
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<td></td>
<td>(aspirin, clopidogrel, etc)</td>
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<td>Anticoagulant drugs</td>
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<tr>
<td></td>
<td>(Heparin, Warfarin, etc)</td>
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<td></td>
<td>Antidiabetic drugs</td>
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<td></td>
<td>Cholesterol lowering drugs</td>
</tr>
<tr>
<td></td>
<td>Others</td>
</tr>
<tr>
<td></td>
<td>Unknown</td>
</tr>
<tr>
<td><strong>M2-5</strong></td>
<td>What is vital status at day 28?</td>
</tr>
<tr>
<td></td>
<td>Patient alive</td>
</tr>
<tr>
<td></td>
<td>Death related to stroke</td>
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<td></td>
<td>Death unrelated to stroke</td>
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<tr>
<td></td>
<td>Death unknown cause</td>
</tr>
<tr>
<td><strong>M2-6</strong></td>
<td>If patient death at day 28 indicate day of death</td>
</tr>
<tr>
<td></td>
<td>D D M M Y Y Y Y</td>
</tr>
</tbody>
</table>
### M2-7 National Health Institute Stroke Scale (within 48 hours of admission)

- Level of consciousness (alertness)
- Level of consciousness (questions)
- Level of consciousness (commands)
- Gaze (only horizontal eye movement)
  - Visual field testing
  - Facial paresis
- Motor function of upper extremities
  - Left
  - Right
- Motor function lower extremities
  - Left
  - Right
- Limb ataxia
- Sensory
- Best language
- Dysarthria
- Extinction and inattention

**TOTAL NIHSS SCORE (00 to 42)**

### M2-8 Modified Rankin scale 28 days after stroke onset

(Select one)

- No symptoms at all
- No significant disability despite symptoms: can do all usual activities
- Slight disability: unable to do all previous activities, but able to look after own affairs without assistance
- Moderate disability: requiring some help but able to walk without assistance
- Moderate disability: unable to walk without assistance, and unable to attend to own bodily needs without assistance
- Severe disability: bedridden, incontinent, and requiring constant nursing care and attention
- Unknown

1
2
3
4
5
6
7
8
9

### M2-9 Follow-up for the Modified Rankin scale

- Physical examination
- Telephone interview
- Other
- Unknown

1
2
3
4
5
6
7
8
9

50
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<th>Response</th>
<th>Data Entry</th>
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<td><strong>M3-1</strong></td>
<td>Which of the following diagnostic techniques were used?</td>
<td>CT scanning 1</td>
<td>☐ ☐</td>
</tr>
<tr>
<td></td>
<td></td>
<td>MRI scanning 2</td>
<td>☐ ☐</td>
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<tr>
<td></td>
<td></td>
<td>Angiography 3</td>
<td>☐ ☐</td>
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<tr>
<td></td>
<td></td>
<td>Lumbar puncture 4</td>
<td>☐ ☐</td>
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<tr>
<td></td>
<td></td>
<td>Other 5</td>
<td>☐</td>
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<tr>
<td></td>
<td></td>
<td>Does not apply 7</td>
<td>☐</td>
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<td></td>
<td></td>
<td>Unknown 9</td>
<td>☐</td>
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<tr>
<td><strong>M3-2</strong></td>
<td>Timing of the first scan after onset of stroke symptoms</td>
<td>Within 24 hours 1</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Between 24 h and 7 days 2</td>
<td>☐</td>
</tr>
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<td></td>
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<td>Between 8 to 14 days 3</td>
<td>☐</td>
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<td>More than 14 days 4</td>
<td>☐</td>
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<td></td>
<td></td>
<td>Does not apply 7</td>
<td>☐</td>
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<tr>
<td></td>
<td></td>
<td>Unknown 9</td>
<td>☐</td>
</tr>
<tr>
<td><strong>M3-3</strong></td>
<td>What type of stroke was diagnosed?</td>
<td>Ischemic stroke 1</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Intracerebral hemorrhage 2</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Subarachnoid haemorrhage 3</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unknown 9</td>
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## Step 2  Fatal stroke events in community

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<th>Routine data or Verbal autopsy</th>
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<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>2</td>
<td></td>
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<tr>
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<tr>
<td><strong>M4-3</strong> If Yes, Has the patient had a previous stroke?</td>
<td>Yes, records seen</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes, records not seen</td>
<td>2</td>
<td></td>
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<tr>
<td></td>
<td>No, records seen</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No, records not seen</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Insufficient data</td>
<td>5</td>
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<tr>
<td><strong>M4-4</strong> Date of death</td>
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<td></td>
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<tr>
<td><strong>M4-5</strong> What was vital status at day 10?</td>
<td>Patient alive</td>
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<td></td>
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<td></td>
<td>Death related to stroke</td>
<td>2</td>
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<td>Death unrelated to stroke</td>
<td>3</td>
<td></td>
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<tr>
<td></td>
<td>Death unknown cause</td>
<td>4</td>
<td></td>
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<tr>
<td><strong>M4-6</strong> What was vital status at day 28?</td>
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<tr>
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<td>Death unknown cause</td>
<td>4</td>
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<td><strong>M4-7</strong> Which International Disease Classification system was used? (encircle)</td>
<td>ICD 8</td>
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<tr>
<td></td>
<td>ICD 9</td>
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<td></td>
<td>ICD 10</td>
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<td>Module 5</td>
<td>Autopsy (medical or verbal)</td>
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<td>M5-2</td>
<td>Definite stroke</td>
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<tr>
<td></td>
<td>No</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Insufficient data</td>
<td>2</td>
<td></td>
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<tr>
<td>M5-3</td>
<td>If Yes, Has the patient had</td>
<td>Yes, records seen</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>a previous stroke?</td>
<td>Yes, records not seen</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>No, records seen</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No, records not seen</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Insufficient data</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>M5-4</td>
<td>Date of death</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>D D M M Y Y Y Y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>M5-5</td>
<td>What is vital status at day</td>
<td>Patient alive</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>10?</td>
<td>Death related to stroke</td>
<td>2</td>
</tr>
<tr>
<td></td>
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<td>Death unrelated to stroke</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Death unknown cause</td>
<td>9</td>
</tr>
<tr>
<td>M5-6</td>
<td>What is vital status at day</td>
<td>Patient alive</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>28?</td>
<td>Death related to stroke</td>
<td>2</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td>Death unknown cause</td>
<td>9</td>
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<tr>
<td>M5-7</td>
<td>What type of stroke was</td>
<td>Ischemic stroke</td>
<td>1</td>
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<td>diagnosed?</td>
<td>Intracerebral hemorrhage</td>
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<td>Subarachnoid hemorrhage</td>
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<tr>
<td></td>
<td></td>
<td>Unknown type</td>
<td>9</td>
</tr>
</tbody>
</table>
## Step 3  Non-fatal stroke events in community

<table>
<thead>
<tr>
<th>Module 6</th>
<th>Core data</th>
<th>Response</th>
<th>Data Entry</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>M6-1</strong> Date of stroke</td>
<td>[ ] [ ] D D M M Y Y Y Y</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>M6-2</strong> Definite stroke</td>
<td>Yes</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Insufficient data</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td><strong>M6-3</strong> If Yes, Has the patient had a previous stroke?</td>
<td>Yes, records seen</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes, records not seen</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No, records seen</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No, records not seen</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Insufficient data</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td><strong>M6-5</strong> What is vital status at day 28?</td>
<td>Patient alive</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Death related to stroke</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Death unrelated to stroke</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Death unknown cause</td>
<td>9</td>
<td></td>
</tr>
</tbody>
</table>
Appendix B: Population scheme
# The WHO STEPwise approach to Stroke Surveillance

## Source population scheme

1. WHO SSS Collaborating Centre name and code:  

2. Calendar year for which information is being provided:  

3. Complete the following table (do not include population groups which are excluded from the survey or event registration)

<table>
<thead>
<tr>
<th>Age group (years)</th>
<th>Number of</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males</td>
<td>Females</td>
</tr>
<tr>
<td>25 – 29</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30 – 34</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35 – 39</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40 – 44</td>
<td></td>
<td></td>
</tr>
<tr>
<td>45 – 49</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50 – 54</td>
<td></td>
<td></td>
</tr>
<tr>
<td>55 – 59</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60 – 64</td>
<td></td>
<td></td>
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<tr>
<td>65 – 69</td>
<td></td>
<td></td>
</tr>
<tr>
<td>70 – 74</td>
<td></td>
<td></td>
</tr>
<tr>
<td>75 – 79</td>
<td></td>
<td></td>
</tr>
<tr>
<td>80 – 84</td>
<td></td>
<td></td>
</tr>
<tr>
<td>85 – 89</td>
<td></td>
<td></td>
</tr>
<tr>
<td>90 – 94</td>
<td></td>
<td></td>
</tr>
<tr>
<td>95 or more</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. Total number of inhabitants in the WHO STEPS Stroke Reporting Unit, including all ages and sexes without any exclusions

5. If you recorded the numbers in item 4 by hand, please write above each number printed to the right the numbers as used for item 4

| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |

6. Source of information: (enter correct code in box to the right)
   a. Direct census count
   b. Intercensal estimate
   c. Population register
   d. Other (please explain):

7. Person providing information:  
   Date:  
   (Please type or print)  
   (Signature)  
   d  m  y  

8. Comments or reservations about data provided: (continue on the back or on other page.)
Appendix C: Study information sheet
Identification of stroke events:

Hot pursuit
Cold pursuit
Mixed pursuit

Autopsy method:

Medical autopsy
Verbal autopsy

Start of study (date)

End of study (date)

Expected number of stroke events included per year

Expected number of stroke events included in total

STEPS Stroke modules included:

Additional data collected: