



World Health Organization

WHO PROTOCOL
EPIDEMIOLOGIC STUDIES OF NEUROLOGIC DISORDERS

Currently there is little accurate information on either the frequency of neurological diseases among the inhabitants of developing countries or on the risk factors contributing to their occurrence. Such information is extremely important in assessing priorities, in recognizing unusual patterns of disease occurrence, in providing clues to the cause of disease, and in initiating programs of prevention and control.

However, the epidemiologic investigation of neurologic diseases poses a number of methodologic problems. The nervous system is complex and accurate diagnosis requires a high degree of sophistication in the clinical neurosciences. Most neurologic disorders do not have pathognomic signs or symptoms, and minimal criteria for diagnosis have not been agreed upon. Individuals with neurologic disorders may never be seen by a physician with training in clinical neurology.

The most important consideration in these investigations are the accuracy of the diagnosis and the representativeness of the population surveyed. Diagnostic accuracy is a direct function of the neurologic expertise available to evaluate the population. Trained clinical neurologists are in short supply worldwide, but the shortage is particularly acute in developing countries. Because of this, we must utilize a research strategy which minimizes the time commitment of clinical neurologists. Other problems in carrying out neuroepidemiologic studies include the high cost of such investigations, lack of census data necessary to determine the population at risk, and lack of uniformity in research methods from study to study. The following two-stage technique is designed to meet these special needs:

Stage I: Census-Interview-Screening: This first step will be conducted by lay interviewers or by paramedical personnel, who are specially trained to administer the questionnaire and conduct the examination. It is intended to hold a week's training course of selected interviewers in the participating Collaborating Center for Research and Training in Neurosciences in the region concerned.

Stage I will involve the following:

- A) Census of the population to be studied - with documentation of basic demographic characteristics - age, sex, ethnic subgroup, household affiliation, consanguinity, religion, occupation, previous abode.
- B) Questionnaire: to be administered to **all** in the selected population.
 - 1) determine the presence of symptoms of major neurological disorders (appropriate questionnaires are attached).
 - 2) a brief examination to detect major neurological dysfunction (examination form is attached).

In order to obtain meaningful rates by 4-5 age groups and two sexes and to allow comparison between different populations, it is estimated that a target population of about 50,000 individuals in each area would be adequate (assuming the prevalence of major neurologic diseases in each region approximates the published figures for developed countries).

Stage II: Neurological examination: All or a sample of all individuals identified in

Stages I. B. 1. and I. B. 2. who are suspected of having neurologic disease will be evaluated by clinical neurologists who will

- a) document the presence of neurologic dysfunction
- b) classify the neurologic dysfunction as to type: cerebrovascular disease, epilepsy, peripheral neuropathy, or other selected diseases.

In addition, it may be necessary to evaluate a sample of those negative on the screening in Stage I in order to estimate the number of false negatives. Each questionnaire will be pre-tested to assure adequate sensitivity in detecting neurologic disease. A pilot study (lasting not less than 2 weeks) of the entire procedure will be carried out prior to the main survey. Any deficiencies in methods will be corrected before proceeding with the investigation. The pilot study will be carried out by individuals who will later serve as supervisors for the actual investigation.

There should periodically be an evaluation of the efficiency and accuracy of the interview. A suggested mechanism for accomplishing this task is to assign a supervisor to reinterview a sample of the population already surveyed and resolve all inconsistencies.

To maximize cooperation by the population studied, Stages I and II should be as close together in time as is practical. The survey must also include all medical facilities (hospitals, nursing homes, etc.) caring for the population.

The other important consideration noted earlier is the representativeness of the group which is studied. The heterogeneity of populations in developing countries makes it difficult to generalize from an investigation done in one particular region. Because of this, target populations should be selected such that:

- a) the group is not overtly different from the much larger population of which it is a part
- b) members of the group will willingly cooperate in the investigation
- c) members of the group can be identified without ambiguity

A population contained in a relatively small geographic region will be selected. The area will be divided into smaller units, each being served by a team of interviewers and a supervisor. Individuals suspected of having a neurologic disorder will be transported to a nearby central location for evaluation by a neurologist.

Because of severe restrictions on available resources (funding and personnel) to cover the entire country, a study involving the selection of a random sample of the country's population, using traditional statistical procedures, would be difficult to implement.

Based on the results of these initial studies intended to document the frequency of neurologic diseases, a number of case-control studies can be undertaken to identify risk factors.

The field work should optimally be integrated with programs of prevention, control and treatment, whenever practical.

FILL IN THE PROVIDED SPACES ON RIGHT SIDE WHITE SHEET

INSERT THE CARDBOARD BETWEEN BLUE AND PINK SHEETS

FOR SUBJECTS OF 7 YEARS OF AGE AND OLDER

NAME (Surname / First name)

AGE (last completed year)

98 = 98 Years or more 99 = Unknown age

SEX

1 = Male 2 = Female

ETHNIC GROUP

1 = _____ 2 = _____ 3 = _____ 4 = _____ 5 = _____ 6 = Other

RELIGION

1 = _____ 2 = _____ 3 = _____ 4 = _____ 5 = _____ 6 = Other

PAST RESIDENCE: DID YOU LIVE IN THIS AREA ON _____ ?

1 = No 2 = Yes, all my life 3 = Yes, not all my life 4 = Don't know 5 = Didn't respond

OCCUPATION

1 = Preschool 2 = School 3 = Housework 4 = Farmwork 5 = Trading 6 = Artisan 7 = Teacher 8 = Farmer/Landowner 9 = Other 0 = Unknown

RELATION TO RESPONDENT

COMPLETED QUESTIONNAIRE

Fill in the appropriate relation to respondent

1 = Yes 2 = No

TO BE SEEN BY NEUROLOGIST

1 = Yes 2 = No

DATE OF SCREENING EXAMINATION

99 = Unknown day, unknown month or unknown year

Record Day, Month, Year

Q1 Have you ever lost consciousness?

1 = Yes (more than once) 2 = Yes (once) 3 = Never 4 = Don't know 5 = Didn't respond

Q2 Have you ever had episodes where you lose contact with your surroundings?

1 = Yes 2 = Possible 3 = Never 4 = Don't know 5 = Didn't respond

Q3 Have you ever had any shaking of your arms or legs and which you could not control?

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Q4 Is your speech normal?

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Q5 Have you had episodes of pain in the face?

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Q6 Has your face or part of your face ever been paralysed for more than 24 hours?

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Q7 Have you ever had any weakness in your arms or legs for more than 24 hours?

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Q8 Have you ever been unable to walk properly?

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Q9 Have you ever had loss of sensation or abnormal sensation affecting your arms and legs, lasting for more than 24 hours?

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Q10 Have you ever suffered from headache?

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Q11 Do you suffer from severe headaches, chiefly on one side of the head, which come on from time to time?

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond 5 = Not applicable

Q12 In association with these headaches, do you suffer, from visual disturbances; e.g., black spots or zig-zag lines in front of the eyes?

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond 5 = Not applicable

Q13 In association with these headaches, do you suffer from nausea or vomiting?

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond 5 = Not applicable

Q14 In association with these headaches, do you suffer from weakness or numbness in the limbs that lasts less than a few days?

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond 5 = Not applicable

Q15 Do these headaches occur only when you have a febrile illness?

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond 5 = Not applicable

E1 Hold both arms above head for 30 secs.

1 = Both hands successful 2 = Can't test, why _____ 3 = Refused 4 = Doesn't understand 5 = RT hand-unsuccessful 6 = LT hand-unsuccessful 7 = RT and LT unsuccessful

E2 Pick up matchstick from ground

1 = Both hands successful 2 = Can't test, why _____ 3 = Refused 4 = Doesn't understand 5 = RT hand-unsuccessful 6 = LT hand-unsuccessful 7 = RT and LT unsuccessful

E3 Close your eyes. Feel cloth sample. Is it: (1) smooth or (2) rough

1 = Both hands successful 2 = Can't test, why _____ 3 = Refused 4 = Doesn't understand 5 = RT hand-unsuccessful 6 = LT hand-unsuccessful 7 = RT and LT unsuccessful

E4 Put your hands out in front of you. Close your eyes. Touch your nose with the right index. Repeat using left index finger

1 = Both hands successful 2 = Can't test, why _____ 3 = Refused 4 = Doesn't understand 5 = RT hand-poor control 6 = LT hand-poor control 7 = RT and LT poor control

E5 Walk heel to toe along the white line (2 metre cloth)

1 = Successful 2 = Can't test, why _____ 3 = Refused 4 = Doesn't understand 5 = Stands with difficulty 6 = Unsuccessful

E6 Stand with both feet together

1 = Successful 2 = Can't test, why _____ 3 = Refused 4 = Doesn't understand 5 = Unsuccessful

E7 Close your eyes and stand still for 15 secs. (Only if E6 answer is 1)

1 = Successful 2 = Can't test, why _____ 3 = Refused 4 = Doesn't understand 5 = Unsuccessful 6 = Not applicable

Date of examination

99 = Unknown day, unknown month or unknown year

Record Day, Month, Year

Physician's / Neurologist's identification number

Fill in the identification No

= To be seen by Neurologist

Only if Q10 answer is yes

= To be seen by Neurologist

Subject seated on the ground

Stand up

7 YEARS AND OLDER

SHEET No. 3028
10-14

MAP SEGMENT 1 2 3

ROAD 4 5 6 HOUSE 7 8 9

FAMILY 15 16

DATE OF CENSUS 17 18 19 20 21 22
day month year

INTERVIEWER'S NAME _____

INTERVIEWER N° 23 24

25-26	SUBJECT 01	SUBJECT 02	SUBJECT 03	SUBJECT 04	SUBJECT 05	SUBJECT 06	SUBJECT 07	SUBJECT 08	SUBJECT 09	SUBJECT 10	SUBJECT 11	SUBJECT 12
urname												
Name												
27-28												
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53	—	—	—	—	—	—	—	—	—	—	—	—
1-69	// // // // // // // // // // // //											

Neurological diseases

1. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

2. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

3. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

4. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

5. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

6. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

7. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

Other diseases

1. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

2. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

3. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

← INSERT THE CARDBOARD BETWEEN
BLUE AND PINK SHEETS

FILL IN THE
PROVIDED SPACES
ON LEFT SIDE
PINK SHEET

FOR CHILDREN UNDER 7 YEARS OF AGE

NAME (Surname / First name)

AGE (last completed year)

99 = Unknown age

SEX

1 = Male 2 = Female

ETHNIC GROUP

1 = 2 = 3 = 4 = 5 = 6 = Other

RELIGION

1 = 2 = 3 = 4 = 5 = 6 = Other

PAST RESIDENCE: DID YOU LIVE IN THIS AREA ON _____ ?

1 = No 2 = Yes, all my life 3 = Yes, not all my life 4 = Don't know 5 = Didn't respond

OCCUPATION

1 = Preschool 2 = School 3 = Housework 4 = Farmwork 5 = Trading 6 = Artisan 7 = Teacher 8 = Farmer/Landowner 9 = Other 0 = Unknown

RELATION TO RESPONDENT

Fill in the appropriate relation to respondent

COMPLETED QUESTIONNAIRE

1 = Yes 2 = No

TO BE SEEN BY NEUROLOGIST

1 = Yes 2 = No

DATE OF SCREENING EXAMINATION

99 = Unknown day, unknown month or unknown year

Record Day, Month, Year

Q1 Have this child ever lost consciousness?
1 = Yes (more than once) 2 = Yes (once) 3 = Never 4 = Don't know 5 = Didn't respond

Q2 Does this child have episodes characterised by vagueness and unawareness of surroundings?
1 = Yes (frequently) 2 = Possibly 3 = Never 4 = Don't know 5 = Didn't respond

Q3 Have you ever seen this child shaking and unable to control the arms or legs?
1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Q4 Has this child ever had paralysis of the face or part of the face?
1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Q5 Has this child ever had paralysis of the arms or legs?
1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Q6 Is your child developing normally?
1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Q7 If the child is over 6 months: Can this child sit upright without any support?
1 = Yes 2 = No 3 = Not applicable 4 = Don't know 5 = Didn't respond

Q8 If the child is over 18 months: Can this child walk?
1 = Yes 2 = No 3 = Not applicable 4 = Don't know 5 = Didn't respond

Q9 If the child is between 2 and 3 years: Can this child say any meaningful words?
1 = Yes 2 = No 3 = Not applicable 4 = Don't know 5 = Didn't respond

Q10 If the child is over 2 years: Can this child run normally?
1 = Yes 2 = No 3 = Not applicable 4 = Don't know 5 = Didn't respond

Q11 If the child is over 3 years: Can this child speak normally?
1 = Yes 2 = No 3 = Not applicable 4 = Don't know 5 = Didn't respond

Q12 Has this child ever suffered from headache?
1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Q13 Does this child suffer from severe headaches, chiefly on one side, which come on from time to time?
1 = Yes 2 = No 3 = Don't know 4 = Didn't respond 5 = Not applicable

Q14 In association with these headaches, does this child suffer from visual disturbances, e.g. black spots or zig-zag lines in front of the eyes?
1 = Yes 2 = No 3 = Don't know 4 = Didn't respond 5 = Not applicable

Q15 In association with these headaches, does this child suffer from nausea or vomiting?
1 = Yes 2 = No 3 = Don't know 4 = Didn't respond 5 = Not applicable

Q16 Do these headaches occur only when the child has fever?
1 = Yes 2 = No 3 = Don't know 4 = Didn't respond 5 = Not applicable

= To be
seen by
Neurologist

Only if
Q12 answer
is yes

Date of examination

99 = Unknown day, unknown month or unknown year

Record Day, Month, Year

Physician's / Neurologist's identification number

Fill in the Identification No.

NEUROLOGICAL DISEASES

72-75

76

77

78-81

82

83

84-87

88

89

90-93

94

95

96-99

100

101

102-105

106

107

108-111

112

113

OTHER DISEASES

114-117

118

119

120-123

124

125

126-129

130

131

Neurological diseases

1. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

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Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

2. Specify type

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ICD code

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Certainty of diagnosis

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3. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

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Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

4. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

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Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

5. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

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Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

6. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

7. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

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Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

Other diseases

1. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

1 = Yes 2 = No 3 = Don't know 4 = Didn't respond

Certainty of diagnosis

1 = Definite 2 = Possible 3 = None present

2. Specify type

Write in the appropriate space

ICD code

Disease present on reference day

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Certainty of diagnosis

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