PURE STUDY

FIELD STAFF MANUAL OF INSTRUCTIONS
FOR VERBAL AUTOPSY REPORT
INTRODUCTION

The aim of the PURE follow-up study is to estimate the number and cause of fatal and non-fatal events. Once a death has occurred it is important to find the cause of death. Some of these deaths may have occurred in health care institutions and some outside of it. And of these deaths, varying proportions may be certified by a medical practitioner as due to a particular illness. Due to the differences in availability of medical personnel, health care utilization, reporting and certifying practices prevalent in various regions, it is important to have a standardized method of obtaining information on the cause of death. Hence the method called Verbal autopsy has been introduced in the PURE study.

As field staff, you will conduct the verbal autopsy, which will be used to determine the cause of death. This manual provides information on conducting verbal autopsy, and instructions for filling the following verbal autopsy forms.

> Verbal autopsy is an investigation of train of events, circumstances, symptoms and signs of illness leading to death through an interview of relatives or associates of the deceased.

Verbal autopsy has been introduced in the PURE study as:
- It is feasible and practical
- It gives good cause of death information
- It has been used successfully earlier in India and other countries

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INSTRUCTIONS FOR COMPLETING VERBAL AUTOPSY FORMS

The verbal autopsy information collected by you from the family members of the deceased will be used by a physician to assign a cause of death. Therefore, you should devote sufficient time to canvass verbal autopsy forms and gather information in great detail. The instructions for filling in the verbal autopsy forms are as follows.

**Verbal Autopsy Form** for adult death

**The Symptom List** is a separate sheet that has key features to ask about the symptoms that the respondents report.

The verbal autopsy form has 4 parts:

**Part I** is a structured questionnaire which includes general information on the respondent and deceased.

**Part IIa** is a structured questionnaire to probe about the onset of illness, nature of symptoms and the course of illness that led to death.

**Part III** is the written narrative. You will write the detailed verbal autopsy report in this section of the form after collecting detailed information from the spouse/close associates of the deceased/ neighbours including information from hospital reports, death certificate, etc., if available.

Part IV is for supporting evidence (in the form of investigation reports, prescriptions, discharge summary, death certificate, etc.) collected as photocopies or captured as picture images from the household or health centre.

**Respondent:**

The respondent refers to the principal person from whom you are collecting information on all the questions. S/he should be the one who has been with the deceased during the illness. The best respondent is usually an adult spouse. The choice of the respondent should be done in the following order.

- Spouse
- Parents
- Son/ daughter
- Son- or daughter-in-law
- Close relative
- Friend/ associate / neighbour or the informant

More than one respondent may be interviewed in case the death is due to a stigmatizing condition such as AIDS, suicide, or homicide, etc. In such conditions, family members may not reveal full details of the illness. The village health/nutrition worker or other social worker or an associate/ neighbour may provide additional information in such cases.
Section 1: contains information on the location, identity and socio-demographic details of the respondent and the deceased, and details of death occurrence.

Q1. Name of respondent 
Q2. Record the relationship of the deceased with the head of the household, using the categories provided. (In case of more than one respondent, record the principal respondent) 
Q2a. If respondent is a family member, record the unique ID no. assigned to that individual. 
Q3. record presence or absence of the respondent during the events that led to the death 
Q4. Deceased’s age in completed years, as accurately as possible. 
Q5. Deceased’s sex 
Q6. Deceased’s marital status at the time of death 

Q7. Date of death - Date of death should be recorded in yyyy/mm/dd format. In some instances, the exact date may not be recalled by the family members; in such cases, the month and year should be recorded accurately 
Q8. Place of death. When the death occurs at an accident site, or in transit between home and hospital, enter the code 3. The details about the place and circumstances of death should be recorded in the history 
Q9. Record whether the death was registered, not registered, or whether it’s unknown. 
Q10. Ask the respondent -- what do you think the deceased died of? The reported reply should be recorded exactly as stated, using the local term and language. Do not probe further at this stage. The respondent may relate the death to supernatural or evil spirit, etc.

Section 2 – Past History: is a structured questionnaire to find out about the onset of illness, nature of symptoms and course of illness that led to the death.

Q11a-Q11i. These questions represent the most common past medical conditions present among adults that are of interest to us in this study. All the questions are to be asked in order to get a better understanding of their contribution to ill-health in population. Ask if any doctor (allopathic) has ever stated that the deceased had the following conditions. The “Yes” code should only be checked if the respondent specifies that a doctor had diagnosed the condition; otherwise check “Unknown”. 
Q11a. High blood pressure (hypertension) -- When blood pressure is more than 140/90 mm of Hg or the person is taking drugs to lower blood pressure on the advice of a qualified doctor. 
Q11b. Diabetes (also known as sugar disease) -- There is sugar in urine. The person is taking drugs or injections to lower sugar on the advice of a qualified doctor. Some manifestations are:  
- Increased appetite, thirst, increased frequency of urination;  
- Weight loss / weight gain;  
- Unhealed ulcer, amputation;  
- Gangrene (blackening of the skin due to serious and permanent arterial obstruction);  
- Diabetic coma (unconsciousness). 
Q11c. Heart Disease -- A person has pain in chest which spreads to left arm or neck and may also have breathlessness on exertion. There may be swelling of feet and hands. 
Q11d. Stroke -- Person has paralysis of limbs, some times one-half of the body, on right or left side is paralysed. There may be difficulty in speaking.
Q11e. Asthma/COPD -- breathing difficulty with wheezing (whistling sound); usually seasonal. Chronic Obstructive Pulmonary Disease (COPD) or chronic bronchitis or emphysema – lung disorder associated with chronic breathing difficulty, for many months in a year and lasting for years; progressing to swelling of legs in late stages

Q11f. Tuberculosis -- Tuberculosis person has prolonged cough and fever; there may be blood in sputum and marked loss of weight. History of consuming drugs for TB on the advice of a qualified doctor.

Q11g. Cancer -- Person loses weight, has lumps or ulcers and is bleeding from various body sites. Undergoing cancer treatment. Write the site of the cancer and details on spread of cancer, if possible, in the narrative.

Q11h. HIV/AIDS. HIV/AIDS various symptoms are given below:
   - Increasing loss of weight and degree (percentage) of weight loss (this is a key symptom).
   - Any ulcers or sores in the genital area (sexually transmitted infection or venereal disease).
   - History of prolonged unexplained fever for more than 1 month (intermittent or continuous).
   - Diarrhoea for more than 30 days.
   - Persistent cough for more than 30 days.
   - Generalised swelling of nodes in arm pits, neck, groin.
   - Generalised itching and skin rash.
   - White sores in mouth (white patches).
   - Skin disease.
   - TB (refer above under Respiratory tuberculosis)

If any test was done to confirm HIV/AIDS, write name of the facility and when it was done.

Q11i. Other chronic diseases -- If any disease not included above is noted, list it here (eg. kidney disease) and write details in the narrative.

Q12-Q20. Some individuals may be suffering from specific physical complaints but may not have had a diagnosis made by a doctor or may not recall the exact diagnosis by a doctor as above. Hence it is important to ask for specific symptoms and record the details as below

Q12. Did the deceased report/experience chest pain in the month before death? If yes, the chest pain lasted for how long?

Q13. Where exactly was the pain located?

Q13i. Was the chest pain accompanied by any sweating?

Q13ii. Was the chest pain accompanied by any loss of consciousness?

Q13iii. Was the chest pain accompanied by any vomiting?

Q13iv. Was the chest pain accompanied by any other specific problems?

Q14. Find out how the chest pain was associated with exertion or physical activity and grade accordingly.

Q15. Was there chronic (long lasting) cough daily lasting for more than 3 months a year over 2 years?

Q15a. If yes, was it associated with a particular season (i.e., more in summer/ winter/ monsoon)

Q16. Find out how the breathlessness was associated with exertion or physical activity and grade accordingly.

Q17. Ask if there was breathlessness at night causing the person to wake up after few hours of sleep?

Q18. Find out if there was swelling of feet in a person with breathing difficulty or chest pain.
Q19. Was there wheezing or a whistling sound in the chest along with breathing difficulty?
Q19a. If yes, was it associated with a particular season (i.e., more in summer/monsoon)
Q20. Enquire if the deceased report/experience paralysis (or weakness) of any part of the body (one-half of the body) in the month preceding death?
Q20a. If yes, was it associated with the person losing consciousness also?

Q21a-Q21i. These questions relate to any diagnosed heart condition before the death and specific details about the diagnosed condition.
Q21. Find out if ‘heart disease’ was diagnosed as a health problem at anytime before death or at the time of death.
Q21a. If yes, record the exact diagnosis.
Q22a. Heart attack (Myocardial infarction)
Q22b. Chest pain (Angina)
Q22c. Heart failure (or cardiac failure or congestive cardiac failure or CHF/ CCF)
Q22d. Heart beat abnormality (irregular heart beat) or arrhythmia
Q22e. Heart valve defect (stenosis or regurgitation)
Q22f. Birth defect of heart or blood vessels (congenital problem)
Q22g. Fluid around the heart (pericardial effusion or pericarditis)
Q22h. Undergone any heart/cardiac surgery
Q22i. Any other heart conditions
Section 3 (Narrative): contains a narrative history of the symptoms of illness and events leading to the death.

- While recording history of illness for adults with long standing illness, the description should include details that occurred in the month preceding death, with other information recorded as past history.
- Use the symptom list to probe on the reported symptoms
- Write a good story of the onset, sequence, duration & severity of symptoms
- Write details of health care sought – place of treatment, investigations ordered or done, reports of tests, advice given by the health professional, treatments advised, diagnosis, prognosis (outcome) offered by the health professional
- Regularity of treatment taken
- Any other medical or surgical treatment offered, declined or accepted
- Details of terminal illness – onset of symptoms, severity and other characteristics (as detailed in the symptom list)

Instructions for use of the Symptom List

The symptom list should be used for probing the details of symptoms so as to write the verbal autopsy report.
The symptom list has 12 main symptoms or conditions called ‘lead’ or ‘filter’ symptoms.

- If the respondent is able to give the major symptoms and circumstances leading to death, you should ask additional probing questions about the other symptoms using the symptom/sign list. For each symptom, the duration of the symptom, any treatment received (type of treatment received), if admitted in the hospital (e.g. tuberculosis hospital, cancer hospital, coronary care unit etc), name and location of the hospital and duration of hospitalization should be recorded. If a death certificate has been issued, its information should be recorded.

- If the respondent is not able to give sufficient information on the symptoms prior to death or has difficulty in remembering any major symptom, you should use the following procedure to obtain more information:
  - Read out the filter symptom/sign of each module in the symptom/sign checklist
  - Check responses to each, and note down positive responses
  - Where there is a positive response, then additional details on that symptom and associated symptoms, if any, should be obtained.
  - Details on any treatment received (type of treatment received), if admitted in the hospital (e.g. tuberculosis hospital, cancer hospital, coronary care unit etc), name and location of the hospital and duration of hospitalization should be recorded.

- If the history is vague, then go symptom by symptom and include negative symptoms (e.g., “no fever”, “no cough”, “no diarrhoea”).

- Also, wherever necessary, supervisor should collect information from other family members who may have more detailed information regarding the symptoms / treatment etc. In other words, collateral sources of information may be used to obtain as detailed and accurate information as possible on the illness
**Tips For A Successful Interview**
- Always ask about duration, type of problem, treatment sought or received
- Always probe for each key symptom provided
- Note down key points, and then explore for all positive symptoms
- If the history is unclear (e.g., he just died), then list all negative symptoms (e.g. no fever, no cough, no diarrhoea, etc, just died in his sleep)
- Always write the name of the hospital/clinic visited
- Always read back the history to the family member at the end to confirm if what you wrote is their understanding of what happened

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**Section IV (supporting information):** contains any other evidence collected from the family of the deceased or in some cases from the health professional or health centre where the individual may have taken treatment

- Investigation slip or report
- Prescription(s)
- Medical certificate or Discharge summary from a hospital
- Death certificate
- Tablet strip or medicine container

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Respondents’ cooperation of interview. Rate the cooperation in interview as high, medium, and low as given below.
- **High:** Most of the questions were answered and required information collected.
- **Medium:** In between good and the poor. Majority of the questions answered.
- **Low:** Respondent did not cooperate, required information not forthcoming. Only few questions answered. Respondent was hesitant and shy for some reason and did not appear to share the required information.

**Interviewer’s name:** Write your complete name (or code).
**Date of interview:** Write date in the yyyy/mm/dd format.
**Result Codes:** fill in the final result of the verbal autopsy report according to the codes.
Workflow management of Verbal Autopsy reports (PURE study)

1. Collect Field VA reports
2. Make 2 photocopies & keep original
3. Cause of death Assignment
   - Physician 1
   - Physician 2
   - Diagnosis match
4. Close record & send for data entry
5. 2 different Diagnoses
6. Make photocopies of both ICD reports & exchange VA reports with other physician
7. Reconciliation
   - Physician 2
   - Physician 1
   - Diagnosis match
8. Close record & send for data entry
9. 2 different diagnoses
10. Adjudication
    - Hand over to Adjudicating physician (Dr. Prem)
11. Close record & send for data entry