

EPIDEMIC ALERT & RESPONSE

Investigating cause of death during an outbreak of Ebola virus haemorrhagic fever: *draft verbal autopsy instrument* 



World Health Organization

Department of Communicable Disease Surveillance and Response

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## 1. Background

An essential component of control during outbreaks of Ebola haemorrhagic fever (EHF) is investigation of the causes of recent unexplained deaths. It is particularly important during the earliest part of the epidemic, in order to identify both individuals who have died of EHF and their contacts. Close contacts of individuals believed to have died of EHF can then be kept under observation and isolated if they develop disease, in order to interrupt further transmission.

Verbal autopsy consists of retrospective interviews with the next of kin. It is an alternative to autopsies, when cadavers are not available for examination, or when laboratory services for confirmation of cause of death are not accessible or feasible. Experience has shown that verbal autopsies work well for causes of death that have distinctive and noticeable features, not commonly found in other causes of death (WHO, 1995). The fact that cases of EHF have had exposures to other cases or to infected animals, coupled with the dramatic symptoms and signs of EHF, meets those criteria to some extent. Therefore, it should be possible to use verbal autopsy for investigating deaths during outbreaks of EHF. In fact, verbal autopsy instruments have been used in a number of past outbreaks, but each of these outbreaks used different instruments. To date, there is no standard, verbal autopsy instrument for use during outbreaks of EHF.

This document presents a draft verbal autopsy instrument based on best judgement and previous experience in a variety of settings including outbreaks and research. It has been circulated widely to professionals involved in previous outbreaks and revised accordingly. This questionnaire is a first attempt at developing a standard questionnaire. It is part of a wider effort by the Global Outbreak Alert and Response Network (GOARN) to develop tools for testing in advance of outbreak situations. The draft needs to be field tested, validated, and if necessary revised, before it can be considered as a standard questionnaire. A similar process was carried out in developing a standard verbal autopsy for investigating causes of death in infants and children (Anker et al., 1999).

To this end, the current document also contains information on how to carry out a validation study, which compares the results of a verbal autopsy questionnaire with the results of a "gold standard" – such as laboratory test or clinical diagnosis. The questionnaire itself can be used during an outbreak before a validation study is undertaken – since it is most likely to be needed during the early phases of an outbreak, for investigating causes of deaths that took place before EHF was recognized. However, the "gold standard" needed for a validation study would most likely be available either during the late stages of an outbreak (when cases are hospitalized) or after an outbreak is finished. A validation study is needed to identify those questions that differentiate EHF from other causes of death, and to evaluate the extent to which the instrument is able to accurately classify cause of death. The questionnaire should then be revised on the basis of the validation study.

The document is structured as follows. First, previous experience using verbal autopsy in a number of different settings is reviewed, providing the rationale for using verbal autopsy in outbreaks of EHF. This is followed by a discussion of practical issues related to carrying out verbal autopsy in outbreak, selection of interviewers, adapting the questionnaire to the local situation, selecting respondents, rescheduling interviews, and coding the questionnaire. This is followed by the methodology for carrying out a validation study and a brief summary of the proposed questionnaire and its format, and by in-depth discussions and descriptions of the sections used for eliciting information on the cause of death. A practical instruction page, the draft questionnaire, and considerations for coding cause of death are annexed.

## 2. Review of previous experience with verbal autopsy

#### 2.1 Instruments used in previous outbreaks of EHF

Available instruments from Gulu, Uganda, and Gabon were used in formulating the attached questionnaire. Retrospective interviews with families to evaluate causes of death have been used during the outbreak of EHF in Gulu, Uganda, 2000–2001 and in Kikwit, Democratic Republic of the Congo, 1995 (Roels et al., 1995). During the EHF outbreak in Gabon, 2001–2002, a section on contacts with infected animals was developed (but not implemented) in view of the importance of these exposures in the local setting. That section may be particularly relevant to some special groups of people or those with unique activities such as hunters, minors, tourists to caves, etc. and for establishing the index case or the first few cases.

#### 2.2 Instruments used in other settings

Verbal autopsy has been used for many years to estimate cause-specific mortality in populations in which medical certification of causes of death is rare. In an attempt to evaluate how well this method works, a number of validation studies have compared the results of the verbal autopsy with medical evidence. These studies indicate that there is considerable variability in the ability of verbal autopsy to accurately classify deaths, and that causes of death with distinct features that are easily remembered by respondents are most suitable for verbal autopsy. Previous verbal autopsy instruments have focused mainly on common causes of death, and have developed algorithms based on symptoms and signs of illness.

The verbal autopsy for EHF differs from previous work in several important ways. First, the questionnaire includes considerable information on previous exposure to EHF, in addition to the usual questions on symptoms and signs of illness. This should be an added advantage. Second, the EHF verbal autopsy can become of primary importance for tracing contacts during outbreaks, which means that the consequences and relative importance of high levels of sensitivity and specificity are different from the requirements of sensitivity and specificity for estimation alone. For example, when **estimating** cause-specific mortality rates, misclassification errors may be acceptable if they are counterbalancing, because the overall estimate will not be affected. However, counterbalancing errors are not acceptable when the verbal autopsy is being used as a tool for deciding whether the contacts of the deceased should be contacted and followed up. Nonetheless, the tool can still be used to quantify the impact of an outbreak.

## 3. Practical considerations for conducting verbal autopsy studies during Ebola haemorrhagic fever outbreaks

The EHF verbal autopsy instrument is meant to be used during and after outbreaks of EHF. Although the circumstances surrounding any death are always painful, and interviewers using verbal autopsy must be sensitive and sympathetic to the families of the deceased, verbal autopsies during an EHF outbreak have additional problems that non-outbreak settings do not have. First, many of the respondents who may need to be interviewed are fearful for their own health, as they could have been exposed to EHF. They may therefore be very reluctant to describe an episode during which they themselves may have been exposed to EHF. This makes the interview process more difficult during outbreaks of EHF than in post-outbreak situations when the respondent has survived and may be more willing to describe what happened. Another problem during EHF outbreaks is that of finding suitable respondents. Because EHF is often spread to family members, the next-of-kin of deceased persons may themselves have died. In this case it may be necessary to interview more that one respondent to obtain information on a case being verified. Third, the urgency of the outbreak makes speed of utmost importance. While in other circumstances it may be practical to return to the household several times in order to interview the ideal respondent, this may not be feasible during an EHF outbreak. Fourth, the purpose of verbal autopsy during EHF is somewhat unusual, as it is needed primarily for contact tracing. Its use for estimation purposes is secondary. This means that classifying a death as not caused by EHF when it actually was may have serious direct health

consequences. The sensitivity of the instrument needs to be high to avoid missing potential cases. On the other hand, since each EHF death might imply following up on many contacts, it is also important that deaths not due to EHF are correctly classified. However, given the direct health consequences of poor sensitivity, it is probably fair to say that high sensitivity is more important than high specificity in EHF outbreak investigation. This is in contrast to the typical use of verbal autopsy for estimation purposes, where specificity is more important than sensitivity in determining the accuracy of the estimation.

## 3.1 Identifying recent deaths

During an outbreak of EHF, deaths that require verbal autopsy investigation can be identified in a number of different ways during different phases of the outbreak including:

## The initial phase

- Community-based ask local key informants about recent deaths and funerals.
- Health facility-based, including hospitals and primary health care facilities review records and ask health facility staff to identify recent deaths.
- Maternity wards it is important to identify recent deaths in maternity wards because EHF often results in genital bleeding and in spontaneous febrile abortions.

#### During the investigation

• Some deaths may be identified during the contact history part of the verbal autopsy questionnaire itself.

#### Once surveillance activities are well established

- Deaths are routinely reported and investigated with the verbal autopsy questionnaire.
- Sometimes deaths of cases already reported may require further verification for clarity.

## 3.2 Adapting the verbal autopsy questionnaire to the local situation

The draft questionnaire included in this document is based on the literature and the best judgement of many individuals who were involved in previous epidemics. Since every epidemic is different, the questionnaire will need to be modified in each setting to capture the specific characteristics of the epidemic. In particular the section on contacts will need adaptation. Some questions, such as those about participation in unsafe funeral practices, or venturing into the forest, may be deleted if they are not relevant to the specific culture, and some questions relevant to the particular circumstances may need to be added.

Behavioural scientists, if available, can be very helpful in the adaptation of the verbal autopsy to local conditions. In particular, full use should be made of any ethnographic studies that have been conducted in the area. It is important to understand local belief systems, local practices surrounding illness and death, and local vocabulary with reference to illness. Note that the local commonly used

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