

# 1. DEVELOPMENT OF VERBAL AUTOPSY STANDARDS

## 1.1 Purpose and content

The purpose of this manual is to disseminate new standard data collection and cause-of-death assignment resources for verbal autopsy, and to provide some general guidelines for their use. These resources include:

- Verbal autopsy questionnaires for three age groups (under four weeks; four weeks to 14 years; and 15 years and above) (Part 2);
- Cause-of-death certification and coding guidelines for applying the *International statistical classification of diseases and related health problems*, tenth revision (ICD-10) [1] to verbal autopsy (Part 3, sections 3.2–3.8); and
- A cause-of-death list for verbal autopsy with corresponding ICD-10 codes (“correspondence table”, Part 3, section 3.9).

This manual and the resources it contains are the consensus products of a three-year effort by an expert group led by the World Health Organization (WHO), consisting of researchers, data users, and other stakeholders under the sponsorship of the Health Metrics Network (HMN). They are intended to serve the needs of various users and producers of mortality information including researchers, policy-makers, and programme managers and evaluators. In order to make these resources as easily and widely accessible as possible, they will be published on the WHO web site and in printed form, and incorporated into the HMN’s web site and forthcoming resource kit for strengthening national vital statistics systems. As new language versions become available, these too will be put into the public domain, with WHO serving as a repository for all rigorously translated and back-translated materials that are consistent with the standard procedures published here.

The expert group on verbal autopsy systematically reviewed, debated and refined the accumulated experience and evidence from the most widely used and validated verbal autopsy questionnaires and procedures. This resulted in standard verbal autopsy questionnaires for three age groups. In addition, the expert group reached agreement on the use of standardized methods for certification, coding and tabulation of causes of death from verbal autopsy according to ICD-10 procedures. Application of these standardized tools will introduce more consistency and cross-comparability of verbal autopsy-derived mortality data. The correspondence table allows for easy access to ICD-10. It also allows the assignment of a group/subgroup level for causes-of-death corresponding to ICD-10 codes, if a specific cause of death cannot be assigned because information from the verbal autopsy is not sufficient. Where more information is available, the full ICD-10 is to be used for coding (see section 3.9 of Part 3 for an explanation of the purpose and use of this correspondence table).

## 1.2 The need for standardization in verbal autopsy methods

The dearth of reliable data on the levels and causes of mortality for those living in poorer regions of the world continues to limit efforts to build a solid evidence base for health policy, planning, monitoring and evaluation. In settings where the majority of deaths still occur at home and where

civil registration systems do not function, there is little chance that deaths occurring away from health facilities will be recorded at all, let alone certified as to the cause or causes of death.

As a partial solution to this problem, verbal autopsy has become the primary source of information about causes of death in populations lacking vital registration and medical certification [2]. Verbal autopsy is an interview carried out with family members and/or caregivers of the deceased using a structured questionnaire to elicit signs and symptoms and other pertinent information that can later be used to assign a probable underlying cause of death. Verbal autopsy is an essential public health tool for obtaining a reasonable direct estimation of the cause structure of mortality at a community or population level, although it may not be an accurate method for attributing causes of death at the individual level.

The past two decades have seen a proliferation of interest, as well as research and development, in all aspects of the verbal autopsy process, including data-collection systems where verbal autopsy is applied (e.g. demographic surveillance sites, sample or sentinel registration systems, censuses or household surveys); questionnaire content and format; application to different age groups; cause-of-death assignment process; coding and tabulation of causes of death according to the ICD-10 rules; and the vexing issue of validation [3]. As a result, cause-specific mortality data have become available for populations that otherwise would have none.

Verbal autopsy is used in three main ways. First, it is used primarily as a research tool in the context of longitudinal population studies, intervention research or epidemiological studies, usually in children or to determine maternal cause(s) of death. Second, it has become a source of cause-of-death statistics to meet the demand for population-level disease-burden estimates to be used in policy, planning, priority-setting and benchmarking (as in global burden-of-disease studies [4]). Third, data derived from verbal autopsy are gaining acceptance as a source of cause-of-death statistics to be used for monitoring progress and evaluating what works and what does not.

Given the strong connection to focused research programs, there has been little coordination among producers and users of verbal autopsy data and – despite some attempts at promoting standard tools [5–7] – those active in the field have not tended towards a convergence on best practices. The design of first- and second-generation verbal autopsy questionnaires, for example, has been driven largely by the needs of researchers and the specific questions to be answered. Initially at least, there was no overriding concern to ensure comparability of data sets from country to country. In addition, the costs and complexity of verbal autopsy validation, the inherent limitations of validation protocols and the scarcity of comparative validation studies of the same questionnaires in multiple countries have left the users of verbal autopsy without a compelling scientific case for adopting a particular “standard”. Rather, there has been a tendency to cannibalize from previous forms and questionnaires, or simply to start from scratch. It should also be noted that there have been some attempts to publish, document and advocate for standardized approaches to cause-of-death assignment in verbal autopsy [8–12]. This a critical component of the process of implementing verbal autopsy methods, and, as we discuss below, must go hand in hand with the standardization of data collection tools in order to ensure the production of comparable data sets.

In the past five to seven years, however, the importance of verbal autopsy-derived mortality data as a source of comparative population health outcome statistics has grown rapidly, making the necessity to standardize approaches all the more compelling. For example, meta-analyses of existing verbal autopsy data sets have been attempted in order to set some global “benchmarks” for the mortality burden among children due to various diseases [13–17]. Because of the lack of standard data collection and cause-of-death attribution and tabulation procedures, however, the

comparability of these precious information sources is seriously limited. Assessments of data consistency and reliability are further constrained by lack of public availability of data sets themselves [18], by the scarcity of rigorous validation studies and by the frequent problem of small and non-representative samples.

At the same time, there are great demands for direct measures of impact to track progress in meeting the Millennium Development Goals and to evaluate disease control programmes and major global health initiatives – including interventions aimed at reducing mortality due to specific diseases or conditions. Where the coverage of medical death certification is high and representative, and the quality of medical records is high and consistent, civil registration and health records are the preferred source of information to calculate these indicators. The reality is that for poor, often rural populations – for whom new interventions and policies are designed to reduce mortality, often due to specific diseases or conditions – verbal autopsy, for all its shortcomings, remains the only practical option for measuring levels and trends in specific causes [2].

Finally, decades of health sector reform have put a premium on “evidence-based” planning and priority setting – often at the sub-national level. Mortality data (often generated from verbal autopsy) have been critical inputs into these processes [19]. These data have allowed national and district intervention packages to be based on better evidence.

The need for consensus on a core set of technical standards and on guidelines for verbal autopsy, together with their widespread endorsement and adoption, has, therefore, become urgent. While there are questions about the accuracy of verbal autopsy for assigning some causes of death, it is hard to overstate the benefits to be gained by applying a standardized verbal autopsy process to obtain representative mortality statistics in countries with inadequate vital registration systems.

Verbal autopsy methodologies are still evolving; many areas of active and important research in verbal autopsy methods remain. These include topics such as further optimization of questionnaires and statistical methods for assigning causes of death from verbal autopsy that are both reliable and that remove human bias from the assignment process [20]. For the present, however – and in order to ensure that data on cause-specific mortality derived from verbal autopsy in coming years have the greatest possible benefits to those producing them as well as to those using them for comparative purposes – it is urged that these new standard resources become the foundation for efforts in verbal autopsy data collection wherever possible.

### 1.3 References

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