

APPENDIX H: MONITORING MORTALITY AMONG PLHIV

A robust civil registration system that provides high quality, directly measured HIV-related mortality data is the best way to monitor mortality. As recommended in the United Nations Statistics Division (UNSD), Principles and Recommendations for a Vital Statistics System for every death, civil registration systems should collect information such as date and cause of death (COD), age, sex and place of residence.

Any time activities to reach and reengage patients on treatment are conducted and it is concluded that an ART patient has died, the death should be reported into the formal civil registration system if it is established that this has not already been done. Where it has been done, in settings where death registration systems are active, it may be possible to link existing civil registration records of death and COD with ART patient records to ascertain those who have experienced an interruption in treatment (IIT).

PEPFAR teams should work collaboratively with their Ministries of Health in conjunction with civil registration authorities (often located within Ministries of Interior or Home Affairs) to enhance civil registration and vital statistics systems and to establish consistent procedures for collecting and linking mortality data (i.e., to ensure the same data elements are collected for matching purposes). WHO guidance is available to help countries establish or strengthen civil registration systems. CDC has a team dedicated to strengthening CRVS systems internationally, within the National Center for Health Statistics (NCHS), which is available to provide technical assistance.

Deaths among ART patients that occur in the health facility: Deaths occurring within the health facility should be immediately recorded in the ART register and/or other relevant tracking register, which may or may not already include cause of death. The Medical Certificate of Death and Cause of Death (MCCD) should be filled to ascertain COD and is also a data source for obtaining mortality-related data for patients who died in the facility. If filled according to WHO/ICD guidelines, and coded correctly, the underlying cause of death (UCOD) will be identified. When filled correctly, the MCCD will also include a sequence of events leading to the immediate cause of death. It will also list conditions that are not in the causal chain but are related to the cause of death. If these are entered electronically (through the WHO DHIS mortality module or alternative electronic system), these fields (Part I, a-d, and Part II) can all be coded and/or searched.

MCCD forms are typically embedded in national death reporting forms, which include demographic information and other country-specific requirements for registration. Completed death reporting forms should be sent to the national registration authorities for legal registration. Even without COD, recording and reporting all deaths among HIV-infected patients, and the general population, as well as knowing mortality rates, etc., is valuable.

Deaths among ART patients that occur outside the health facility: Deaths that occur outside the facility should be confirmed by unambiguous report of family or close acquaintance (i.e., it should not be presumed). COD in community settings is commonly ascertained through verbal autopsy. Verbal autopsy is a method of gathering health-information about a patient that has died in order to determine their probable COD; it typically includes an interview with a caregiver to elicit known diagnoses, signs, and symptoms experienced by the deceased as well as an open narrative describing the circumstances of the death. Where a system for verbal autopsy is in place, PEPFAR teams should coordinate with local authorities to identify the best COD information available (e.g., reported conditions, open narrative, probable COD assigned). Where such a system is not in place, verbal autopsy could be introduced or, for purposes of this indicator, unvalidated family reporting can be accepted to determine cause of death. For more information on verbal autopsy, see the WHO verbal autopsy standards.

Caveats:

It is widely acknowledged that even where reporting is required, mortality data, especially cause of death, are often underreported or inaccurate. Where high quality MCCD is available, PEPFAR teams can expect to find UCOD according to the standard definitions provided. However, where systems are weak, teams may need to use whatever COD information is available for reference to best describe conditions co-existing at the time of death. For verbal autopsy, it should also be noted that since verbal autopsy results are generally considered valid only at the population level, teams are likely to be able to elicit information about conditions coexisting at the time of death rather than a specific UCOD. For reference, the National Center for Health Statistics at CDC