

## Review Instructions



### Instructions for the review of the 'CoDe' Cause of Death form

The review of causes of death in the CoDe project should be based on a synthesis of the information provided in the CoDe Case Reporting Form. The review should result in a specific coding of the cause(s) of death (underlying, contributing and/or immediate) as well as coding of relatedness to immunodeficiency. For each of these, the reviewer should also indicate the degree of certainty by which the code is made, as the intention is to reduce the classification category of unknown, but at the same time allow for sensitivity analysis depending on degree of certainty.

Each case is reviewed by at least two reviewers.

#### **General:**

Please complete page one of the form by marking the appropriate box with an 'X', by completing a numeric field, or by completing text fields as indicated in the form. Page 2 is provided only for reference and does not need to be submitted.

#### Section 1: ***Underlying cause of death and conditions contributing to death***

Please complete the table by recording the name of the illness/condition/injury and the corresponding CoDe category for the:

- Immediate cause of death: The disease(s) or injury directly leading to death.
- Contributing cause of death: The disease(s) or injury, which contributed to a fatal outcome.
- Underlying cause of death: The disease or injury, which initiated the train of morbid events leading directly or indirectly to death, or the circumstance of the accident or violence, which produced the fatal injury.

Only one cause should be entered in each row of the table. The first row (immediate cause of death) must *always* have an entry. If the condition in the first row resulted from a contributory or underlying condition, put this condition on the next row, and so on, until the full sequence is reported. Always enter the underlying cause of death in the lowest row. If the underlying cause of death is the same as the immediate cause of death, please reintroduce the code (but not necessary to reintroduce the text under 'Illness/Condition/Injury')

#### ***The CoDe algorithm:***

For all causes of death (underlying, contributing and/or immediate), but in particular for the underlying cause, the coder should attempt to allocate this in to one of the specific CoDe categories (1-19; please refer to the categories listed in the table in the review form). Only when the coder is unable to code the cause of death in categories 1-19 with a degree of certainty of more than 50% (see below), should he/she use the next level in the algorithm (general categories 20-30). Only if the cause of death cannot be classified in any of these, the categories 90-92 should be used.

#### ***For the immediate and the underlying causes of death - ICD10 codes (optional):***

If the reviewer wants to include a more precise code describing the specific disease entity, this can be recorded in the column labelled 'ICD10'. To facilitate the lookup of specific codes, this tool at CDC may be useful (please specify ICD10 in top)

<http://wonder.cdc.gov/wonder/cgi-bin/asp/ICDFinder.asp?finder=icd9> .

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#### ***Certainty:***

In addition to the codes, the *certainty* of the coding should also be indicated. The certainty should be indicated on a scale from 0% to 100% (comparable to a visual analogue scale). If the reviewer is less than 50% sure then the next “level” of the coding scheme should be used.

If two or more possible sequences appear to have resulted in death, or if two conditions seem to have added together, please describe this under comments.

#### Section 2: ***Death related to immunodeficiency?***

Please evaluate the relatedness of the death with immunodeficiency by using the below algorithm. The CD4 count(s) that should be taken in to consideration are the CD4 count prior to last stopping ART, and the most recent prior to death (CoDe CRF section 6). The former (*the CD4 count at last stopping ART*) should be weighed the highest.

Death related to immunodeficiency?

- **‘Yes, definitely’:** underlying or contributing cause of death a CDC C disease or Hodgkin’s lymphoma
- **‘Yes, likely’, ‘Yes, possibly’ or ‘Assumed not’ :** see table below
- **‘No, definitely not’:** the underlying, contributing and immediate causes of death is of such a nature that it is inconceivable that the person died of causes related to immunodeficiency.

<i>CD4 count(s) prior to death</i>	<b><i>CD4 &lt; 50 cells/μL</i></b>	<b><i>CD4 50-199 cells/μL</i></b>	<b><i>CD4 ≥ 200 cells/μL</i></b>
<b><i>Sudden</i></b>	<b>Possibly</b> immunodeficiency-related	<b>Assumed not</b> immunodeficiency-related	<b>Assumed not</b> immunodeficiency-related
<b><i>Not sudden</i></b>	<b>Likely</b> immunodeficiency-related	<b>Possibly</b> immunodeficiency-related	<b>Assumed not</b> immunodeficiency-related

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#### Appendix.

##### **AIDS defining illnesses: Modified CDC Category C 1993 Definition**

- Candidiasis of bronchi, trachea, or lungs
- Candidiasis, esophageal
- Cervical cancer, invasive
- Coccidioidomycosis, disseminated or extrapulmonary
- Cryptococcosis, extrapulmonary
- Cryptosporidiosis, chronic intestinal (> 1 month's duration)
- CMV disease (other than liver, spleen, or nodes)
- CMV retinitis
- Encephalopathy, HIV-related (including AIDS Dementia Complex)
- Herpes simplex, chronic ulcers (> 1 month's duration); or bronchitis, pneumonitis, or esophagitis
- Histoplasmosis, disseminated or extrapulmonary
- Isosporiasis, chronic intestinal (> 1 month's duration)
- Kaposi's sarcoma (mucocutaneous or visceral)
- Lymphoma, Burkitt's (or equivalent term)
- Lymphoma, primary, of the CNS
- Mycobacterium avium complex or M. kansasii, disseminated or extrapulmonary
- M. tuberculosis, any site (pulmonary or extrapulmonary)
- Mycobacterium, other species or unidentified species, disseminated or extrapulmonary
- Pneumocystis carinii pneumonia
- Pneumonia, recurrent bacterial (2 documented episodes within 1 year of each other)
- Progressive multifocal leukoencephalopathy
- Salmonella septicemia, recurrent (2 documented episodes within 1 year of each other)
- Toxoplasmosis of brain
- Wasting syndrome due to HIV (weight loss (over 10% of baseline) with no other cause, and 30 days or more of either diarrhoea or weakness with fever)

##### **Additions to CDC Definition**

- Aspergillosis, invasive
- Bartonellosis
- Chagas disease (American trypanosomiasis) of the CNS
- Herpes zoster, multi-dermatomal ( $\geq 10$  lesions in a non-contiguous site)
- Leishmaniasis, visceral (kala-azar)
- Lymphoma, Hodgkin's
- Lymphoma, non-Hodgkin's, all cell types
- Microsporidiosis (> 1 month's duration)
- Nocardiosis
- Penicillium marneffii, disseminated
- Pneumocystis carinii, extrapulmonary
- Rhodococcus equi disease