Mortality and causes of death among HIV patients in the UK

This online tool should be used to report information on all deaths among patients attending for HIV care at your clinic. Any questions left incomplete at the time of submission will be defaulted to "unknown".

Deaths can be reported as and when they occur. However, deadline for submission of 2019 deaths is the 30th of June, 2020.

This form can save partial responses, to be completed at a later date. Click "Save" and bookmark the unique link that is generated. Return to this link to resume inputting information.

If you have any queries, please contact Sara Croxford (PHE): sara.croxford@phe.gov.uk or 020 8327 7406.

Contact information

To report a death among a patient with HIV, you must supply your contact information. You may be contacted to verify your identity, clarify your responses or follow-up missing information.

Questions in red and marked with an asterisk (*) are mandatory.

Q1 Name of data reporter*: 

Q2 Email of data reporter*: 

Q3 NHS clinic of HIV care*: 

Q4 NHS Trust of HIV care:
Patient information

In this section, please provide demographic details of the patient who died. These data are pseudo-anonymised to maintain patient confidentiality, with Soundex codes collected instead of surnames.

Q5  **Soundex code of surname (e.g. A123)**:

'Soundex' coding uses a set of eight rules to convert the surname into its first letter followed by three digits. Its use protects patients' confidentiality as no code is unique to a particular surname, but when used with date of birth and sex, likely duplicate reports can be readily recognised.

*Please use the following link to create a soundex code: https://www.ucl.ac.uk/nshpc/soundex

Assistance can also be provided over the phone: 020 8327 7406

Q6  **First initial**:

Q7  **Date of birth (DD/MM/YYYY)**:

Q8  **Gender**:

- Male
- Female
- Trans man
- Trans woman
- Other
- Unknown

Q9  **Clinic ID/Hospital number**:

Q10 **Height (cm)**:

Q11 **Weight at last measurement (kg)**:

Q12 **Date of last weight measurement**:
In this section, please provide information on the patient's risk factors in the year prior to death.

Q13 Risk factors in the year prior to death:

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cigarette smoking</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excessive alcohol consumption**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active illicit injecting drug use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active illicit non-injecting drug use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opiate substitution therapy (methadone)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Excessive alcohol consumption: greater than 2 units of alcohol per day / 14 units per week - documented in notes as such or of concern

Q14 Please specify other risk factors in the year prior to death:


Co-morbidities

In this section, please provide details of the patient's diagnosed chronic conditions and co-morbidities.

Q15  Was the patient diagnosed with any of the following co-morbidities?

<table>
<thead>
<tr>
<th>Condition</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respiratory disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Renal disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental illness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Liver disease</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other chronic condition</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Q16  Please select all the cardiovascular disease(s) that apply:

- [ ] Angina
- [ ] Myocardial infarction
- [ ] Heart failure
- [ ] Stroke
- [ ] Transient ischemic attack (TIA)
- [ ] Peripheral arterial disease
- [ ] Dyslipidemia
- [ ] Other
- [ ] Unknown

Q17  Please specify other cardiovascular disease(s) that apply:

[ ]
Q18 Please select all the cancer(s) that apply:

- Lung cancer
- Bowel cancer
- Prostate cancer
- Breast cancer
- Cancer of unknown primary
- Pancreatic cancer
- Oesophageal cancer
- Liver cancer
- Bladder cancer
- Central nervous system cancer and/or intracranial tumours
- Non-Hodgkin's lymphoma
- Leukaemia
- Kidney cancer
- Stomach cancer
- Ovarian cancer
- Head and neck cancer
- Myeloma
- Mesothelioma
- Uterine cancer
- Other
- Unknown

Q19 Please specify other cancer(s) that apply:

Q20 Please select all the respiratory condition(s) that apply:

- Chronic obstructive pulmonary disease (COPD)
- Asthma
- Other
- Unknown

Q21 Please specify the other respiratory condition(s) that apply:

Q22 Please select all the renal disease(s) that apply:

- Chronic kidney disease
- Acute kidney injury
- Other
- Unknown
Q23 Please specify the other renal disease(s) that apply:

Q24 Please select all the mental illness(es) that apply:
- Depression
- Psychosis
- Anxiety
- Other
- Unknown

Q25 Please specify the other mental illness(es) that apply:

Q26 Please select all the liver disease aetiology(ies) that apply:
- Hepatitis C (HCV)
- Hepatitis B (HBV)
- Hepatitis D (HDV)
- Non-alcoholic steatohepatitis (NASH)
- Autoimmune hepatitis
- Primary biliary cholangitis (PBC)
- Primary sclerosing cholangitis (PSC)
- A1AT deficiency
- Hemochromatosis
- Wilson’s Disease
- Other liver disease
- Unknown

Q27 Please specify the other liver disease(s) that apply:

Q28 Was liver disease controlled/cured with treatment at time of death?
- Yes
- No
- Unknown
Q29 Please select the stage of the patient's liver disease at the time of death:
- No significant fibrosis (F0/F1)
- Mild/moderate fibrosis (F2/F3)
- Compensated cirrhosis (≥F4)
- Compensated cirrhosis with previous decompensation
- Decompensated cirrhosis
- Acute liver failure
- Unknown

Q30 Please specify other chronic condition(s) below:
Patient death

In this section, please provide information on the death of the patient including when and where the patient died and which causes contributed to their death, if known.

Q31 **Date of death (DD/MM/YYYY)**:

Q32 **Place of death**:
- [ ] Hospital
- [ ] Hospice
- [ ] Home
- [ ] Community
- [ ] Nursing home
- [ ] Abroad
- [ ] Other
- [ ] Unknown

Q33 **Was the death of the patient expected?** Please select the longest period of time prior to death that is applicable.
- [ ] Yes, at one week prior to death
- [ ] Yes, at one month prior to death
- [ ] Yes, at three months prior to death
- [ ] No
- [ ] Unknown

Q34 **If no, does the death of the patient meet any of the following criteria that predict an unexpected death?**
- [ ] Death is the result of an accident/untoward incident
- [ ] Death is from a suspected industrial disease
- [ ] Death is due to suspected suicide
- [ ] Death is due to a suspected overdose (including accidental)
- [ ] Death is related to surgery/anaesthetic
- [ ] Cause of death is unknown
- [ ] Concern exists regarding clinician/carer neglect/competence
- [ ] Death is within 24 hours of admission to hospital
- [ ] There are unusual/disturbing features surrounding the death
- [ ] A medical practitioner had not visited the patient in the 14 days preceding death

**Cause(s) of death if known**

Q35 **Condition that directly caused death (immediate cause) (1a):**
Q36 Due to, or as a consequence of (1b):

Q37 Due to, or as a consequence of (1c):

Q38 Due to, or as a consequence of (the underlying condition) (2):
Post-mortem/Autopsy

In this section, please provide information on whether the patient had an autopsy and if so, the autopsy results.

Q39 Has an autopsy been performed?
- [ ] Yes
- [ ] No
- [ ] Unknown

Q40 Have the patient's autopsy results been received?
- [ ] Yes
- [ ] No
- [ ] Unknown

Q41 Did the autopsy reveal any of the following pathologies?

<table>
<thead>
<tr>
<th>Pathology</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central nervous system (CNS)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respiratory organs</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Cardiovascular system</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gastro-intestinal system (including liver)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Uro-genital system</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Muscular-skeletal system</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Endocrine glands</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Q42 Did the autopsy reveal any evidence of intoxication?
- [ ] Yes
- [ ] No
- [ ] Unknown

Q43 Please provide a brief summary of the findings from the autopsy report:


In this section, please provide information on any missed opportunities for the patient to have been diagnosed earlier with HIV. A missed opportunity is defined as an attendance at a health care setting with a condition/symptom due to, or potentially indicative of HIV, or registration with a GP or admission to an acute medical unit in an area of high HIV prevalence.

Q44  Date of HIV diagnosis (DD/MM/YYYY)*: 

Q45  Did the patient die within a year of their HIV diagnosis?  

☐ Yes  
☐ No  
☐ Unknown

Q46  At HIV diagnosis, did the patient have any of the following? (please select all that apply):  

☐ CD4 cell count of <350 cells/mm  
☐ CD4 cell count of <200 cells/mm  
☐ AIDS-defining illnesses  
☐ None of the above  
☐ Unknown

Q47  Were there any missed opportunities for HIV testing in the following settings in the year prior to HIV diagnosis?  

<table>
<thead>
<tr>
<th>Setting</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual health service</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accident &amp; Emergency</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other setting(s)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Q48  Please specify the other setting(s) which may have missed an opportunity for HIV testing in the year prior to HIV diagnosis:

Q49  Were there any missed opportunities for HIV testing in the following settings in the five years prior to HIV diagnosis?  

<table>
<thead>
<tr>
<th>Setting</th>
<th>Yes</th>
<th>No</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual health services</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Accident &amp; Emergency</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other setting(s)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q50 Please specify the other setting(s) which may have missed an opportunity for HIV testing in the five years prior to HIV diagnosis:
Patient care and treatment

In this section, please provide information on the patient's medical care and treatment prior to death.

**Anti-retroviral therapy (ART)**

Q51 Was the patient ever started on ART?  
- Yes  
- No  
- Unknown

Q52 ART initiation date (DD/MM/YYYY):

Q53 Why was the patient not started on ART?

Q54 Was the patient on ART at the time of death?  
- Yes  
- No  
- Unknown

Q55 Date ART discontinued (DD/MM/YYYY):

Q56 Why was ART discontinued?

**Latest bio-markers**

Q57 Latest CD4 count available (cells/mm):

Q58 Date of latest CD4 count (DD/MM/YYYY):

Q59 Latest viral load measurement available (copies/mL):

Q60 Date of latest viral load measurement (DD/MM/YYYY):
Q61 Was end-of-life care discussed with the patient and/or family?
- Yes
- No
- Unknown

Q62 Did the patient have an advanced end-of-life care plan in place?
- Yes
- No
- Unknown

Q63 Where did the patient want to die?
- Hospital
- Hospice
- Home
- Community
- Nursing home
- Abroad
- Other
- Unknown

Q64 Was there a valid do not resuscitate (DNR) form in place?
- Yes
- No
- Unknown
Adverse effects to NHS intervention

In this section, please provide information on whether the patient's death was likely due to an NHS intervention, for example a medication and/or surgical or investigative procedure.

Q65 Was the patient's death considered to be related to clinically significant drug reactions?
- Yes, to an antiretroviral (ARV) medication
- Yes, to other non-ARV medication
- No
- Unknown

Q66 ARV medication 1:

Q67 Date of first initiation of ARV 1 (DD/MM/YYYY):

Q68 Association between death and ARV 1:

--- Select ---
- Definite association
- Probable association

Q69 ARV medication 2:

Q70 Date of first initiation of ARV 2 (DD/MM/YYYY):

Q71 Association between death and ARV 2:

--- Select ---
- Definite association
- Probable association

Q72 ARV medication 3:

Q73 Date of first initiation of ARV 3 (DD/MM/YYYY):

Q74 Association between death and ARV 3:

--- Select ---
- Definite association
- Probable association

Q75 Other medication 1:

Q76 Date of first initiation of other medication 1 (DD/MM/YYYY):

Q77 Association between death and medication 1:

--- Select ---
- Definite association
- Probable association
Q78 Other medication 2:

Q79 Date of first initiation of other medication 2 (DD/MM/YYYY):

Q80 Association between death and medication 2:

   --Click Here--

   Definite association
   Probable association

Q81 Other medication 3:

Q82 Date of first initiation of other medication 3 (DD/MM/YYYY):

Q83 Association between death and medication 3:

   --Click Here--

   Definite association
   Probable association

Q84 Please provide a brief narrative of the drug association(s):

Q85 Was the death considered to be related to a health care intervention (e.g. surgical or investigative procedure)?

   ○ Yes
   ○ No
   ○ Unknown

Q86 Intervention:

Q87 Date of intervention (DD/MM/YYYY):

Q88 Association between death and intervention:

   --Click Here--

   Definite association
   Probable association

Q89 Please provide a brief narrative of the intervention association(s):
Additional information

Q90  If you would like to add any further comments about the circumstances surrounding the death of this patient, please do so in the space below.
On behalf of PHE and BHIVA,
THANK YOU VERY MUCH
for your input!

Please press SUBMIT to enter patient data.