Version 1.0

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:

Risk factors in the year prior to death

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:

	Yes	No	Unknown
Cigarette smoking	○	○	○
Excessive alcohol consumption**	○	○	○
Active illicit injecting drug use	○	○	○
Active illicit non-injecting drug use	○	○	○
Opiate substitution therapy (methadone)	○	○	○
Other	○	○	○

*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?

	Yes	No	Unknown
Cardiovascular disease	○	○	○
Diabetes	○	○	○
Cancer	○	○	○
Respiratory disease	○	○	○
Renal disease	○	○	○
Mental illness	○	○	○
Liver disease	○	○	○
Other chronic condition	○	○	○

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?

	Yes	No	Unknown
Central nervous system (CNS)	○	○	○
Respiratory organs	○	○	○
Cardiovascular system	○	○	○
Gastro-intestinal system (including liver)	○	○	○
Uro-genital system	○	○	○
Muscular-skeletal system	○	○	○
Endocrine glands	○	○	○

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:

[   ]

Potential missed opportunities for an earlier HIV diagnosis

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 <u>year</u> prior to HIV diagnosis?

	Yes	No	Unknown
Primary care	☐	☐	☐
Sexual health service	☐	☐	☐
Accident & Emergency	☐	☐	☐
Other setting(s)	☐	☐	☐

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

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

	Yes	No	Unknown
Primary care	☐	☐	☐
Sexual health services	☐	☐	☐
Accident & Emergency	☐	☐	☐
Other setting(s)	☐	☐	☐

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):

Patient care

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:

--Click Here-- ▼
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:

--Click Here-- ▼
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:

--Click Here-- ▼
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:

--Click Here-- ▼
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.