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INTRODUCTION

- The new pan-European consensus definitions of HIV-related mortality and preventable HIV-related mortality were published in 2023 to enable monitoring towards global targets and implementation of appropriate interventions to improve person-centred HIV care.¹
- Using mortality data from the NHMR matched to patients in the UKHSA HIV surveillance datasets, we describe deaths occurring among people living with HIV in the UK in 2022 and apply the new definitions.

METHODS

- The National HIV Mortality Review (NHMR) was launched by the UK Health Security Agency (UKHSA) and the British HIV Association (BHIVA) to better recognise causes of death and preventable death, and to describe end-of-life care, among people with HIV.
- NHMR data were submitted to UKHSA for cleaning and analysis using a secure online form and included: comorbidities, treatment, clinical markers, causes of death, missed opportunities and end-of-life care, and clinicians' opinion on whether each death was expected or unexpected.
- An NHMR working group brings together regional representatives and specialists to review progress and findings from the reviews and to guide future development of the NHMR.
- Cause of death was categorised by an epidemiologist and four clinicians using the Coding Causes of Death in HIV protocol (CoDe).²
- NHMR data was linked to the HIV & AIDS New Diagnoses and Deaths (HANDD) and the HIV and AIDS Reporting System (HARS).
- HIV-related/possibly-related deaths were defined using CoDe categories, specific causes of deaths and late diagnoses (CD4<350 cells/mm³ excluding people with evidence of recent infection).²
- HIV-related and possibly-related deaths were subsequently classed as preventable/potentially preventable on the basis of clinical indicators (AIDS, late diagnoses, ART-related adverse events, and treatment and care markers).²

RESULTS

HIV-related and preventable mortality

- 115 UK HIV services submitted data to NHMR
- 573 deaths among people with HIV were reported
- 507 deaths were matched to the HIV surveillance databases
- Age at death: 58 [interquartile range (IQR): 50 to 68]
- 79% (400/507) were men (Figure 1).

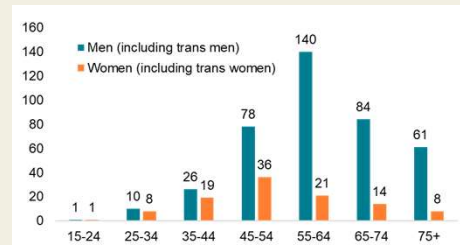


Figure 1. Deaths by age at death and gender: UK, 2022

Cause of death

- 402 (79%) deaths with ascertainable cause: 126 for non-AIDS-related cancer (31%), followed by AIDS (55, 14%), cardiovascular disease (52, 13%) and non-AIDS-defining infections (41, 10%) (Figure 2).
- Among women aged 45-54, the most common cause of death was AIDS (11, 37%), followed by non-AIDS cancer (6, 20%).

HIV-related and preventable mortality

- 65 (16%) deaths were HIV related and an additional 38 (9%) possibly HIV related (Figure 3).
- Of the 103 (26%) HIV-related or possibly HIV-related deaths,
 - 13 (13%) were considered preventable as reported among people who died from an AIDS-defining illness within 12 months of a late HIV diagnosis.
 - 40 deaths (39%) were classified as potentially preventable.
- Overall, 13% of all NHMR deaths with known causes (53/402) might have been preventable.

HIV diagnosis

- Median time from HIV diagnosis to death: 15 years [IQR: 9-23].
- 24 (5%) people died within a year of HIV diagnosis:
 - 83% (20) diagnosed late
 - 63% (19) diagnosed with ≥ 1 AIDS-defining conditions, of these 15 with AIDS as primary cause of death
 - 46% (11) had a documented missed opportunity for earlier diagnosis, of these 10 were late diagnoses.

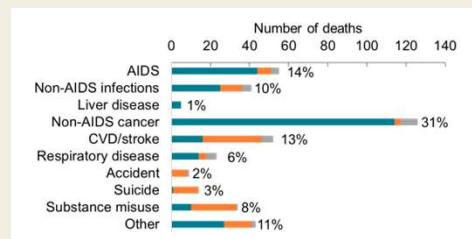


Figure 2. Cause of death among people with HIV according to whether the death was expected or not: UK, 2022

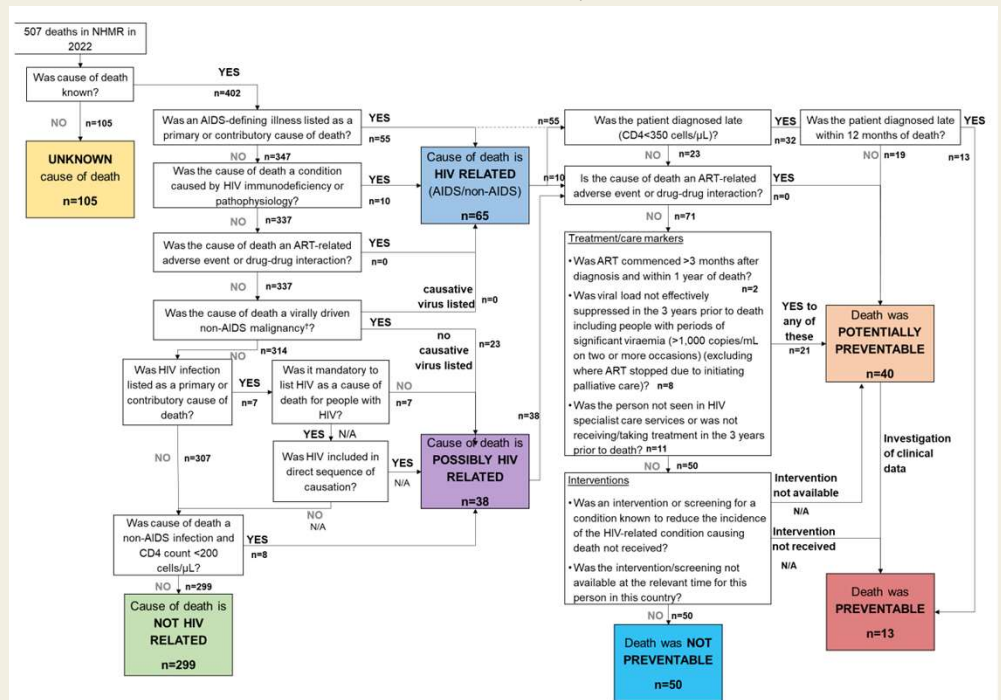


Figure 3. Application of the HIV-related and HIV-related and preventable mortality definitions to the NHMR 2022 dataset.

DISCUSSION , CONCLUSIONS & FUTURE WORK

- For 1 in 8 deaths among people with diagnosed HIV in the UK, cause of death was AIDS, largely due to late diagnosis (in two-thirds of deaths with AIDS as cause of death).
- One in 20 people died within 12 months of HIV diagnosis. Of these, almost 1 in 2 had a documented missed opportunity for earlier HIV diagnosis.
- We applied new definitions for HIV-related and preventable mortality and estimated that 1 in 4 deaths could be HIV-related, and overall, 1 in 8 might be HIV-related and preventable.
- Causes of death can become available over 12 months after death occurred, therefore ascertainment of death is expected to increase as we include further details in the database. This also creates a lag on the categorisation using CoDe and the application of the new mortality definitions.

- Unfortunately, not all deaths from NHMR could be matched to the UKHSA HIV databases. In addition, some deaths reported to UKHSA were not reported through NHMR.
- These issues are due to discrepancies in patient identifiers (e.g., clinic ID, Soundex, date of birth, date of diagnosis, date of death etc.) and unmatched deaths are currently being reviewed.
- We welcome feedback and suggestions from data reporters on the reporting form and validation of data submitted to NHMR to improve data quality and linkage.
- The current deadline for submission of 2023 deaths is April 30, 2024. However, information can be entered in real time, and we have already received reports of deaths for 2024.
- Sustained efforts to increase HIV testing and support long-term engagement of people into care and treatment are needed to reduce these preventable deaths.

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REFERENCES

- Croxford SE and others. Recommendations for defining preventable HIV-related mortality for public health monitoring in the era of Getting to Zero: an expert consensus. *The Lancet HIV* 2023; **10**(3):e195-e201.
- Kowalska JD and others. The Coding Causes of Death in HIV (CoDe) Project: initial results and evaluation of methodology. *Epidemiology* 2011; **22**(4):516-23.