Mortality among people with HIV in the UK in 2021: findings from the National HIV Mortality Review

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INTRODUCTION

The National HIV Mortality Review (NHMR) was launched by UK Health Security Agency (UKHSA) and British HIV Association (BHIVA) to better recognise causes of death and preventable death, and to describe end-of-life care, among people with HIV.

Clinical participation is encouraged by the BHIVA Audit and Standards Sub-Committee, for services to meet the BHIVA-Standards of Care 2018 which recommend review of all deaths among people known to have HIV (Standards 4A and 4B).

An NHMR working group brings together regional representatives and specialists to review progress and findings and to guide future development of the review.

We describe deaths occurring among people with HIV in 2021.

METHODS

In 2021, UK HIV services submitted data on all known deaths among people with HIV under their care to the NHMR through a secure online SNAP survey form ([https://snapsurvey.dtype.org.uk/nationalhivmortalityreview](https://snapsurvey.dtype.org.uk/nationalhivmortalityreview)).

Information collected included: comorbidities, treatment, clinical markers, causes of death, missed opportunities and end of life care. Clinicians were also asked to make a decision as to whether each death was expected or unexpected.

Data were submitted to UKHSA (previously Public Health England) for cleaning and analysis.

Cause of death was categorised by an epidemiologist and four clinicians using the Coding Causes of Death in HIV protocol (CoDe)1.

RESULTS

Overall, 102 services participated in the NHMR in 2021 reporting 646 deaths among people with HIV in 2021.

Median age at death was 58 (interquartile range (IQR): 50-66).

At death (within one year):

• 98% of people with HIV who died were ever on ART (median ART at death: UK, 2021)

Risk factors and co-morbidities

There were a variety of reported risk factors in the year preceding death, with a high prevalence of co-morbidities

HIV diagnosis

• Median time from diagnosis to death: 16 years (IQR: 10-22)

Clinical care prior to death

98% of people with HIV who died were ever on ART (median time on ART before death: 13 years (IQR: 8-20))

DISCUSSION, CONCLUSIONS & FUTURE WORK

• One in ten deaths were a result of AIDS diagnoses.

• People with HIV continue to die from AIDS, largely due to late diagnosis.

• Sustained efforts to increase HIV testing and support long-term engagement of people into care and treatment are needed to reduce these preventable deaths.

• Of people who died within a year of diagnosis, one in three had documented missed opportunities for earlier HIV diagnosis.

• The process of categorising deaths using CoDe is ongoing therefore ascertainment of cause of death is expected to increase after all the deaths have been categorised.

• To identify HIV-related and possibly HIV-related preventable deaths, NHMR data need to be integrated into UKHSA HIV databases.

• Preliminary integration of data has shown several issues in matching of individuals due to discrepancies in identifiers (such as: clinic ID, soundex code of surname, date of birth, date of diagnosis, date of death etc.) and is being reviewed.

• We welcome feedback and suggestions from data reporters on the snap survey data reporting form and validation of data matching of deaths, NHMR data need to be integrated into UKHSA HIV databases.

We gratefully acknowledge all the HIV clinical service staff participating in the NHMR, as well as the continuing collaboration of people living with HIV.

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REFERENCES


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