



# 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 8B)<sup>1</sup>.
- 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.phe.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)<sup>2</sup>.

## 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].

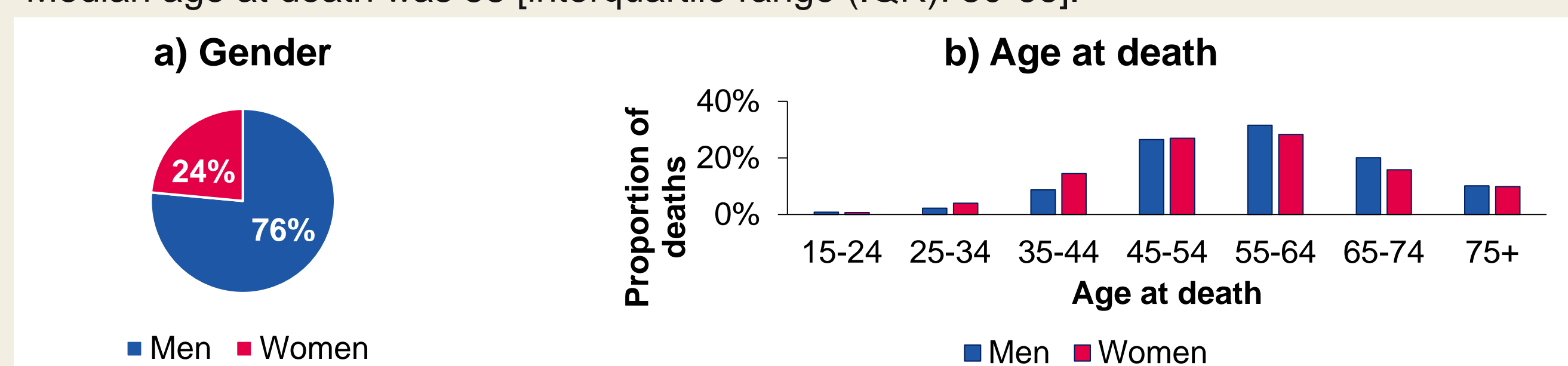


Figure 1. Proportion of deaths by a) Gender and b) Age at Death and gender: UK, 2021

### Cause of death

- Ascertainment of cause of death: 80%
- Non-AIDS cancers was the most common cause of death (24%).
- Of the 646 deaths, death had been expected for 313 individuals and unexpected for 194 individuals.

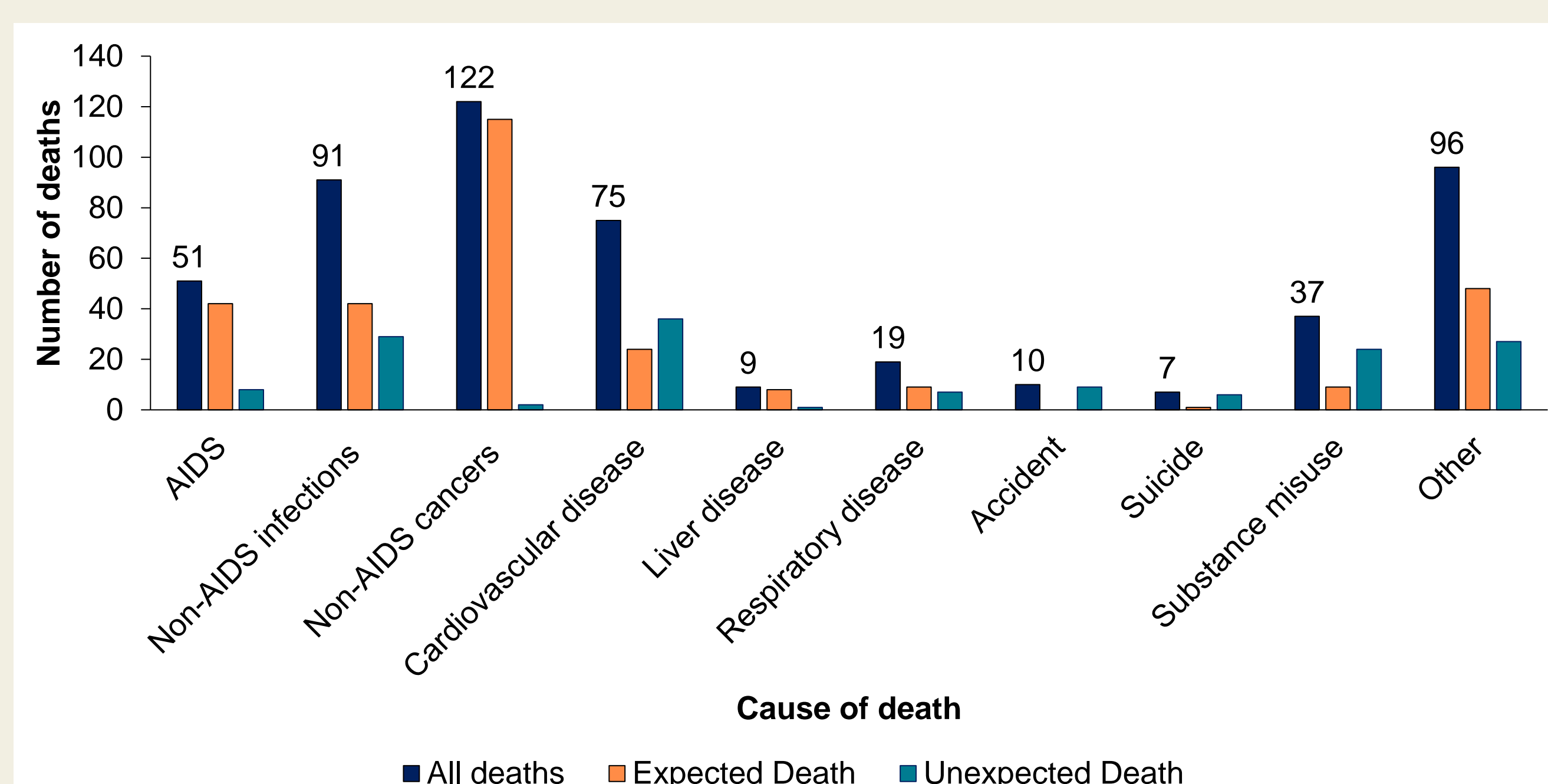


Figure 2. Cause of death among people with HIV by whether the death was expected: UK, 2021

- Among people who died of AIDS, 39% died of AIDS infections, 47% died of AIDS cancers and 14% of unspecified AIDS illnesses.
- COVID-19 caused or contributed to 13% of all deaths.

### End-of-life care

- Of the individuals with expected deaths, 78% had discussed end-of-life care and 36% had a documented advanced end-of-life care plan in place.
- Of the expected deaths, 69% individuals had a valid do-not-resuscitate (DNR) order in place.

### 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

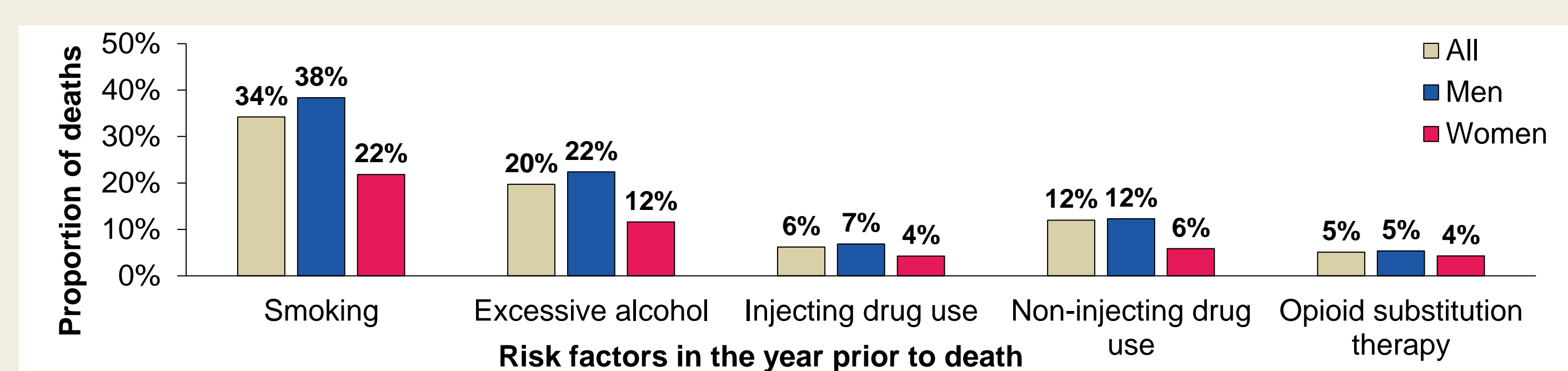


Figure 3. Risk factors among people with HIV in the year prior to death: UK, 2021

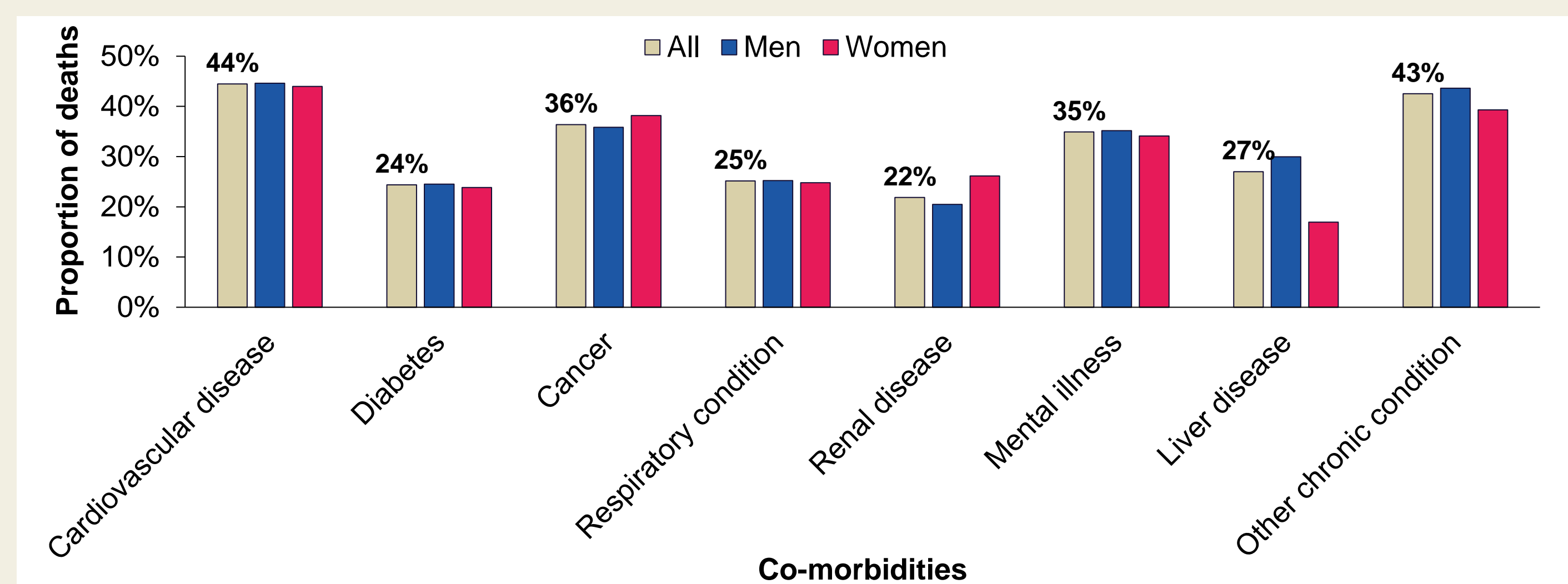


Figure 4. Prevalence of co-morbidities among people with HIV who died: UK, 2021

### HIV diagnosis

- Median time from diagnosis to death: 16 years [IQR: 10-22]
- 34 people died within a year of HIV diagnosis of whom:
  - 77% diagnosed very late (CD4 count <200 cells/mm<sup>3</sup>)
  - 90% diagnosed late (CD4 count <350 cells/mm<sup>3</sup>)
  - 54% diagnosed with at least one AIDS-defining illness
  - 29% had a documented missed opportunity for earlier diagnosis

### 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])

#### At death (within one year):

- 94% of people were on ART
- Median CD4 count: 309 [IQR: 125 - 550]
- 56% of people had a CD4 count <350 cells/mm<sup>3</sup>
- 37% of people had a CD4 count <200 cells/mm<sup>3</sup>
- 86% of people were virally suppressed <200 copies/mL

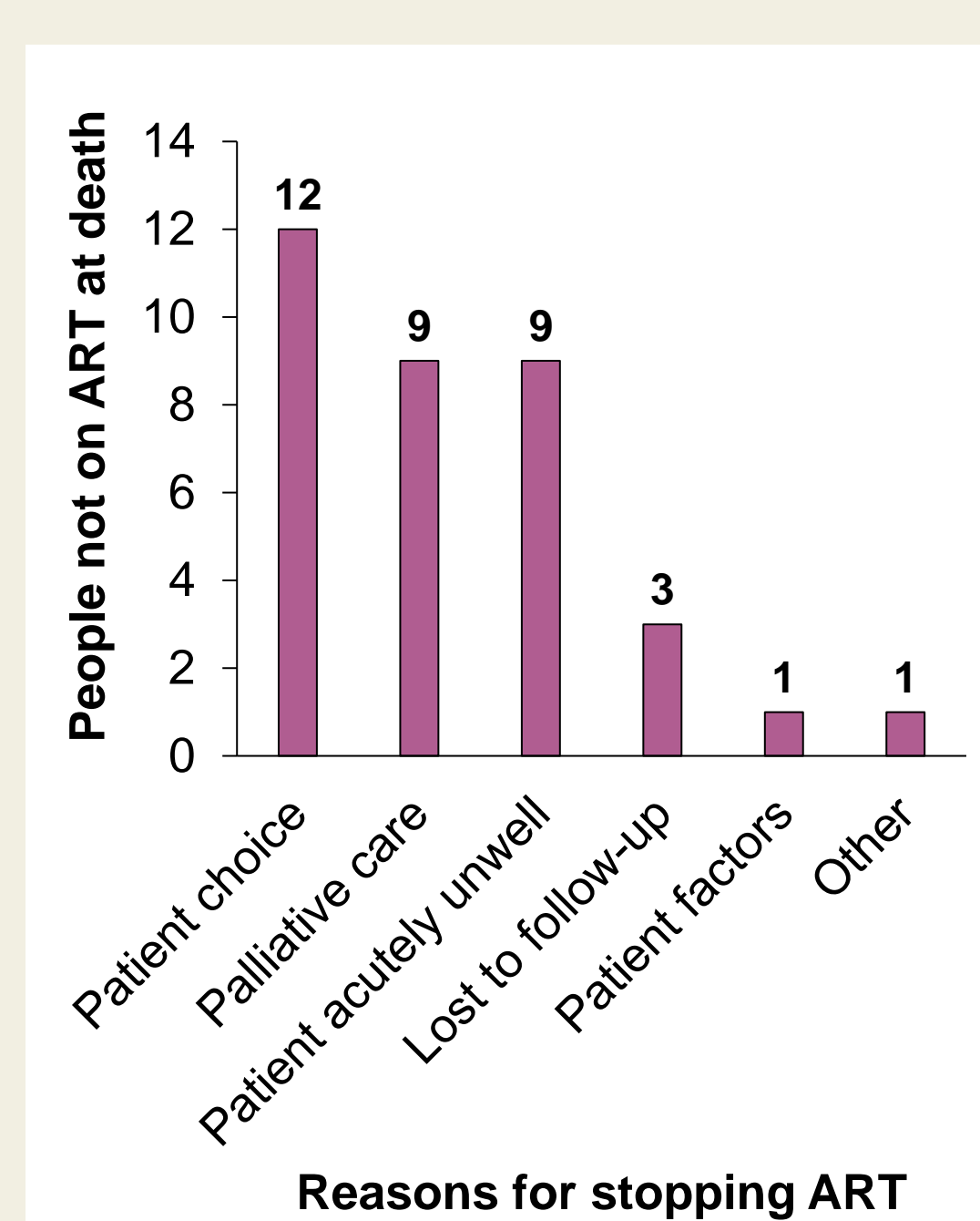


Figure 5. Reasons for not being on ART at death: UK, 2021

## 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 submitted to NHMR to improve data quality and linkage and improve engagement with data reporters.
- The current deadline for submission of 2022 deaths is May 31, 2023. However, information can be entered in real time, and we have already received reports of deaths in 2023.

## ACKNOWLEDGEMENTS

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