



Mortality among people with HIV in the UK in 2019: findings from the first year of the PHE/BHIVA National HIV Mortality Review

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Protecting and improving the nation's health

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INTRODUCTION

- In early 2020, Public Health England (PHE) and the British HIV Association (BHIVA) launched the National HIV Mortality Review (NHMR) to better understand causes of death and preventable mortality among people with HIV in the United Kingdom (UK).¹
- Based on a working model that has been running in London since 2013², the NHMR was designed to be carried out on an annual basis with data submitted by all HIV clinical services.
- While voluntary, participation is encouraged by the BHIVA Audit and Standards Sub-Committee, as a way for services to meet the BHIVA Standards of Care 2018 which recommends review of all deaths among people known to have HIV (Standards 4A and 8B).³
- Here we reflect on the success of the first year of the NHMR and present the findings, describing deaths occurring among people with HIV in 2019.

METHODS

Clinical services commissioned to provide HIV care

Secure SNAP survey software

Public Health England (PHE)

- All HIV clinical services were invited to report data on all patients who died in 2019 either at their centre (inpatients) or who attended their centre for routine HIV care (outpatients).
- Submission using a modified Causes of Death in HIV (CoDe)⁴ reporting form:
 - Co-morbidities and risk factors
 - Antiretroviral therapy (ART) and clinical markers
 - Cause of death
 - Missed opportunities for HIV testing
 - 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 PHE via SNAP survey for cleaning and analysis.⁵
- Cause of death was categorised by an epidemiologist and two clinicians.

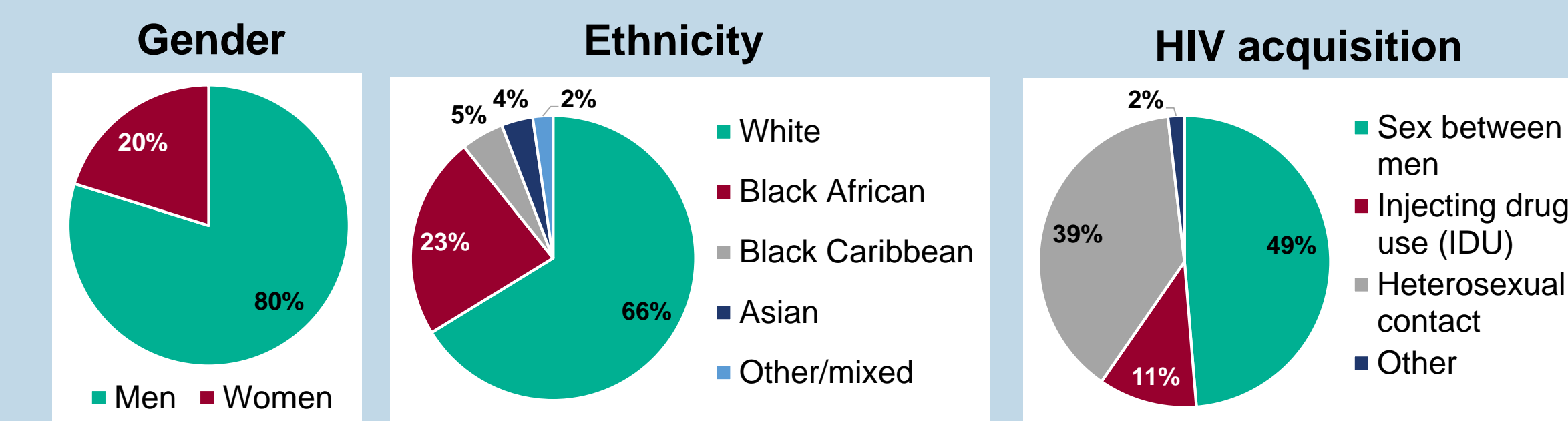
<https://snapsurvey.phe.org.uk/nationalhivmortalityreview>

RESULTS

- Overall, **73** services participated in the NHMR in the first year, reporting **406** deaths among people with HIV in 2019.
- This represents:
 - 38% of all HIV clinical services in the UK
 - 65% of the 622 deaths reported through existing PHE HIV surveillance mechanisms

Demographics

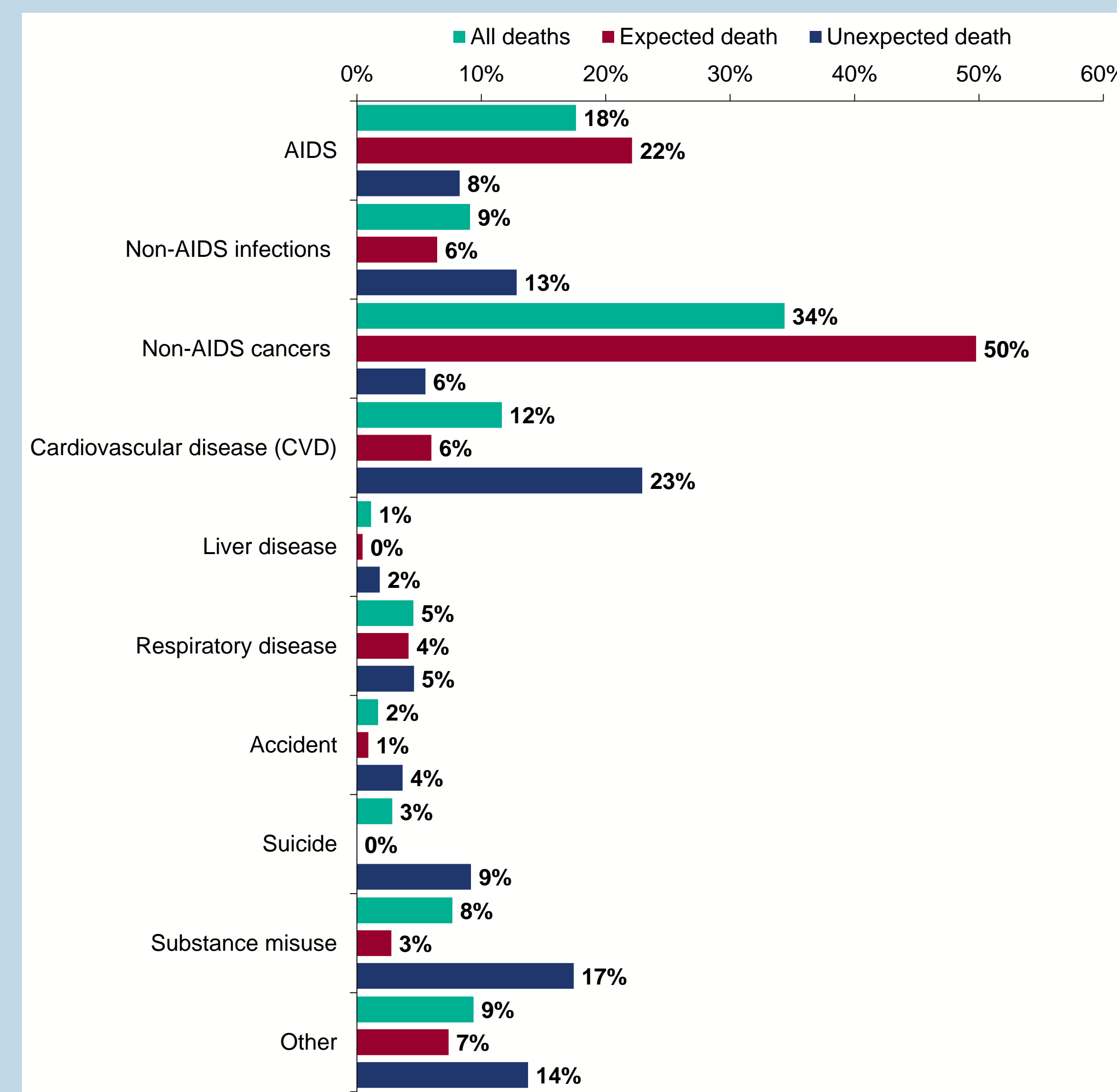
- Median age of death: 54 years [interquartile range (IQR): 46-62]



Cause of death

- Ascertainment of cause of death: 87%

Cause of death among people with HIV by whether the death was expected: UK, 2019

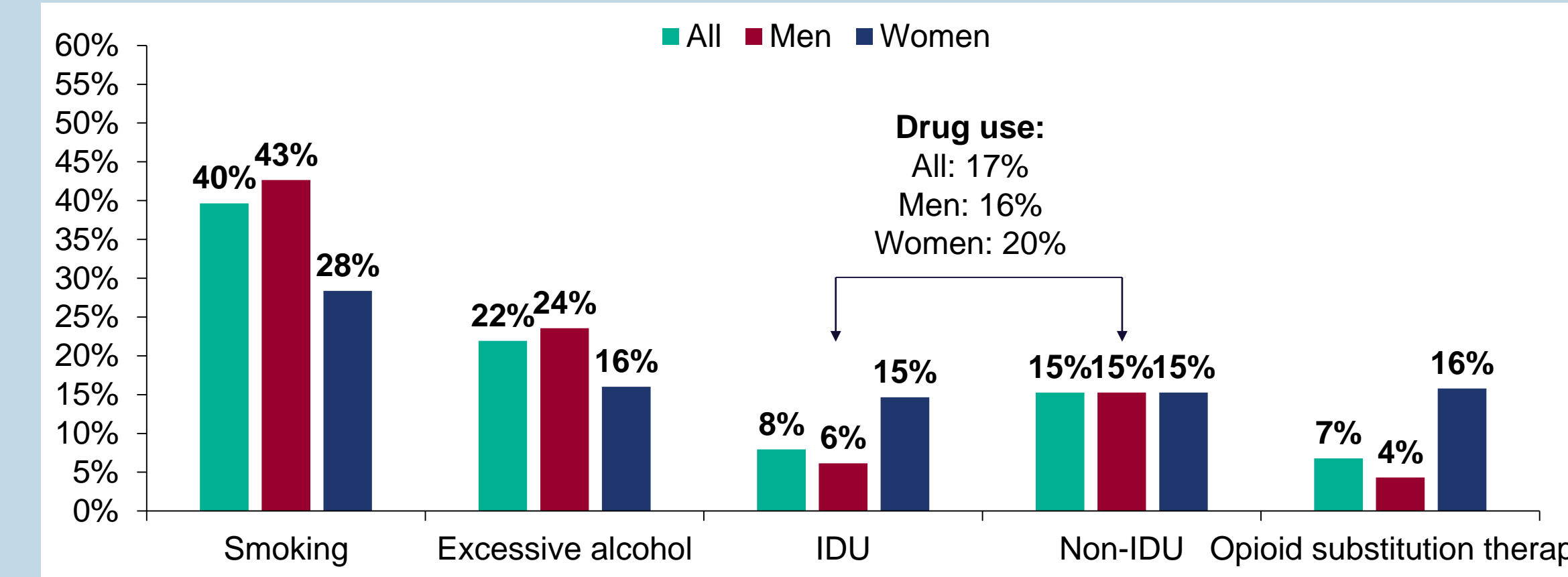


- Among people who died of AIDS, 50% died of AIDS infections, 42% died of AIDS cancers and 8% of unspecified AIDS illnesses.

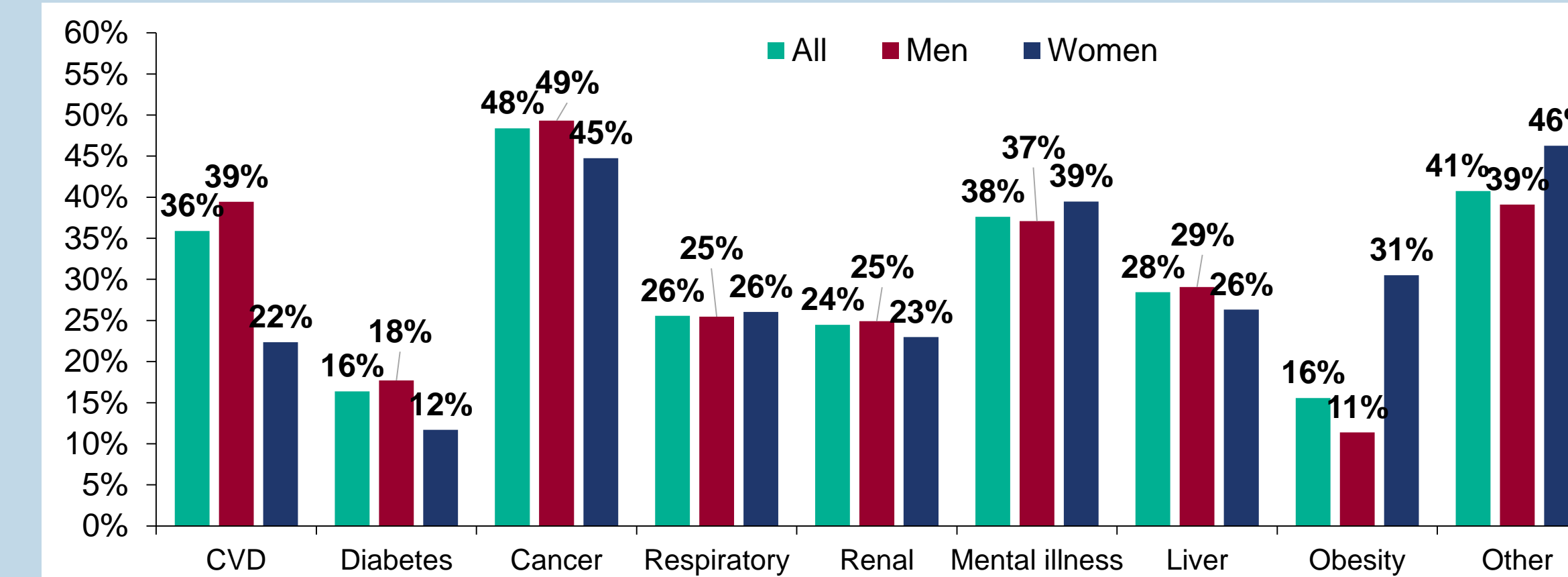
Risk factors and co-morbidities

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

Risk factors among people with HIV in the year prior to death: UK, 2019



Prevalence of co-morbidities among people with HIV who died: UK, 2019



Clinical care prior to death

- Median time from diagnosis to death: 13 years [IQR: 7-21]
- 39 (10%) people died within a year of HIV diagnosis:
 - 73% diagnosed very late (CD4 count <200 cells/mm³)
 - 85% diagnosed late (CD4 count <350 cells/mm³)
 - 88% diagnosed with at least one AIDS-defining illness
- 96% of people with HIV who died were ever on ART (median time on ART before death: 10 years [IQR: 5-17])
- At death (within one year):
 - 90% of people with HIV were on ART
 - Median CD4 count: 275 [IQR: 119-496]
 - 60% of people with HIV had a CD4 count <350 cells/mm³
 - 17% of people with HIV had a viral load ≥200 copies/mL
- Reasons for not being on ART at death included: patient choice (43%), being in palliative care (23%), lost to follow-up (11%), poor adherence (3%) and being too unwell (9%).
- Two-thirds (66%) of people who died received end-of-life care, 96% of expected deaths and 15% of unexpected deaths.

DISCUSSION

- Participation in the NHMR was high, despite competing priorities in 2020 due to COVID-19.
- However, coverage of 2019 deaths was sub-optimal. PHE and BHIVA are in the process of forming a NHMR working group made up of interested clinicians from across the UK to encourage uptake.
- NHMR data show that despite free care and treatment in the UK, **one in five** people with HIV continue to die from AIDS, largely due to late diagnosis and/or a lack of engagement with care services.
- Sustained efforts to increase HIV testing and support long-term integration of HIV patients into care and treatment are needed to reduce these preventable deaths.
- The high levels of mental health conditions and deaths due to accident/suicide and overdose are also of concern.
- These data highlight the importance of risk reduction, particularly addressing psychological needs and substance misuse, among people with HIV.
- People with HIV can also benefit from regular health assessments and should be promptly referred to relevant services, including those providing support for modifying cardiovascular risk factors.

ACKNOWLEDGEMENTS

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