

Mortality and causes of death among HIV patients in London in 2017

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BACKGROUND

- In 2017, there were 101,600 (95% credible interval (CrI): 99,300-106,400) people living with HIV in the UK, of whom 38,600 (95% CrI: 37,900-39,800) (38%) were resident in London.¹
- London continues to account for the largest proportion of new HIV diagnoses in the UK (39% in 2017), particularly among men who have sex with men, and has the highest HIV prevalence (5.7 per 1,000 residents aged 15-59 in 2017).²
- The number of deaths (from any cause) among people with HIV in the region have remained relatively stable over the past decade, at about 200 per year.²
- Since 2013, the London HIV Mortality Review Group, made up of HIV and palliative care clinicians, pathologists, and public health professionals, has conducted annual reviews of deaths among HIV patients to reduce preventable death and improve patient care.
- Here we present findings of the 2018 audit of 2017 deaths.

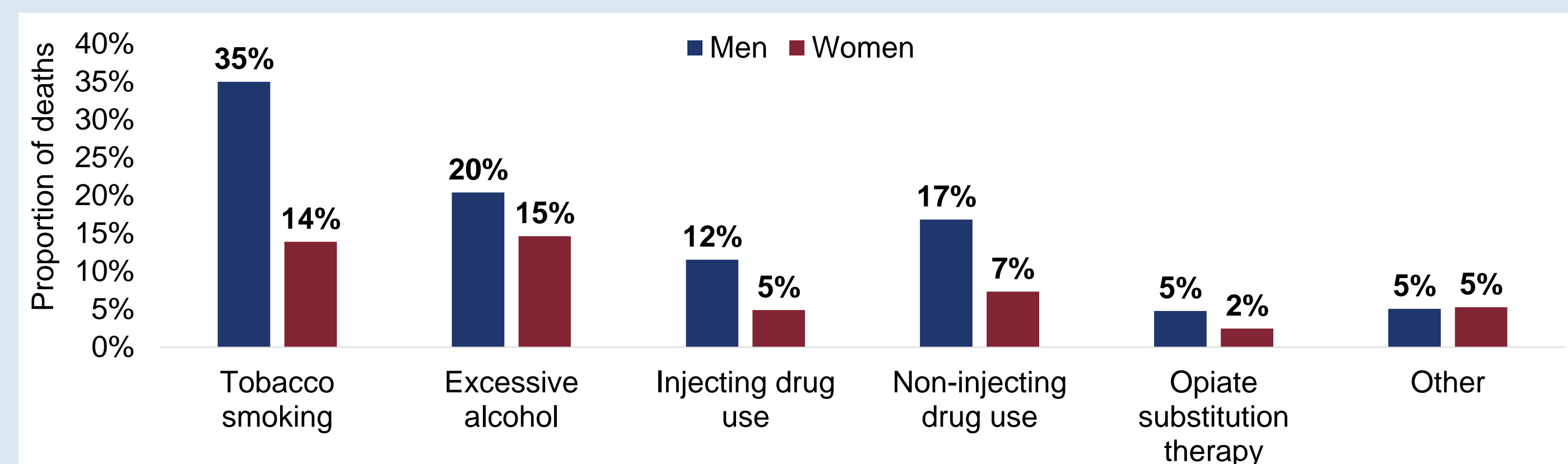
RESULTS

- All 19 London trusts provided death data, reporting 174 deaths in 2017; 75% (128) of deaths were among men and median age of death was 52 years (IQR: 44-64).

Risk factors and co-morbidities

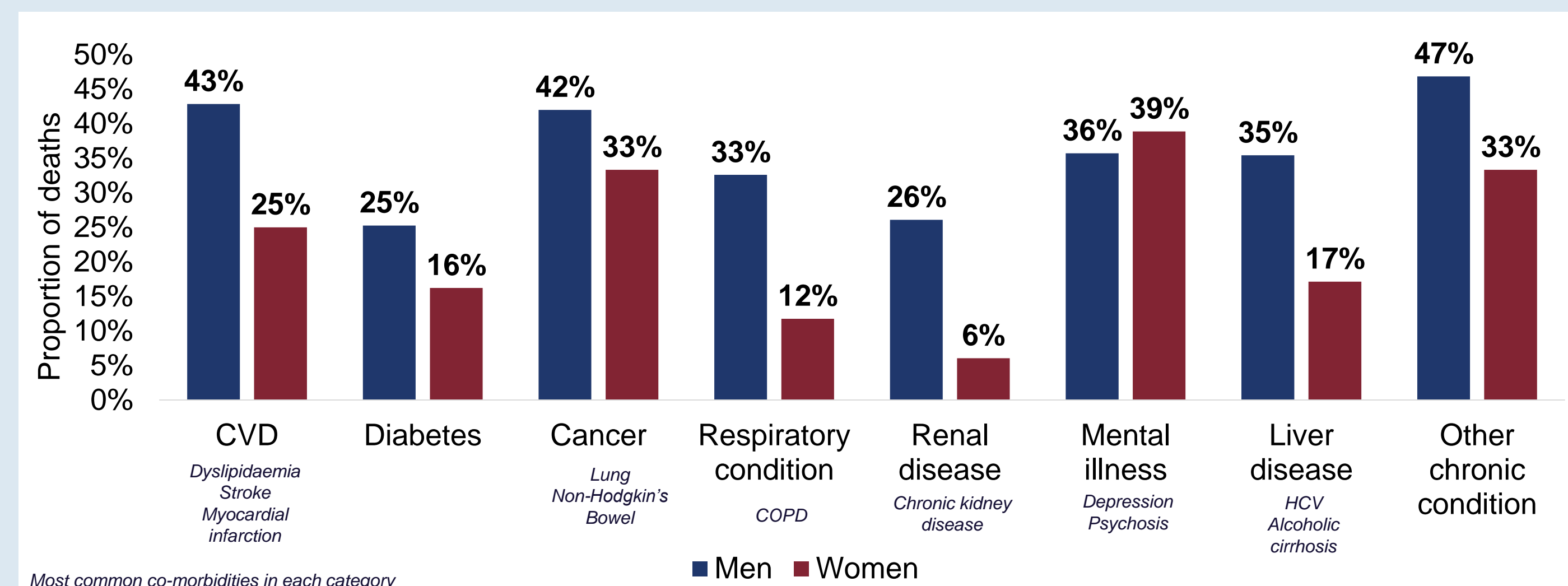
- Reported risk factors in the year prior to death included: tobacco smoking (29%; 40/136), excessive alcohol consumption (19%; 27/144) and injecting (10%; 14/145) and non-injecting (14%; 20/142) drug use (Figure 1).

Figure 1. Risk factors in the year prior to death by gender: London, 2017



- Several co-morbidities were reported: cancer (40%; 55/139), cardiovascular disease (CVD) (38%; 54/141), mental illness (37%; 49/134), liver disease (31%; 40/131), respiratory conditions (27%; 33/123), diabetes mellitus (23%; 30/132), renal disease (21%; 26/125) and other conditions (43%; 47/109) (Figure 2).

Figure 2. Prevalence of co-morbidities among people who died by gender: London, 2017



Clinical care prior to death

- Overall, 95% (165/173) of patients were ever on ART, with a median time of 10 years (IQR: 7-14) on treatment before death.
- At the time of death, 84% (124/147) of people were on ART, 63% (90/142) had a CD4 count of <350 cells/mm³ and 26% (41/157) a viral load of ≥200 copies/ml.
- Reasons for the 23 patients not being on ART at death included: patient choice (30%), being lost to follow-up (26%), non-adherent (17%), in palliative care (13%), too unwell (9%) and to reduce pill burden (4%).

DISCUSSION & CONCLUSIONS

- In 2017, 81% of deaths were due to non-AIDS conditions and the majority of HIV patients in London were on ART and virally suppressed at their last clinic visit.
- However, this review revealed that almost 2 in 5 deaths among HIV patients in London were potentially preventable.
- Despite the availability of free NHS care and treatment, 1 in 5 deaths among HIV patients were HIV-related, as a direct result of late diagnosis and/or a lack of engagement with care services. Innovative approaches to further expand HIV testing outside of sexual health services⁴ should be complemented by strategies to support long-term integration into care and improve treatment uptake.
- To further reduce preventable mortality from non-HIV related conditions, risk reduction strategies must be promoted, including support for modifying cardiovascular risk factors and addressing psychological needs and substance misuse.

METHODS

- All trusts commissioned by NHS England to provide HIV care in London were invited to report data on all patients who died in 2017 either at their centre or who attended their centre for routine HIV care.
- Data were submitted using a modified Causes of Death in HIV (CoDe)³ reporting form, including information on: comorbidities, antiretroviral therapy (ART), clinical markers, cause of death, missed opportunities and end of life care.
- Clinicians were also asked to make a decision as to whether each death was expected (e.g. those receiving planned end of life care or with a terminal condition) or unexpected (e.g. late presenters admitted at diagnosis and not responsive to treatment).
- Data were submitted to PHE via SNAP survey for cleaning and analysis.
- Cause of death was categorised by an epidemiologist and two clinicians.

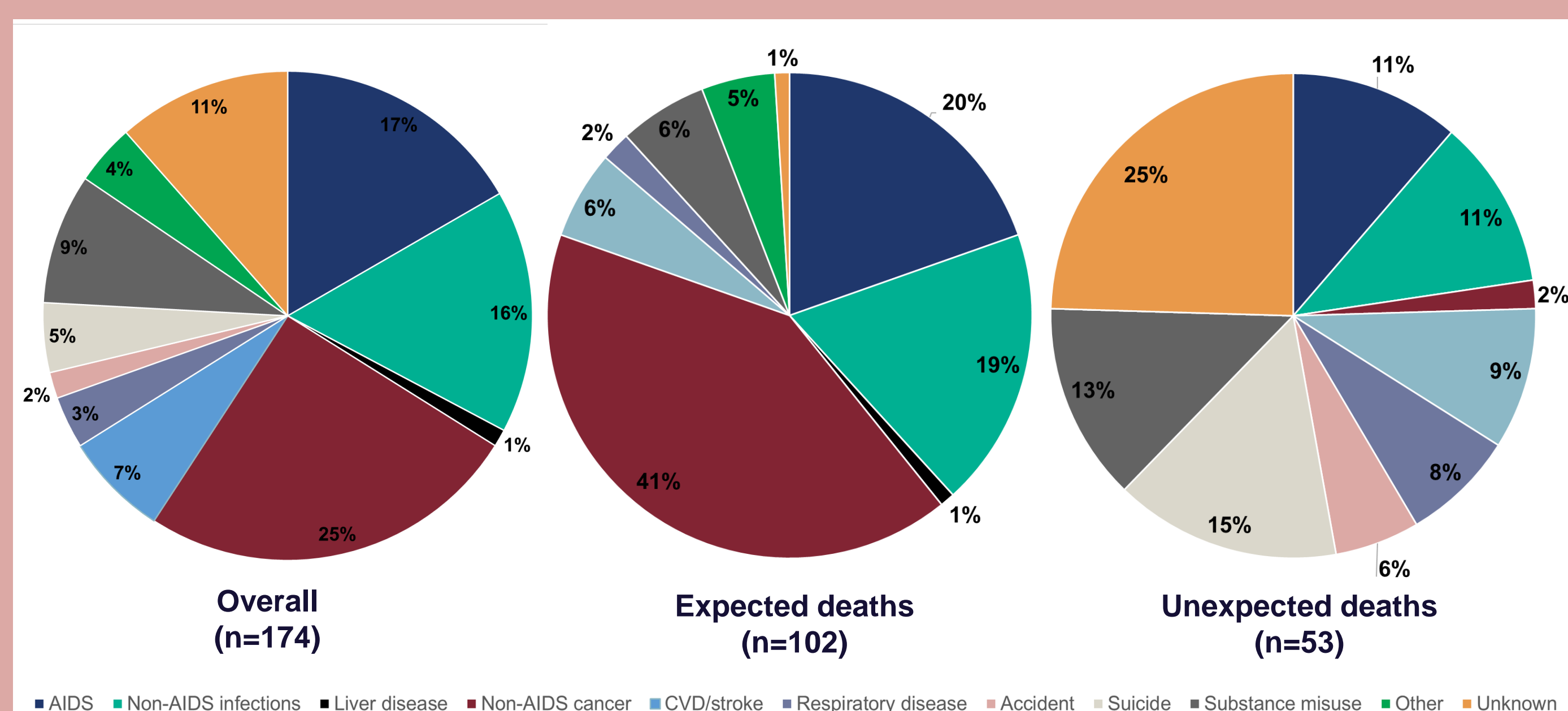
Death and end of life care

- Median time from diagnosis to death was 13 years (IQR: 7-19).
- There were 14 patients who died within a year of diagnosis (at diagnosis: CD4<350 cells/mm³: 64%; AIDS: 50%).
- Death was expected for 66% (102) of patients and of these, 74% (75) had a prior end-of-life care discussion.
- Where place of death was known (96), 65% of expected deaths were in hospital, 16% in a hospice, 7% in a nursing home, 6% at home and 1% elsewhere.

Causes of death

- Cause of death was ascertained for 88% (154) of patients, with the most common cause being non-AIDS cancers (29%) followed by AIDS (19%), non-AIDS infections (18%), substance misuse (10%), CVD/stroke (8%), accident/suicide (7%), respiratory disease (4%), liver disease (1%) and other causes (5%) (Figure 3).
- Cause of death by whether the death was expected can also be seen in Figure 3.

Figure 3. Cause of death overall and by whether the death was expected: London, 2017



Preventable death

- Overall, 18% (32) of deaths were HIV-related and potentially preventable
 - Cause of death an AIDS-defining illness
 - Died within a year of diagnosis, diagnosed late or with AIDS at diagnosis
 - Missed opportunities for earlier diagnosis
 - Never on ART, not adherent or lost to follow-up
- Twenty percent (35) of deaths were not HIV-related but potentially preventable
 - Suicide
 - Substance misuse including alcohol, drugs and tobacco

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REFERENCES

- Nash S, Desai S, Croxford S, Guerra L, Lowndes C, Connor N, Gill ON. Progress towards ending the HIV epidemic in the United Kingdom: 2018 report. London: Public Health England; 2018.
- Forde J, Kirwan P, Louth R, Corkin H, Crook P. Annual epidemiological spotlight on HIV in London - 2017 data. London: Public Health England; 2018.
- Kowalska JD, Friis-Moller N, Kirk O, Bannister W, Mocroft A, Sabin C et al. The Coding Causes of Death in HIV (CoDe) Project: initial results and evaluation of methodology. *Epidemiology* 2011; **22**(4):516-23.
- National Institute of Health and Care Excellence. HIV testing: encouraging uptake. London: NICE; 2017.