Public Health England

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Late diagnosis and a lack of engagement with care and treatment are still causing deaths among HIV patients in London

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Background

UNAIDS targets - London 2018

Additional FTCi target

- Deaths among HIV patients in London reviewed annually since 2013 to identify opportunities to reduce avoidable mortality and improve patient care.
- London HIV Mortality Study Review Group - HIV and palliative care clinicians, pathologists, and public health professionals
- **Objective:** describe deaths among HIV patients in London over a three-year period (2016-2018) to explore HIV-related preventable mortality

Methods

- All Trusts commissioned by NHS England to provide HIV care in London were invited to report data on all adult patients (aged ≥15 years) who died either at their centre or who attended their centre for routine HIV care.
- Data were submitted securely to PHE using a modified Causes of Death in HIV (CoDe)[1] form through SNAP survey.
- Information collected: co-morbidities, treatment, clinical markers, causes of death, missed opportunities and end of life care
- Cause of death was classified by an epidemiologist and two clinicians.
- Analysis of 2016-2018 data (χ^2 test for trend - statistical significance $p<0.05$)

[1] 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.

Results

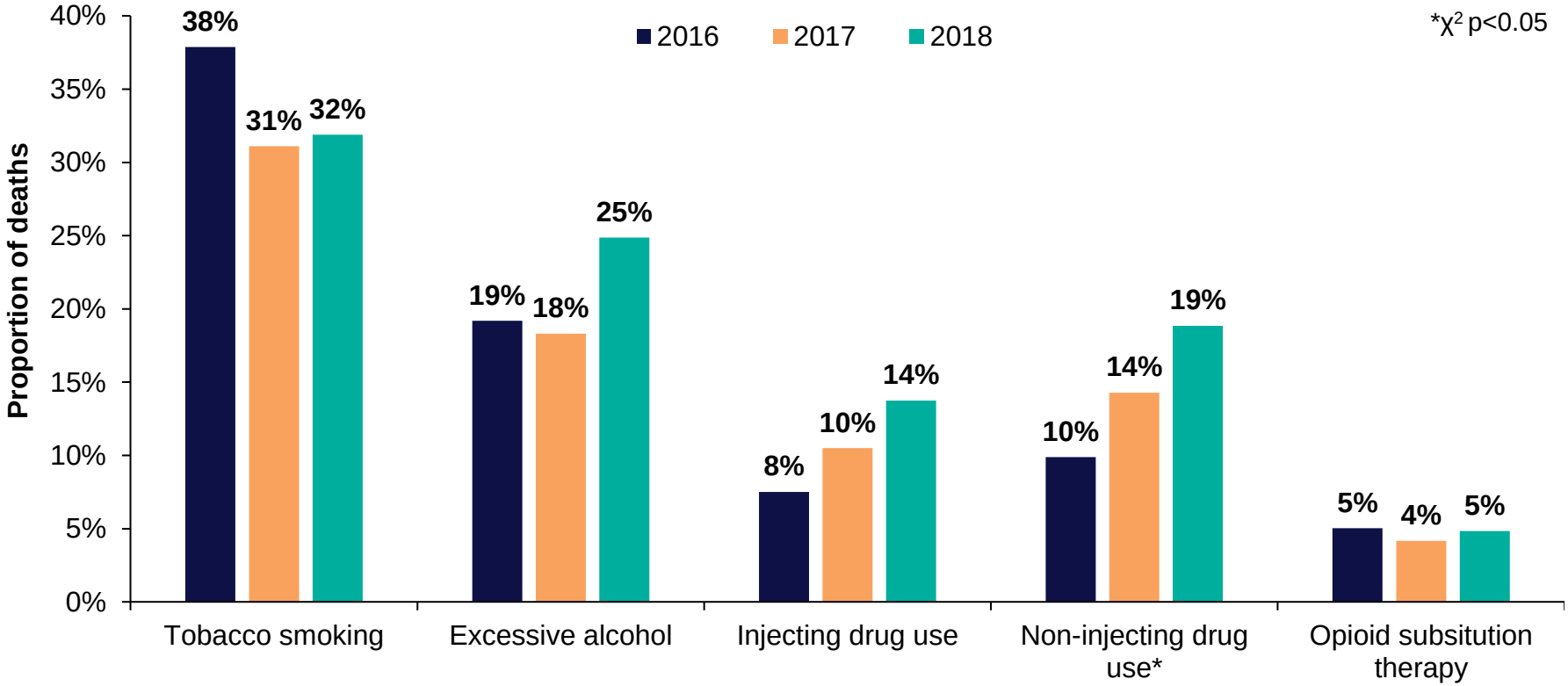
- All 16 Trusts submitted data for 2016-2018: **599** deaths reported

Demographic characteristics of people who died: London, 2016-2018

		2016			2017			2018			Total	
		n	%	Rate*	n	%	Rate*	n	%	Rate*	n	%
Deaths		**200**		**5.43**	**167**		**4.45**	**232**		**6.32**	**599**	
Gender	Men	157	79%	6.00	126	75%	4.75	172	74%	6.62	455	76%
	Women	43	21%	4.04	41	25%	3.81	60	26%	5.68	144	24%
Median age at death		55 [47-62]		-	52 [44-64]		-	53 [47-61]		-	53 [47-62]	
Age at death	15-24	1	1%	0.87	0	0%	0.00	3	1%	3.31	4	1%
	25-34	6	3%	1.07	10	6%	1.88	13	6%	2.62	29	5%
	35-49	58	29%	3.39	53	32%	3.17	72	31%	4.60	183	31%
	50-64	96	48%	8.46	66	40%	5.31	103	44%	7.91	265	44%
	≥65	39	20%	24.25	38	23%	20.84	41	18%	20.56	118	20%

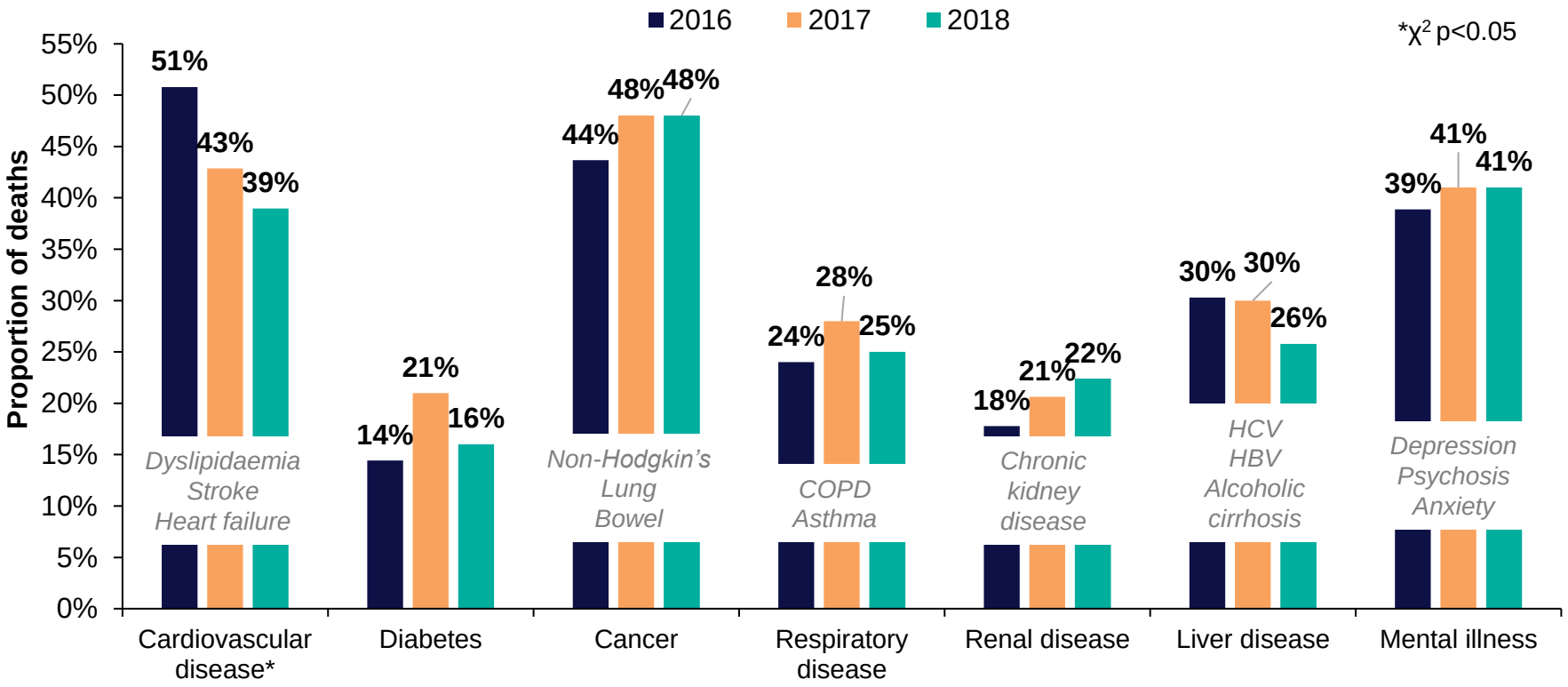
**Mortality rate per 1,000 HIV patients accessing care*

Risk factors in the year prior to death: London, 2016-2018



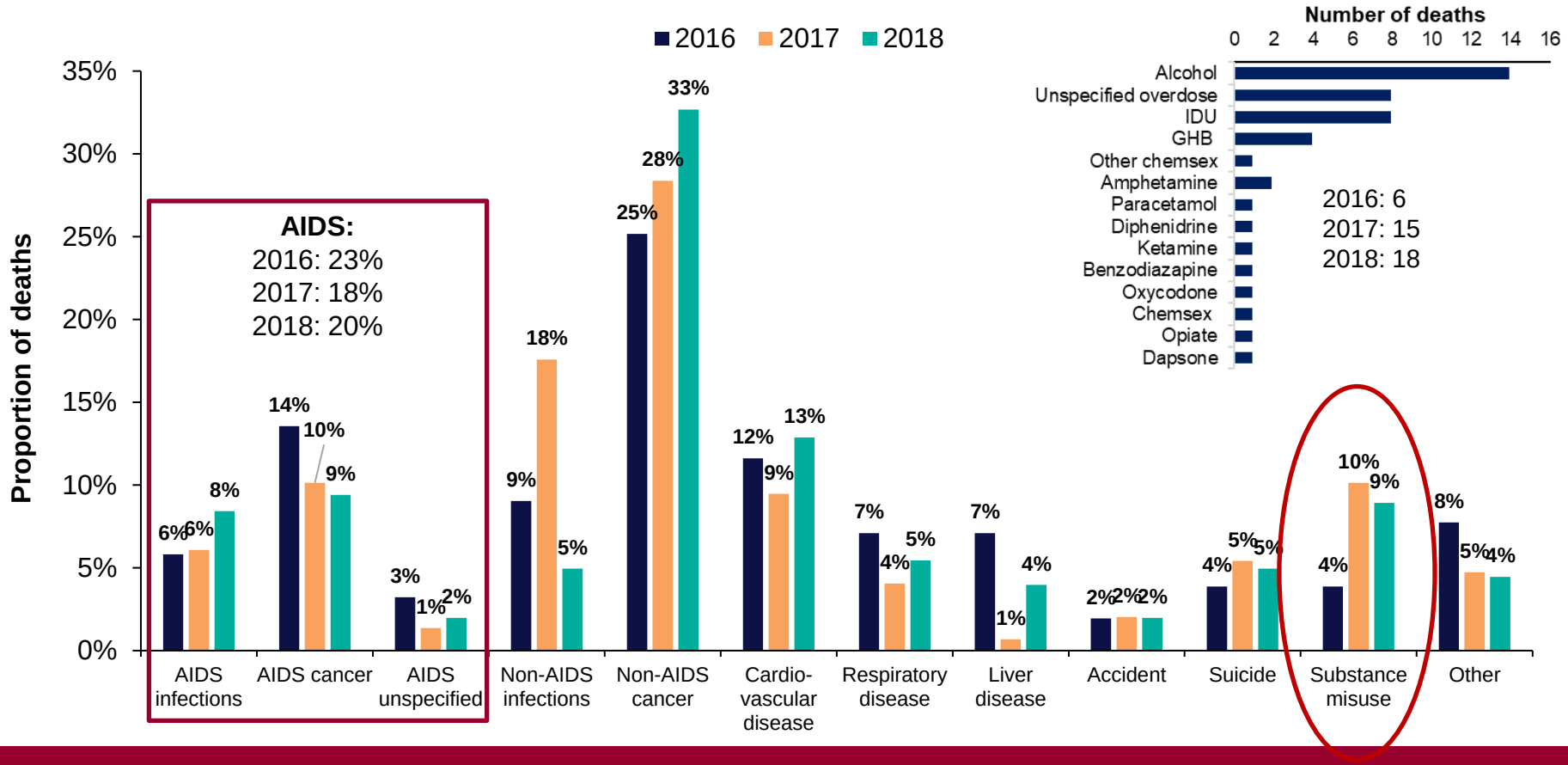
Completeness: smoking 86%; excessive alcohol: 87%; injecting drug use: 88%; non-injecting drug use: 87%; opioid substitution therapy: 89%

Co-morbidities: London, 2016-2018



Completeness: cardiovascular disease: 92%; diabetes: 89%; cancer: 91%; respiratory disease: 88%; renal disease: 88%; liver disease: 87%; mental illness: 88%

Cause of death: London, 2016-2018



Clinical care

- No change in the quality of HIV clinical care between 2016 and 2018.
- **97%** (559/578) of patients were ever on antiretroviral therapy (ART).
- Median time on HIV treatment before death: **10 years** [IQR: 4-16 years]
- **84%** (439/536) of patients were on ART at death*.
- Median CD4 count at death*: **252 cells/mm^3** [IQR: 97-490]
  - **62%** CD4<350 cells/mm^{3*}; **41%** CD4<200 cells/mm^{3*}
- **77%** (424/552) of patients were virally suppressed (<200 copies/mL) at death*.

**in the year prior to death*

Diagnosis information

- Median time diagnosis to death*: **13 years** [IQR: 6-20 years]
- **101** patients died within a year of diagnosis.
  - **80%** (66/82) diagnosed late**; **66%** (54/82) diagnosed very late***
  - **48%** (39/82) with an AIDS-defining illness at diagnosis
- **46** patients with documented missed opportunities for earlier HIV testing

Setting	1 year prior to diagnosis	5 years prior to diagnosis
Primary care	28	21
Sexual health service	5	3
Accident & Emergency	9	7
Other†	12	9

†*Private clinics, mental health services, ophthalmology, gynaecology, gastroenterology, cardiology, renal, rheumatology, dermatology*

**2017/2018 – data on diagnosis not collected in 2016; ***Late diagnosis: CD4 <350 cells/mm^3; ****Very late diagnosis: CD4 <200 cells/mm^3*

Strengths

- High level of engagement with HIV care Trusts – all Trusts returned highly complete data for the 3 years
- Longitudinal data to explore trends in mortality over time
- Data able to be linked to national HIV surveillance systems
- Rollout of HIV mortality review nationally this year - collaboration between PHE and BHIVA

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

Limitations

- No information on:
  - Extent to which co-morbidities were controlled
  - Whether patients had the ability to change their life-style risk factors
  - Socio-economic factors
  - Ethnicity
  - HIV acquisition
- Limited generalisability to the underlying population of HIV patients
- May have missed deaths in the community among people not in care

Conclusions

- There has been little change in the clinical profile of HIV patients who died in recent years.
- One in five deaths were HIV-related and potentially preventable, as a result of late diagnosis and/or sub-optimal engagement with care and treatment.
- To meet the Fast Track Cities Initiative (FTCi) target of zero HIV-related preventable deaths we need:
  - Rapid scale-up of HIV testing
  - Interventions to improve retention
  - Promotion of the benefits of early ART and U=U

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