Oral Session 2

06 Mortality among people with HIV in the UK in 2020: findings from the National HIV Mortality Review

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Mortality among people with HIV in the UK in 2020: findings from the National HIV Mortality Review

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Background

National HIV Mortality Review (NHMR)

- Launched early 2020 by BHIVA and UKHSA (previously Public Health England)
- Based on a working model that has been running in London since 2013
- Participation as a way for services to meet the BHIVA Standards 4A/8B - review of all deaths among people known to have HIV
- **Objective**: to understand mortality among people with HIV in the context of HIV elimination.

• Here, we reflect on the success of the 2\textsuperscript{nd} year of the NHMR, in the context of the COVID-19 pandemic, describing deaths occurring among people with HIV in 2020.
Methodology

• All HIV clinical services were invited to report data on all HIV inpatients and outpatients who died in 2020 (aged ≥15 years).

• Submission using a modified Causes of Death in HIV reporting form¹ (Snap):
  – 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 asked to make a decision as to whether each death was expected or unexpected.

• Cause of death was categorised by an epidemiologist and two clinicians.

Results

Participation

- **115** services participated in the NHMR
  - Coverage: two-thirds of all HIV clinical services (n=~195)
  - Increase from 2019: 73 services

621 deaths reported
Results

Demographics

- Median age at death: 56 years [interquartile range (IQR): 47-65]

![Gender (N=621)](image)
- 77% Women
- 23% Men

![Ethnicity (N=585)](image)
- 62% White
- 25% Asian
- 4% Black African
- 4% Black Caribbean
- 5% Other/mixed

![HIV acquisition (N=570)](image)
- 47% Injecting drug use
- 45% Sex between men
- 1% Heterosexual contact
- 6% Other
Results

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Cause of death

- **AIDS**
  - Proportion of deaths: 14%
- **Non-AIDS infections**
  - Proportion of deaths: 17%
- **Non-AIDS cancers**
  - Proportion of deaths: 22%
- **CVD**
  - Proportion of deaths: 23%
- **Liver disease**
  - Proportion of deaths: 6%
- **Respiratory disease**
  - Proportion of deaths: 3%
- **Accident/suicide**
  - Proportion of deaths: 3%
- **Substance misuse**
  - Proportion of deaths: 3%
- **Other**
  - Proportion of deaths: 4%

**COVID-19**
- Proportion of deaths: 80% (n=123)
- (23% of all deaths due to COVID-19)

**Ascertainment**: 87%

**n=39**
- 36% Alcohol
- 26% Agent unspecified
- 15% Poly-drug use

**Obesity**: 33%

**Dementia**: 7%

CVD: cardiovascular disease; COPD: chronic obstructive pulmonary disease
Results

Risk factors in the year prior to death

Completeness: tobacco smoking 90%; excessive alcohol: 87%; injecting drug use: 87%; non-injecting drug use: 88%; opioid substitution therapy: 88%
Results

Co-morbidities

Proportion of deaths

Dyslipidaemia  38%  45%  44%
Stroke  22%  27%  26%
Heart failure  23%  39%  36%
Dyslipidaemia
Stroke
Heart failure

CVD Diabetes Cancer Respiratory Renal Mental illness Liver Other

Results

Clinical care

- **98%** (601/616) of people with HIV who died ever received ART
- Median time on HIV treatment before death: **12 years** [IQR: 6-19 years]
- At death (within one year):
  - Median CD4 count: **330 cells/mm³** [IQR: 153-510]
  - 53% (238/453) had a CD4 <350 cells/mm³
  - 82% (464/567) were virally suppressed (<200 copies/mL)
  - 91% (506/559) were on ART
- Documented end of life care among those whose deaths were expected was **93%** (238/255).
Results

HIV diagnosis

• Median time from diagnosis to death: **14 years** [IQR: 8-21]

• **55** (8.9%) people died within a year of HIV diagnosis:
  - 70% diagnosed very late (CD4 count <200 cells/mm$^3$)
  - 86% diagnosed late (CD4 count <350 cells/mm$^3$)
  - 70% diagnosed with AIDS-defining illnesses

• **63** (10%) people had a documented missed opportunity for earlier HIV testing
  - 4 in sexual health services, 32 in primary care, 14 in A&E, 21 in other services (gastroenterology, dermatology, haematology, rheumatology, OH, drug services)
## Conclusions

### Strengths

- High level of engagement with HIV clinical services
- Increase of coverage in 2\textsuperscript{nd} year
- Data can be linked to national HIV surveillance systems
- Creation of NHMR Steering Group in 2021 with regional representation should increase participation in future

### Limitations

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

• Participation in the National HIV Mortality Review increased compared to the previous year, despite competing priorities due to COVID-19.

• These important data highlight that in 2020, almost a quarter of deaths among people with HIV occurred in individuals diagnosed with COVID-19.
  – People with HIV at higher risk of dying of/with COVID-19 compared to general population\(^2,3,4\)

• Although most died from non-AIDS-related causes, 1 in 5 people with HIV in the UK died from AIDS and at least 10\% had a missed opportunity for earlier HIV diagnosis.

• To meet the Fast Track Cities 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
  – Delivery of the BHIVA standards of care

• The BHIVA standard on palliative care is met for 93\% of those with expected death.


\(^3\) Bhaskaran K et al. HIV infection and COVID-19 death: population-based cohort analysis of UK primary care data and linked national death registrations within the OpenSAFELY platform. Lancet HIV. 2020;8:E24-E32.

We gratefully acknowledge the time and effort taken by HIV care services to report to the NHMR and continuing collaboration of people with HIV, clinicians, microbiologists, and other colleagues who contribute to the surveillance of HIV.
BHIVA
British HIV Association

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