Background
In the UK, HIV services are responsible for reporting all deaths of HIV positive individuals to Public Health England (PHE). Death reports on all cause mortality are also received from the Office for National Statistics (ONS).

In 2013 there were an estimated 107,800 people living with HIV infection in the UK of which 33,863 were resident in London. There were 530 reported deaths among people diagnosed with HIV in 2013 compared to 486 deaths in 2004. All cause mortality among people living with diagnosed HIV aged 15-59 years in England and Wales declined from 11 per 1,000 in 2004, to 4.3 per 1,000 in 2013. 1 In 2013, 374 of these deaths were of patients receiving their care in London. 2

In the era of antiretroviral therapy (ART) the spectrum of causes of death (CoD) has changed from being dominated by HIV-related causes to non-HIV-related causes of death compared to the pre-ART era.

Objective
Our aim was to describe the reported CoD for HIV positive patients dying during 2014, who either died in London or died elsewhere but routinely received their HIV care in London.

Methods
All 19 trusts commissioned by NHS England to provide HIV care in London were invited to report data on all patients who died in 2014 either at their centre or who attended their centre for their routine HIV care. Data submitted by the HIV centres were sourced from locally recorded mortality data and records of all deaths held by PHE. Data extracted included demographic data, HIV diagnosis date, cause and place of death, most recent CD4 count and viral load (VL), HIV treatment status and reported adherence. HIV centres were also asked to comment on whether the death was expected. Data were analysed for the whole cohort and also for patients dying within one year of their HIV diagnosis.

Results
Data were submitted by 16 centres (84%), who reported a total of 189 deaths. The median age at death was 52 years for men (range 29-92) and 46 years for women (range 29-80). Data published in September 2015 from the ONS reports life expectancy at birth for men in the UK as 79.1 years and for women 82.8 years.3

Almost all patients (175, 93%) were on HAART; 125 (71% of those on treatment, 67% of total deaths) had an undetectable VL and the median CD4 count was 262 cells/µL (range 1-1182 cells/µL). Of 59 patients with a detectable VL, 15 were recently diagnosed.

There were 38 patients (20%) who died within one year of HIV diagnosis; 33/37 had a CD4 cell count <350 cells/µL and 16 <50 cells/µL. Of all deaths, 136 (72%) were not directly related to HIV (compared to 32% in 2005) 4. Where data were available 33/58 (57%) deaths were expected.

<table>
<thead>
<tr>
<th>CoD</th>
<th>Malignancy</th>
<th>RESP*</th>
<th>Liver*</th>
<th>Substance misuse</th>
<th>CVA</th>
<th>OI</th>
<th>Sepsis</th>
<th>Suicide</th>
<th>CVD</th>
<th>Other**</th>
<th>Other*</th>
<th>NK</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>25 (13)</td>
<td>32 (17)</td>
<td>29 (10)</td>
<td>13 (7)</td>
<td>11 (6)</td>
<td>10 (6)</td>
<td>10 (6)</td>
<td>6 (3)</td>
<td>5 (3)</td>
<td>18 (10)</td>
<td>17 (9)</td>
<td>11 (6)</td>
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<tr>
<td>Non-AIDS</td>
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<td></td>
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<tr>
<td>Died &lt;5y after HIV diagnosis</td>
<td>17 (45)</td>
<td>2 (5)</td>
<td></td>
<td>5 (13)</td>
<td></td>
<td>6 (16)</td>
<td></td>
<td>8 (21)</td>
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</tbody>
</table>

*non-AIDS/HIV related, **AIDS/HIV related, RESP=respiratory, CVA=cerebrovascular accident, CVD=cardiovascular, OI=opportunistic infection, NK=not known

Conclusions
People with HIV continue to die from AIDS related illnesses and as a direct result of late diagnosis; the majority of these deaths are preventable. Almost all patients dying within a year of their diagnosis were diagnosed late and HIV testing must increase to reduce these avoidable deaths. However in 2014, the majority of deaths were not directly HIV-related and the majority of patients who died were on effective HAART. For those living with HIV longer term we need to improve health promotion through risk reduction, including modifying cardiovascular risk factors and addressing psychological needs and substance misuse. Those with more predictable deaths (57% expected deaths) through irreversible causes alongside some uncertainty of prognosis, they require better care planning. For this group, it is essential that good communication and coordination establishes preferences and goals of care, and that palliation is introduced early enough in the disease course to ensure that care at the end of life is available and can deliver a "good death".

References