# HIV & AIDS New Diagnoses & Deaths (HANDD)

## 1. What is the HIV & AIDS New Diagnoses & Deaths Database?

The HIV & AIDS New Diagnoses & Deaths Database at PHE Colindale collects information on new HIV diagnoses, first AIDS diagnoses and deaths in HIV-infected individuals. Information is received from laboratories, genito-urinary medicine (GUM) clinics, GPs and other services where HIV testing takes place in England, Wales and Northern Ireland. Scottish data (Health Protection Scotland) and data concerning paediatric infections (Institute of Child Health) are collected separately and collated to produce the national surveillance tables.

## 2. What is being measured?

Key outputs from the HIV & AIDS New Diagnoses & Deaths Database include:

1. Number of individuals newly diagnosed with HIV infection in the UK by sex, age, ethnicity, probable route of HIV transmission and region of diagnosis.
2. Number of individuals diagnosed with an AIDS-defining illness in the UK.
3. Number of deaths in individuals with HIV infection.
4. Together with data from SOPHID and the CD4 Surveillance Scheme, proportion of individuals diagnosed late (CD4 cell count less than 350 cells/mm³) at local authority level are generated.
5. The proportion of infections that are acquired in the UK among those born in the UK and abroad is estimated through a new method (1).

## 3. Why is it being measured?

Timely data from the HIV & AIDS New Diagnoses & Deaths Database provide essential information on the changing profile of people being diagnosed HIV infection for public health monitoring, prevention monitoring and the commissioning of HIV-related services.

## 4. Who does it measure?

All individuals newly diagnosed with HIV in the UK.

## 5. When does it measure it?

The survey is run bi-annually, from January to June and from July to December.

**Please note:** Annual outputs can be accessed through the PHE website. For further information please contact HARSQueries@phe.gov.uk.

## 6. Will it measure absolute numbers or proportions?

Results are presented in absolute numbers.

## 7. Where does the data come from?

New HIV diagnoses, AIDS and death reports are collected and collated by Public Health England, Colindale. Data are received from clinics and laboratories in England, Wales and Northern Ireland.

Scottish data (Health Protection Scotland) and data concerning paediatric infections (Institute of Child Health) are collected separately and collated to produce the national surveillance tables.

Death data is also collected by the database however the data are also linked to data from the Office of National Statistics (ONS) death register.

## 8. How accurate and complete are the data?

Upon receipt, the data is checked using a validation process. Records that have missing or invalid key fields (e.g. patient identifiers and risk for HIV) are not added to the database. These are followed up with reporting sites for correction or clarification. Once these data are of sufficiently high quality, it is accepted into the final database.

Data are received from detailed clinician reports and supplemented with reports from laboratories. Data are also linked with other sources, e.g. SOPHID, to ensure the data is as complete as possible.
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<td><strong>9</strong> Are there any known caveats/problems/weaknesses within the data?</td>
<td>The open access nature of HIV clinics means HIV patients can and do access multiple sites, and the confidential nature of HIV means NHS numbers and names are not collected. Thus, a patient using different identifiers in different clinics cannot be identified. As reporting is voluntary, there is an issue of reporting delay. This usually affects the most recent year of reporting and as such a table (Table 1A) is produced which adjusts data for missing variables and reporting delay.</td>
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<td><strong>10</strong> Are particular tests needed?</td>
<td>No standardisation required.</td>
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<td><strong>11</strong> Data availability</td>
<td>HIV and AIDS new diagnoses and deaths data are freely available to the public on the PHE website. Due to the confidential nature of the data, local outputs are restricted to the level of detail appropriate to the data user and disseminated in accordance to data confidentiality guidelines: Website - HIV and AIDS new diagnoses and deaths surveillance tables are presented at UK and regional level and also nationally by risk groups. HIV and AIDS new diagnoses anonymised disaggregate data are produced for each PHE centre and region and published on the secure PHE web portal made only available to Regional Epidemiologists at each of the Centres and Regions in England and to appropriate contacts in Wales and Northern Ireland. Data requests – any analyses that are not already available via other means will be undertaken by the New Diagnoses team providing there are no disclosure issues and the time required to produce the data can be justified by it’s usefulness.</td>
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<td><strong>12</strong> Frequency of data updates</td>
<td>Biannual update</td>
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<td><strong>13</strong> Indicator lay summary</td>
<td>In 2012, there were 6,364 people diagnosed with HIV infection (4,559 men and 1,805 women).</td>
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**Methods and frequently asked questions**

**Methods**

Voluntary reports of HIV diagnoses in England, Wales and Northern Ireland are sent to the Public Health England, Centre for Infectious Disease Surveillance and Control (CIDSC) - Colindale. Reports are received from laboratories and clinicians. Laboratory report forms provide the initial information relating to HIV diagnoses. Subsequently clinician report forms contain much more detailed epidemiological information than laboratory forms and are essential in describing the HIV epidemic. For a variety of reasons, it is not always possible for a clinical report form to be completed (for example, the patient does not return to the clinic for their result) which is why it is essential that laboratories also report HIV diagnoses. Without information from laboratories we may underestimate the total number of HIV diagnoses. Clinician reports are also sent in the event of the first AIDS diagnosis or death in an HIV infected individual in England, Wales and Northern Ireland.

**Inclusion Criteria: Who should be reported to the Health Protection Agency Centre for Infections**

- All adults (15 years and above at diagnosis) diagnosed with HIV infection in England, Wales and Northern Ireland
- All adults (15 years and above at diagnosis) with a first AIDS diagnosis in England, Wales and Northern Ireland
- All deaths in HIV-infected adults (15 years and above at death) in England, Wales and Northern Ireland

**Exclusion Criteria: Who should not be reported**

- Children (aged reported to the Institute of Child Health).
- Individuals newly diagnosed with HIV in Scotland, who should be reported to Health Protection Scotland.

**Frequently asked questions:**

**Is new HIV diagnoses data an estimate of incidence?**
No - numbers include individuals who have an existing infection as well as those who have a newly acquired infection.

**Is new HIV diagnoses data an estimate of prevalence?**
No. Due to late reporting of deaths and individuals subsequently leaving the UK, an estimate of prevalence of...
diagnosed HIV infection cannot be gained by subtracting the number of deaths from the number of diagnoses. Numbers take no account of undiagnosed HIV infections in the population. Estimates of diagnosed prevalence can be attained from the Survey of Prevalent HIV Infections Diagnosed (SOPHID).

In the latest year there appears to be a flattening / decline in the observed number of new HIV diagnoses, is this representing a real decline? Maybe. Due to reporting delay, data presented for more recent years will increase. Reporting delay can result in numbers slightly increasing for any previous years.

When presenting data by area do the numbers relate to a resident population? No. An area is defined by where an individual was first diagnosed (i.e. where the clinic or GP practice was located). There is evidence that a large proportion of individuals seek their HIV related care or treatment outside of their area of residence, with large cities in particular attracting individuals from outside of area. SOPHID provides residence and treatment based results for the diagnosed prevalent population.

On occasions when presenting data by two levels of geography you sometimes state for the smaller level geography “Not known”, how can this be? For some diagnosing centres (particularly GP practices) with the available information it is possible to map to the larger area but not the smaller area.

Why are the variables “infection route / exposure group” and/or “country of infection” usually prefixed by “probable”? It is often difficult to determine, both for the patient and their doctor, with certainty the route by which and the location where an individual acquired their HIV infection. Therefore the term “probable” is used.

Aggregate data: the figure you report for the clinic/area I work within differs to the total number of diagnoses we have made at our clinic/area, why is this? The numbers we present refer to the number of new diagnoses in the UK. With some individuals receiving an HIV diagnoses at multiple sites (for example, due to transfer policy or re-testing) it is possible that some individuals reported to us from your site/area have already been entered on the system due to receiving a UK diagnosis elsewhere.

Disaggregate data: the figure you report for the clinic/area I work within differs to the total number of diagnoses we have made at our clinic/area, why is this? It is possible that we may not have not been able to enter some reports of diagnoses due to missing key fields (such as soundex, date of birth, sex and date of specimen); it is also possible that we have not as yet received reports that you have recently completed.

What confidentiality procedures are in place? We ask that all data be sent to us electronically via the secure HIV & STI web portal. All staff are briefed on Caldicott guidelines and are aware of the sensitive nature of the data. When ad hoc queries come in we do not provide any breakdowns below local authority level.

To maintain patient confidentiality, Soundex codes are used instead of names. All data are stored on restricted and secure databases, with strict adherence to the Data Protection Act and Caldicott Guidelines. HIV & AIDS New Diagnoses & Deaths Database has approval under the section 60 regulations of the Health and Social Care Act 2001.

For confidentiality reasons, data is not broken down within a region smaller than a local authority and all outputs are presented in aggregate form. No identifiers are provided.

For further information on safeguarding the confidentiality of patient information whilst protecting public health please see: http://www.hpa.org.uk/confidentiality/

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References