# The CD4 Surveillance Scheme

## 1 What is CD4 surveillance?

The CD4 Surveillance Scheme began in 1995 and monitors immunosuppression among adults living with a diagnosed HIV infection in England, Wales and Northern Ireland. Over 60 laboratories that perform CD4 T-lymphocyte counts and are involved in the NEQAS quality assurance scheme currently participate in the scheme. Scottish data is collected by Health Protection Scotland. The data are incorporated to produce data for the United Kingdom (UK).

## 2 What is being measured?

Key outputs from CD4 surveillance include:

1. Together with New HIV and AIDS Diagnoses and Deaths Database and the Survey of Prevalent HIV Infections Diagnosed (SOPHID), proportion of diagnosed HIV-infection adults (aged 15 years or more) who have a CD4 counts of less than 350 cells/mm\(^3\) within 91 days of HIV diagnosis
2. Late HIV diagnosis by age, sex, probable route of HIV transmission, ethnicity and local authority of residence
3. The proportion of diagnosed HIV-infection adults (aged 15 years or more) who have a CD4 counts of less than 200 cells/mm\(^3\) within 91 days of HIV diagnosis (severely immunocompromised at diagnosis)
4. One-year mortality (death within a year of diagnosis) associated with late HIV diagnoses
5. Median CD4 counts at diagnosis by age, sex and probable route of HIV transmission
6. Together with the Survey of Prevalent HIV Infections Diagnosed (SOPHID), quality of care indicators are generated annually to measure
   - Prompt integration into care (proportion of individuals having a CD4 count within a month of diagnosis)
   - Immune system response (proportion of patients who have a CD4 count ≥350 cells/mm\(^3\) after at least one year in HIV care)

## 3 Why is it being measured?

Timely data from CD4 surveillance is essential for monitoring late diagnosis, which is the most important predictor of morbidity and mortality among those with HIV infection. It is a critical component of the Public Health Outcomes Framework and monitoring is essential to evaluate the success of expanded HIV testing. Since 2013 the HIV Clinical Dashboard indicators, developed by HIV Clinical Reference Groups, include an indicator monitoring how quickly patients are integrated into HIV care following diagnosis (i.e. length of time from diagnosis to first CD4 count date).

## 4 How is the indicator defined?

CD4 counts from the same patient in each laboratory are linked to track patients over time and a process of de-duplication is then carried out to link reports of patients that have tests in more than one laboratory.

## 5 Who does it measure?

All HIV-diagnosed adults with CD4 counts from participating laboratories.

## 6 When does it measure it?

Data are reported bi-annually, quarterly or monthly to suit individual laboratories. The scheme covers all CD4 counts in a given calendar year.

## 7 Will it measure absolute numbers or proportions?

Results can be presented in absolute numbers and proportions.

## 8 Where does the data come from?

CD4 data are collected and collated by HIV & STI Department, PHE, Colindale

## 9 How accurate and complete are the data?

The CD4 surveillance scheme includes approximately 80% of newly diagnosed HIV individuals. To produce the key outputs, good quality local patient identifiers are required to link between HIV surveillance systems and to de-duplicate to prevent double counting of the same individual.

PHE usually report CD4 data in November for new diagnoses made in the previous
calendar year. Individuals newly diagnosed between October and December of the previous year where their CD4 cell counts were not made available until the following year are included in annual outputs of the following year, that is, the year the CD4 date was taken.

HIV patients can and do access multiple sites, and the confidential nature of HIV means NHS numbers are not collected. Thus, a patient using different identifiers in different clinics cannot be identified. The data may not be representative in areas where residence information is not known for a significant proportion of new HIV diagnoses or where CD4 cell count is not available within 91 days.

HIV and AIDS new diagnoses anonymised disaggregate data which include data from CD4 surveillance are produced for each PHE Centre and published on the secure PHE web portal made only available to regional scientists 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 CD4 team providing there are no disclosure issues and the time required to produce the data can be justified by its usefulness.

Further information can be found at http://www.hpa.org.uk/Topics/InfectiousDiseases/InfectionsAZ/HIV/ or please contact harsqueries@phe.gov.uk.

Over the last decade, the proportion of individuals diagnosed late has declined significantly, from 60% in 2002 to 47% in 2011 (p<0.0001 for trend), and across all exposure groups. The decline in late diagnosis among MSM is particularly noteworthy, 48% in 2002 compared to 35% in 2011.

One-year mortality among persons diagnosed late is high, with a ten-fold increase in death within the first year of diagnosis, compared with those diagnosed with a CD4 count above 350.
Methods and Frequently Asked Questions

Information requested consists of local patient identifiers (soundex codes of the patients’ surname, date of birth, sex, and clinic/hospital/laboratory identification numbers) and details of test results (absolute CD4 count, CD4 test date, CD4 percentage and total lymphocyte count).

Counts from the same patient in each laboratory are linked using laboratory identification numbers. A process of deduplication is then carried out using soundex and date of birth to identify and link reports of patients that have had tests in more than one laboratory.

Patient records on the CD4 database are then matched to patients on the databases for new HIV diagnoses and the Survey of Prevalent HIV Infections Diagnosed (SOPHID) using hierarchical combinations of patient identifiers. This results in a large dataset that includes epidemiological information from the new diagnoses database (such as infection route, ethnicity etc), and SOPHID database (region of residence and treatment information) as well as a history of CD4 cell counts from the CD4 database.

Background information

What are CD4 cells?
- CD4 cells serve an important immune function and are released in response to foreign bodies (‘antigens’).
- CD4 cells attach themselves to these antigens thereby facilitating their destruction by CD8 (suppressor/cytotoxic) T-lymphocytes.
- CD4 cells are T-lymphocyte (helper/inducer) cells which have ‘CD4’ receptors.
- HIV adheres itself to CD4 cells, ultimately destroying the cell. This depletion in CD4 cells results in individuals being susceptible to infection.

What is a CD4 cell ‘count’?
- This is a measure of the number of CD4 cells in a specified volume of blood. CD4 cell counts are usually expressed in cells/mm$^3$.
- Other immunological measures routinely used in HIV positive individuals include the total number of lymphocytes (used to calculate the percentage of all lymphocytes which express the CD4 receptor) and levels of CD8 cells.
- These procedures are performed by immunology or haematology laboratories.

Why are CD4 cell counts performed?
- Enumeration of CD4 T-lymphocytes (CD4 cell ‘counts’) give a measure of the degree to which an individual’s immune system is ‘compromised’.
- This will identify periods in which an individual is vulnerable to opportunistic infections and consequently help inform decisions to initiate antiretroviral treatment and therapies to prevent opportunistic infection (prophylaxis).

Ensuring confidentiality

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 LA 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. CD4 Surveillance 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 LA 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/

What is the HIV & STI Web Portal and how do I use it?
The web portal is a secure Internet site recommended by PHE, which allows transfer of data discreetly and confidentially to a secure server located within PHE. The CD4 data can be placed into the CD4 folder which is
Can you provide data showing an individual’s soundex?
No, no information with identifiers will be disseminated.