AN EVALUATION OF HIV CASE-BASED SURVEILLANCE IN IRELAND:

DESCRIPTION OF THE SYSTEM, SENSITIVITY AND TIMELINESS

November 2015

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ABBREVIATIONS

AIDS	Acquired immune deficiency syndrome / Acquired immunodeficiency syndrome
CDC	United States Centers for Disease Control and Prevention
CIDR	Computerised Infectious Disease Reporting
CUH	Cork University Hospital
DPH	Department of Public Health
ECDC	European Centre for Disease Prevention and Control
EEA	European Economic Area
EU	European Union
GARPR	Global AIDS Response Progress Reporting
GP	General Practitioner
GU	Genitourinary
GUH	Galway University Hospital
HIV	Human Immunodeficiency Virus
HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immune Deficiency Syndrome
HIV-DNA	Human Immunodeficiency Virus- Deoxyribonucleic acid
HIV-RNA	Human Immunodeficiency Virus- Ribonucleic acid
HPSC	Health Protection Surveillance Centre
HSE	Health Service Executive
ICR	Individual Case Based reporting system
ID	Infectious Diseases
MTCT	Mother to child transmission
MSM	Men who have sex with men
NASC	National AIDS Strategy Committee
NGO	Non-Governmental Organisation
NVRL	National Virus Reference Laboratory (Ireland)
P24	P24 capsid protein
PWID	People Who Inject Drugs
STI	Sexually Transmitted Infections
TESSY	The European Surveillance System
UHL	University Hospital Limerick
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

EXECUTIVE SUMMARY

Background

HIV remains a significant public health issue in Ireland. Timely reporting of new HIV cases is essential to get accurate information for relevant and timely action. The length of the delays in providing enhanced surveillance data for HIV is currently unknown. On-going HIV data reviews identified diagnoses that were not being reported due to laboratory notification criteria; those increased significantly in 2013 and were a cause for concern. We described the system and evaluated the HIV surveillance system in terms of its timeliness and sensitivity

Methods

We described the HIV surveillance system based on: a review of documents at the Health Protection Surveillance Centre (HPSC), semi-structured interviews with the National Virus Reference Laboratory (NVRL) staff, and a visit at the Department of Public Health (DPH) in the East region. We estimated underreporting by analysing new HIV diagnoses that were not notified in 2013 by the NVRL because they didn't fit nationally agreed NVRL laboratory criteria for reporting. To identify potential reporting delays, we used the national Computerised Infectious Disease Reporting System (CIDR) and NVRL 2012/2013 data and calculated median time intervals (range) in HIV surveillance steps, from HIV first sample confirmation to completion of enhanced information in CIDR.

Results

The data collection occurs in two different stages: first the notification of the diagnosis through the electronic system, and second the collection of clinical information. Unlike the EU-based HIV surveillance case definition, nationally agreed procedures are that NVRL requires two separate samples from most local laboratories to ensure provenance of the sample. In 2013, 71 diagnoses were not notified in CIDR (sensitivity 82%) because they did not meet these nationally agreed notification requirements: 23 had only one serology HIV positive sample and 48 had a second sample tested for viral loads, but they were undetectable. Overall, 81% of notifications had an enhanced form completed six months after diagnosis confirmation (within CDC standards of 66%), and 73% had a form completed three months after the form was sent (Irish requirements).

Discussion and conclusion

The evaluation identified several issues: formal surveillance objectives have not been documented and the system lacks harmonised procedures across the country.

The main reason for underreporting is related to the two-sample notification threshold required by the nationally agreed reporting procedures for NVRL. Moving to one sample for notification will increase the sensitivity of the system and improve the early detection of outbreaks. However possible impacts on completeness and timeliness have to be carefully anticipated. The notification threshold related to diagnoses from abroad has to be considered in light of the review of the objectives of the system.

Timeliness of the HIV surveillance system was in line with the international standard of 66% of cases reported within six months of diagnosis; reliable analysis of trends could be undertaken within six months.

We recommend documenting the HIV case based surveillance objectives, harmonising the surveillance procedures for the system; and that NVRL should notify on confirmation of HIV in the first sample from all laboratories.

1. INTRODUCTION

The international commitment

Within the framework of the Dublin Declaration on the partnership to fight Human Immunodeficiency Virus (HIV) and AIDS in Europe and Central Asia signed in 2004, Ireland, committed, as did other countries, to "control the incidence and prevalence of sexually transmitted diseases (STIs) [...], particularly amongst those at the highest risk of and most vulnerable to HIV/AIDS", and to "fund, improve and harmonise surveillance systems, in line with international standards, to track and monitor the epidemic, risk behaviours and vulnerability to HIV/AIDS" (1).

The burden of HIV in Ireland

The prevention, surveillance and control of HIV are important priorities in Ireland and the epidemic attributable to HIV remains a significant public health issue in the country. It can cause significant morbidity, particularly if diagnosed late.

Since the early 1980's up to the end of 2014, a total of 7,353 people have been newly diagnosed with HIV in Ireland (2). After reaching a peak of 10.2 per 100,000 in 2003 and 9.5 in 2008, the annual rate of new HIV diagnoses had been relatively stable between 2010 and 2013, ranging from 7.0 to 7.5 per 100,000. In 2014, a total of 377 people were newly diagnosed in Ireland with HIV, giving an increasing rate of 8.2 per 100,000 population (Figure 1).



Figure 1: Rate of new HIV diagnoses (per 100,000 population), 1991 to 2014, Ireland

Source: HIV in Ireland, 2014 report, HPSC (2)

Between 2003 and 2014, overall, heterosexual sex (44%), and sex between men (34%) were the commonest routes of transmission, accounting for 77% of all new diagnoses (Figure 2). People who inject drugs (PWID) accounted for 11%, mother to child transmission (MTCT) 1.3%, and unknown route of transmission for 11% of cases. The number of diagnoses in men who have sex with men (MSM) has increased over time from 76 in 2003 to 183 in 2014. Conversely, the number of diagnoses with heterosexual route of transmission has decreased from 222 in 2003 to 125 in 2014. Finally, the notification rate is usually higher in Health Service Executive (HSE) East area (16.1 per 100,000 in 2014) which includes the counties Dublin, Kildare and Wicklow, compared to the rest of the country.



Figure 2. New HIV diagnoses by probable route of transmission, 2003 to 2014

Source: HIV in Ireland, 2014 report, HPSC (2)

In 2014, 277 (73%) new HIV diagnoses were in men (12.2/100,000 population) and 100 (27%) were in women (4.3/100,000 population), with a male to female ratio of 2.8 (Figure 3). The male to female ratio has been increasing since 2003 with a decreasing number of new HIV diagnoses in women and an increasing number of new diagnoses in men.

In 2014, the median age of adult cases at HIV diagnosis was 33 years (range: 18 to 77 years); 33 years in males (range: 19-77 years) and 33 years (range: 18 to 65 years) in females.



Figure 3: New HIV diagnoses by gender, 2003 to 2014

Source: HIV in Ireland, 2014 report, HPSC (2)

Late diagnosis

Late HIV diagnosis, where a person is unaware of their HIV status for many years, carries an increased risk of HIV-related illness and death. In addition, prompt HIV diagnosis and appropriate treatment can provide an opportunity to prevent further HIV transmission. During 2014, 49% of cases were late presenters (where information on CD4 count or AIDS defining illness at diagnosis was supplied). This is similar to the proportion in recent years (50% in 2013 and 49% in 2012) and to the proportion reported in Europe (47% in 2013) (2).

Notification of those who previously tested HIV positive abroad

Notifications of HIV include all people who test HIV positive for the first time in Ireland and include a number of people who have previously tested HIV positive abroad. In 2014, 17% of the diagnoses were reported to have previously tested HIV positive abroad. This compares to 16% in 2013, 17% in 2012 and 14% in 2011 (data on previous positive tests was not collected prior to 2011).

2. RATIONALE AND CONTEXT OF THE EVALUATION

Since HIV became a notifiable disease in Ireland, HPSC undertook an evaluation of the completeness of the surveillance system over a two year period from January 1st 2012 to December 31st 2013 (3). Regular evaluations of the completeness of the surveillance system had also been undertaken before it became notifiable (in 2008-2011) (4-6). Furthermore, HPSC conducted laboratory surveys of HIV testing practices in 2008, 2009 and 2010-11 (7-9). This is the first examination of the timeliness since HIV became notifiable in Ireland and the first time underreporting and timeliness were appraised in the light of a detailed description of the HIV surveillance system.

Underreporting of new HIV diagnoses in Ireland

NVRL is the only laboratory which initiates the notification process for HIV in Ireland. A previous review of HIV data from 2003 to 2007 by the National Virus Reference laboratory (NVRL) and HPSC identified underreporting of HIV cases (10). At the time, the agreed NVRL criteria for HIV reporting which was defined as two serologically positive results recorded on two separate samples, differed from the European case definition (11). As a result of the review, it was agreed by all surveillance partners to amend the NVRL working case definition to also include all new diagnoses with one antibody positive test and a significant viral load result (where a detectable quantity of HIV nucleic acid is reported). Ongoing review of the data by the NVRL and HPSC in subsequent years identified further new diagnoses which were not being reported due to these laboratory criteria. These were either cases with an anti-HIV serological positive result and subsequent viral loads tests with undetectable viral loads or cases with only one antibody positive and no other subsequent tests. While the number of cases in these categories was small between 2009 and 2012, the number in 2013 increased significantly and was a cause for concern.

Analysis of HIV data

At HPSC, data from HIV surveillance is analysed on a weekly, six-monthly and annual basis. Timely reporting of new HIV cases is essential to get accurate information for relevant and timely action. Key enhanced surveillance data may take some time to be collected. As a result, the interpretation of trends among risk groups and in late diagnoses should take these delays into consideration. The length of these delays in Ireland is not currently known.

Aim of the evaluation

The aim of this report was to evaluate the HIV surveillance system by providing a description of the HIV surveillance system, evaluating its sensitivity in terms of under-reporting related to notification threshold, and its timeliness.

3. OBJECTIVES OF THE EVALUATION

The objectives of the evaluation of the system were to:

- Describe the system;
- Estimate one aspect of the sensitivity of the system: the degree of underreporting related to the difference between laboratory and surveillance thresholds for reporting,
- Assess the timeliness of the system, identify any intervals that could be eliminated or shortened, or if not, to use this knowledge to aid better interpretation of trends;
- Identify challenges and provide recommendations to improve HIV surveillance

4. METHODS

4.1. EVALUATION GUIDELINES AND STAKEHOLDERS

The evaluation followed the United States Centers for Disease Control and Prevention's (CDC) Updated Guidelines for Evaluation of Public Health Surveillance Systems (12) as well as the ECDC handbook on data quality monitoring and surveillance system evaluation (13). The WHO guideline on evaluating a national surveillance system developed by UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance was also used (14).

The EPIET fellow based at HPSC undertook the evaluation, working closely with the HIV/STI surveillance team at HPSC and the surveillance scientist at the NVRL. Prior to commencing the evaluation process, a protocol was reviewed and approved by key stakeholders involved in HIV surveillance. This included the national Public Health STI/HIV Special Interest Group, and the HPSC national HIV/STI operational surveillance group, representing public health, surveillance scientists, laboratory and clinical specialties. Preliminary findings were also reviewed by these groups prior to finalising the evaluation report.

The evaluation focused on the surveillance of HIV in the adult population and excluded the surveillance of HIV in children less than 18 years.

4.2. DESCRIPTION OF THE SYSTEM

We described the HIV surveillance system based on i) a review of documents at HPSC, (including surveillance reports, CIDR database reports, the HIV surveillance form, standard operating procedures, surveillance guidelines and other strategic documents) and ii) semi-structured interviews with NVRL staff in charge of surveillance. The evaluator visited the Department of Public Health (DPH) in the East region and met with the staff in charge of HIV surveillance.

4.3. SENSITIVITY OF THE SYSTEM

According to the CDC and ECDC guidelines, the sensitivity of a system refers to "proportion of the total number of cases in the population under surveillance being detected by the system" (12). It

includes both the case detection/diagnosis component and the disease-reporting component. Due to the non-availability of independent data on HIV notifications in Ireland, we focused the evaluation on the analysis of new 2013 HIV diagnoses that were not notified to CIDR in 2013 by the NVRL.

NVRL provided HPSC with a dataset of new HIV diagnoses in Ireland that were not reported in CIDR as they didn't fit the nationally agreed laboratory criteria for reporting (data provided in August 2014). These data were analysed in order to better understand the profile of these cases.

4.4. TIMELINESS OF THE SYSTEM

"Timeliness reflects the speed between steps in a public health surveillance system" (12). We measured intervals between the various steps in HIV surveillance and identified possible ways of reducing or eliminating them (Figure 4). For this purpose, we merged two sets of data: i) the entire dataset of 2012 and 2013 HIV notifications (extracted from CIDR on 4th February 2015), and ii) the NVRL internal database with the 2012 and 2013 HIV new diagnoses reported to CIDR, (extracted on 21st August 2014). This database was used internally by NVRL to keep a record of new confirmed diagnoses of HIV notified to CIDR. We used the following dates, listed by chronological order: (Figure 3):

- **Date of 1st HIV positive test**: date of the first positive test performed at NVRL that is documented in NVRL database and provided as comments in CIDR by NVRL.
- Date of HIV diagnosis confirmation: date when the result of the HIV confirmed diagnosis is reported within NVRL. It is different from the date when the result is generated which is not documented. This date is notified on CIDR by the NVRL in the field "result date".
- Date form sent to clinicians: date when the enhanced HIV surveillance form is sent by the NVRL to the clinicians after confirmation of the HIV diagnosis. This date is documented in the NVRL database only.
- **Date of notification**: It corresponds to the date when local laboratories authorise the CIDR record that has been uploaded by NVRL, before it goes to the Department of Public Health for event creation. This date is documented in CIDR.
- **Date of event creation**: date when the Department of Public Health validates the notification on CIDR.
- **Date of form completion**: this date is documented on the enhanced surveillance form by the physician / clinic who completed the form. This date is documented in CIDR when the form is

received and entered in CIDR by the Department of Public Health. However it does not provide information on when the form is received and entered into CIDR.

We first described the 2012-2013 records by place and time. Then we described the different dates available in these records and evaluated the data quality.

We calculated the median, 25th and 75th quartiles, and minimum and maximum number of days between the different dates representing the different surveillance steps. For each time interval calculation, we excluded from the analysis records that weren't consistent and logical for that calculation with regard to date orders. For box plots, an outside value was defined as a value that was smaller than the lower quartile minus 1.5 times the interquartile range, or larger than the upper quartile plus 1.5 times the interquartile range. Outside values were not represented on the box plots. Figure 4. Surveillance steps between DPH, local laboratories, NVRL and clinicians, HIV surveillance system in Ireland¹



¹ DPH: Department of Public Health, NVRL: National Virus Reference Laboratory, CIDR: Computerised Infectious Disease Reporting

²³ November 2016–HIV Surveillance system evaluation, Description of the system, Sensitivity and Timeliness, HPSC, Ireland

We compared our results with the CDC minimum performance standards and the Irish national standards in the HIV notification guideline for professionals (12;15).

The CDC considers that for accurate and timely data for monitoring HIV/AIDS trends, and ensuring a reliable measure of the number of persons in need of HIV prevention and care services, HIV surveillance systems should provide complete (greater than or equal to 85%) and timely (greater than or equal to 66% of cases reported within 6 months of diagnosis) reporting (12).

In Ireland, laboratories are expected to report events on a daily or weekly basis and clinical information has to be reported by the end of each quarter. Departments of Public Health should report to HPSC on a weekly basis (15).

5. RESULTS

5.1. DESCRIPTION OF THE SYSTEM

5.1.1. THE HIV SURVEILLANCE SYSTEM IN IRELAND

5.1.1.1. FROM AIDS REPORTING SYSTEM TO HIV CASE-BASED SURVEILLANCE

For many years, the epidemiological monitoring of HIV infection was based on AIDS reporting. Following the decline in AIDS incidence due to antiretroviral treatment, there was a shift in the pattern of disease, which led to a revision of HIV surveillance strategies used throughout Europe. In the late 1990's, it was decided to implement HIV case-based reporting both at a European level, and in Ireland.

Following the establishment of the European HIV case reporting system in 1999², a working group was set up by the surveillance Sub- Committee of the National AIDS Strategy Committee (NASC) in 1999 to establish a national HIV case based reporting system in Ireland (ANNEX 1). The National Disease Surveillance Centre (now known as HPSC) was established in 1998 in order to collate, analyse, and disseminate data on communicable diseases in Ireland. In 2001, the National Disease Surveillance Centre took over reporting of both AIDS and HIV from the Department of Health. A joint HIV/AIDS surveillance form was developed and replaced the AIDS surveillance report form. The Irish HIV case-based reporting system, which was a voluntary system, commenced on 1st July 2001 using initials and date of births as identifiers. However, due to concern from some clinicians about the use of initials, it did not have complete participation and aggregate data only were provided from one large hospital. The surveillance system re-started in January 2003 using soundex codes and dates of births as identifiers. HIV became a notifiable disease in Ireland in September 2011, whereby all clinicians and clinical directors of laboratories have a statutory obligation to notify all new diagnoses

² In 1999, the European Centre for the Epidemiological Monitoring of AIDS (CESES) had a working group to propose a European HIV reporting system that aimed at collating standardised data from HIV reporting systems existing in the countries of the WHO European Region, based on specific objectives (Annex 1).

of HIV in Ireland. A NASC subcommittee established procedures for notification (12). HIV notifications were included in CIDR, a web-based electronic reporting system, in 2012.

5.1.1.2. HIV SURVEILLANCE NETWORK IN IRELAND

The principle stakeholders in HIV surveillance in Ireland are HPSC, consultants in ID medicine, consultants in STI medicine, clinicians and GPs, the NVRL, the local laboratories and the Departments of Public Health.

Other stakeholders include the Department of Health (DoH) and Non-Governmental Organisations (NGO) with respective roles in HIV policy development and advocacy, the latter by promoting HIV screening and enhancing access to HIV diagnosis and care.

5.1.1.3. OBJECTIVES OF THE HIV SURVEILLANCE SYSTEM

The rationale that led to the establishment of national HIV case-based reporting was based on the following points that were listed in the proposal for the establishment of the national HIV Case based reporting system in $2000 (16)^3$:

- to have accurate and complete epidemiological data on the distribution and spread of HIV infection and monitor trends in HIV incidence;
- to quantify the needs of HIV infected individuals in terms of treatment and access to care;
- to respond appropriately with the design and implementation of prevention and treatment strategies;
- to fit with the European Centre for the Epidemiological Monitoring of AIDS that is developing a standardised HIV Individual Case Based Reporting system (ICR) system at EU level, including linking HIV and AIDS cases;

Formal objectives for HIV surveillance in Ireland were not documented prior to the evaluation. As part of the evaluation process we retrospectively developed objectives based on the rationale mentioned above. These were the following:

³ Draft letter, Proposal to establish a national HIV Case Based Reporting System, August 2000, letter from Dr John Devlin, Deputy Chief Medical Officer, on behalf of the Surveillance sub-Committee of the National AIDS Strategy Committee, to Mr Fergus Clavey, Data Protection Commissioner at Data Protection Agency

- to monitor trends in new HIV diagnoses in Ireland over time, by age, gender, location, risk groups and stage of infection
- to identify increases in new diagnoses in Ireland in any particular subgroup in order to inform prevention strategies
- to fulfil international reporting requirements to ECDC and WHO

5.1.1.4. POPULATION UNDER SURVEILLANCE AND GEOGRAPHIC COVERAGE

Surveillance of HIV in Ireland is a comprehensive system that covers the general population living in the country (total population of 4,6 million based on preliminary 2014 census data (17)). Surveillance is conducted at regional level by Departments of Public Health (DPH) and at national level by HPSC.

5.1.1.5. TYPE OF SURVEILLANCE SYSTEM

The Irish HIV surveillance system is a mixture of passive and active surveillance. Reporting by clinicians and NVRL is considered passive surveillance in that the system responds to cases once detected, rather than actively seeking information from laboratories and clinicians that haven't yet been reported. Public health officials have an active role in contacting clinicians to obtain accurate and timely data when forms or key variables are missing.

5.1.1.6. DETECTION OF EVENTS AND CASE DEFINITIONS

In Ireland, the HIV surveillance case definition for notification is based on the EU HIV case definition (Annex 2):

- Positive result of a HIV screening antibody test or a combined screening test (HIV antibody and HIV p24 antigen) confirmed by a more specific antibody test (e.g. Western blot)
- Positive result of an EIA antibody test confirmed by a positive result of a further EIA test
- Positive results on two separate specimens from at least one of the following three:
 - Detection of HIV nucleic acid (HIV-RNA, HIV-DNA)
 - o Demonstration of HIV by HIV p24 antigen test, including neutralization assay
 - o Isolation of HIV

Nevertheless, the HIV surveillance system also complies with the current nationally agreed NVRL protocol for confirmation, which requires positive testing on two separate samples to ensure provenance of the samples.

Nationally agreed NVRL requirements are defined as:

- An anti-HIV confirmed serological positive result on the first sample, with **one** of the following subsequent tests on a separate second sample:
 - A serological anti-HIV positive result
 - A significant viral load result, where a detectable quantity of HIV nucleic acid is reported (>=200 copies/ml).

Therefore, the nationally agreed NVRL case definition is more specific than the surveillance one.

5.1.1.7. DIAGNOSIS OF HIV CASES

a) DIAGNOSIS BY CLINICIANS

HIV testing takes place in a variety of settings. In most cases, a patient may either consult his GP at first, or directly consult at an HIV/STI specialised clinic. On consultation with a GP, the GP may take a first sample and send it to the laboratory, which can be either the local laboratory or the NVRL. If the result is positive, in most circumstances the GP will refer the patient to an HIV/STI specialised clinic for further clinical assessment and management. In that case, the second sample will be taken and sent to the local laboratory for testing by the clinician in the HIV/STI clinic. The local laboratory will then send a sample to the NVRL for confirmatory testing.

b) LABORATORY DIAGNOSIS: LOCAL LABORATORIES AND NVRL

HIV testing is carried out by certain local laboratories and by the NVRL. Once a local laboratory has diagnosed a new HIV positive case, they send a sample to the NVRL for confirmatory testing. If the sample tests positive, NVRL requests a second sample from the local laboratory or clinician to confirm the diagnosis. In some cases, HIV tests are sent directly to the NVRL for testing with no other laboratory involved. In this case, NVRL will request the second sample from the clinician who requested the test.

Certain laboratories (Cork University Hospital (CUH), University Hospital Limerick (UHL) and Galway University Hospital (GUH)) have an arrangement with NVRL, whereby only one sample is sent for confirmatory testing. For CUH and UHL, confirmatory testing at NVRL is performed on one positive sample. NVRL assumes that the additional HIV positive/antibody screen has been completed in CUH and UHL. The GUH laboratory sends its first positive sample to NVRL for confirmation. They then wait for the second sample to come into GUH. Once the HIV positive result has been confirmed at GUH on this second sample, they ask NVRL to initiate the notification procedure.

5.1.1.8. DATA COLLECTION

a) FREQUENCY OF DATA COLLECTION

According to the 2012 *HIV notification- Information for professionals* document developed by a subcommittee of NASC, newly confirmed cases should be notified at the following frequency: laboratories are expected to report events on a daily or weekly basis and clinical information has to be reported by the end of each quarter. Departments of Public Health have to monitor timely notification of the cases as per these standards and should report to HPSC on a weekly basis (via CIDR).

Legislation also states that data has to be reported on a weekly basis. Infectious Diseases Regulations 2003 stipulate that notification should be made by the clinical director of a diagnostic laboratory "as soon as an infectious disease is identified in that laboratory" (Infectious Diseases (Amendment) Regulations 2003. SI No. 707 of 2003).

At European level, HIV data should be reported to ECDC European Surveillance System (ECDC/Tessy) on an annual basis.

b) Reporting format and information to be collected

HIV surveillance in Ireland is case-based. A total of 74 variables, including 18 that are compulsory are collected, via the initial laboratory notification and an enhanced surveillance form (18) (Annex 3). The latter include personal identifiers and geographical information, laboratory information, date of notification, diagnosis confirmation and referring clinician.

c) DATA COLLECTION AND FLOW DIAGRAM OF THE SURVEILLANCE SYSTEM

Figure 5. From HIV diagnosis to notification on CIDR (15)



6 At the Department of Public Health, notification data and supplementary clinical data are linked and anonymised using CIDR. The data are then available to the HPSC for analysis and use in national reports.

Notification and data collection process initiated by the NVRL

The notification is initiated and centralised at NVRL following confirmatory testing and verification that it is a new diagnosis. To determine that this person is newly diagnosed in Ireland and hasn't already been reported, a surveillance scientist working in NVRL (who has a one day per week surveillance commitment, funded by HPSC) reviews its in-house systems to make sure that this person hasn't been reported previously. The surveillance scientist enters the case into CIDR (Figure 5, 4a). The NVRL has its own Laboratory Information Management System (LIMS) from which data is extracted and then uploaded into CIDR. The surveillance scientist includes additional data (if available) in the comments field, including date of first test at NVRL, risk group, P24 antigen result.

For cases diagnosed in GUH, NVRL does not notify a new positive to CIDR until the surveillance scientist in GUH laboratory telephones the NVRL to report that the case has been confirmed.

Once NVRL initiate the notification in CIDR, it goes to the source laboratory (if a source laboratory was involved in the diagnosis), which reviews and authorises the notification. This step corresponds to the "notification date". By authorising the event, the notification is official and goes to the Department of Public Health.

Form completion

In parallel, two documents are prepared by the NVRL; a laboratory report and a paper-based enhanced surveillance form to the physician to collect additional clinical data (18). The NVRL completes the following fields of the surveillance form:

- NVRL Lab ID
- Clinician name
- Source hospital or GP address
- Reported date of confirmatory sample
- Patient DOB
- Patient sex

The NVRL sends the enhanced surveillance form and the laboratory report to the clinician who requested the confirmatory HIV test (Figure 5,4b). However, there are two exceptions: in HSE-Mid West all forms are sent back to a specific clinician. In HSE-West (Galway), NVRL sends all forms to one particular clinician after being informed about cases to notify by the surveillance scientist of the area. The clinician fills the form with clinical and epidemiological information relevant to the case.

Under normal circumstances, if the patient has already been referred to the HIV/STI clinic, the GP will not receive an enhanced surveillance form for completion as the process has been handed over to the HIV/STI specialised clinic and they will be directly in charge of completing the surveillance form. If however the clinical or social needs of the patients require that the GP needs to initiate the confirmatory test, the GP will receive the enhanced surveillance form for completion.

The interview with NVRL provided insights on the difficulties faced by NVRL in sending the form when no GP or clinician name was stated on the test request form and possible consequences in creating some additional delays in collecting the enhanced surveillance information. However this was stated as occurring in rare circumstances.

The role of the Department of Public Health

After the notification is sent through CIDR either directly from NVRL or from the source laboratory to the Department of Public Health (Figure 5), the Department of Public Health creates an event of HIV on CIDR (Figure 5, 6). If necessary, Public Health can also initiate or modify notifications. The date an event is created in CIDR is the "Event Date"; epidemiological reports are usually based on event dates. The Departments of Public health enter the date of diagnosis field in CIDR and are advised to use the NVRL date of diagnosis confirmation.

Once the enhanced surveillance form is completed by the clinician and sent to the Department of Public Health, the latter updates the HIV event in CIDR by manually entering the enhanced clinical data received (Figure 5, 5b).

The meeting with the Department of Public Health in the East provided insights concerning potential difficulties both in receiving information from private clinicians and in getting enhanced surveillance forms in batches. Access to information from some hospitals may also be limited due to internal hospital procedures. On average, Public Health reported that it took between four and 12 minutes to enter the enhanced surveillance form in CIDR. This was considered long and depended on two main elements: the speed of CIDR data entry which depended on the day of the week (a local bandwidth sharing issue within the local HSE area) and because information had to be entered manually.

The Department of Public Health is responsible for following up with specialist clinicians and clinical laboratory directors to ensure that CIDR records are completed in a timely manner and for ensuring information is accurate.

Outputs

HPSC compiles weekly and six monthly (previously quarterly) reports of new HIV diagnoses based on data reported in CIDR. A weekly HIV & STI report is available since March 2013. Six monthly HIV

reports are published on the HPSC website. Since 2011, both detailed and shorter versions of annual reports are produced once the data have been validated and finalised. From 2008 to 2013, technical reports aiming at evaluating the completeness and quality of the data were produced on almost an annual basis.

Detailed epidemiological reports are produced annually, and the information is reported to ECDC through TESSy. HPSC produces reports based on the date of event creation as for all other diseases notified on CIDR. However, ECDC considers the date of diagnosis for their epidemiological reports at European level.

The information is also used to meet other reporting requirements to organisations such as WHO, UNAIDS and Global Aids Response Progress Reporting (GARPR).

5.2. SENSITIVITY OF THE SYSTEM

New diagnoses from 2013 that did not fulfil the nationally agreed NVRL criteria for notification to CIDR were reviewed. A total of 71 (18%) diagnoses in 2013 were not notified in CIDR, as they not fulfil these criteria for notification, against 334 notified on CIDR in 2013 (sensitivity 82%): 23 diagnoses had only one serology positive sample and were therefore not notified, and 48 had one serology positive sample and viral loads tested which were undetectable (Table 1).

Among the 23 diagnoses that had only one serology positive sample, 26% were reported from St James's hospital, 17% from the Mater hospital and 9% from Waterford Hospital. They were not notified because no second sample has been provided to NVRL for confirmation. It is possible that a second sample for some of these cases has been sent in the intervening time period. Among the 48 diagnoses that had a serology positive sample and a subsequent sample (or samples) with undetectable viral loads, 75% (n=36) were from St James's hospital. Mean age was 37 years, ranging from 21 to 69 years, and 73% were male (n=35). Among the 36 diagnoses from St James's hospital, further information was available after investigation by NVRL: one was a duplicate that had been previously notified, one was diagnosed in Ireland (Galway) in 2007. All the others were previously diagnosed abroad between 2005 and 2013.

Table 1. Distribution of non-notified HIV diagnosis in 2013 by ID clinic (source of notified diagnoses:NVRL database)

	Number of notified	Number of non- (proportion of	Total number of cases in	
ID clinic	cases in 2013 (Sensitivity)	One serology positive sample only	Serology and undetectable viral loads	(notified and non-notified)
St James's hospital	130(76%)	6(3.5)	36 (21%)	172
Mater	50(85%)	4(6.8)	5(8.5%)	59
Gay Men's Health Services	3(50%)	2(33)	1(17%)	6
Waterford	10(77%)	2(15)	1(7.7%)	13
Others*	141(91%)	9(5.8)	5(3.2%)	155
Total	334(82%)	23(5.7)	48(12%)	405

* one had missing ID clinic name

5.3. TIMELINESS OF THE SYSTEM

5.3.1. DISTRIBUTION OF CASES BY SOURCE LABORATORIES, HOSPITALS, HSE AREAS AND YEARS

We extracted a total of 669 HIV notifications for 2012 and 2013, including 665 HIV cases reported in the NVRL database. The four notifications that were reported in CIDR but not in NVRL database had an NVRL laboratory ID. Of the notified cases, 50% were notified in 2012 and the other 50% in 2013.

Overall, 71% of notifications were in HSE East, where St James's hospital, Mater hospital and NVRL are located (Table 2). These laboratories are reported as local laboratories in 66% of the notifications (Table 3). The three main HIV specialised hospitals (St James's hospital, Beaumont and Mater hospitals), which account for 67% of the notifications, are also located in the East (Table 4).

HSE area	Numbers	%
East	471	71
South	51	7.7
Mid West	40	6
North East	31	4.7
South East	24	3.6
West	20	3
Midlands	18	2.7
North West	10	1.5
Total	665	100

Table 2. Distribution of 2012 – 2013 HIV notifications by HSE area

Table 3. Distribution of 2012 – 2013 HIV notifications by local laboratories⁴

Source laboratories	frequency	%
St. James's hospital	266	40
Others*	126	10
Mater hospital	103	15
NVRL	71	11
Beaumont hospital	62	9
Cork University Hospital	44	6.6
University Hospital Limerick	39	5.9
Galway University Hospital	16	2.4
Total	665	100
* • • • • • • •		

* see Annex 4, Table 6

Table 4. Distribution of 2012-2013 HIV notifications by hospitals

Source hospital	frequency	%
St James's hospital	266	40
Others	131	20
Mater hospital	120	18
Beaumont hospital	62	9.3
University Hospital Limerick	38	5.7
Cork University Hospital	32	4.8
Galway University Hospital	16	2.4
Total	665	100

5.3.2. DATE ORDER AND DATA QUALITY

We identified some missing date variables and lack of coherence for some date orders, which indicated some data quality issues (Figure 6).

Date of first HIV positive test. Of 665 events, 577 (87%) had a documented date of first positive test, which indicated that the NVRL had tested two samples prior to notification. Among the 88 events which did not have a first positive test in the NVRL records, 94% were from laboratories benefiting from exceptional procedures regarding the two sample requirements (41% from CUH, 40% from UHL, 13% from GUH), 3% were from other laboratories and 3% were from NVRL (Table 5).

⁴ Beaumont and Mater hospitals don't test for HIV but send samples to NVRL

Date of HIV diagnosis confirmation. Among records originating from local laboratories for which two samples need to be tested at NVRL prior to confirmation of diagnosis, 2.9% (n=16) had a date of first HIV positive test subsequent to the date of HIV diagnosis confirmation and 39 (7%) had a date of HIV diagnosis confirmation identical to the date of first HIV positive test.

The date of HIV diagnosis was documented in both the NVRL and CIDR databases. Therefore the dates were expected to be the same, as HPSC advises the Departments of public health to use the NVRL date of diagnosis confirmation in CIDR in the field "Date of Diagnosis"; however these two dates differed for 180 (27%) records out of 665, 79% of them being from the East. The overall median time lag between these two dates was 2 days (range: -10 to 22 days). Based on this finding, we used the date reported in the CIDR database for the time interval analysis.

- The notification date and the date the paper-based enhanced surveillance form was sent by
 post are expected to be close. NVRL uploads the HIV notifications onto CIDR on a weekly
 basis; under normal circumstances, authorisation of events by local laboratories does not
 require time consuming action, and should follow shortly afterwards.
- The **event creation date** at the Department of Public Health should follow closely after the notification date, however as the Department of Public Health is also allowed to create an event on CIDR, the date of event creation can precede the date of notification. We identified that 2.6% (n=17) records had an event creation date prior to date of notification, one record from CUH as source laboratory, six from St James's hospital, two from the Mater and eight from other laboratories.
- Date of form completion. Among all events, 8.4% (n=56) had no enhanced form completed (35 events created in 2012 and 21 in 2013). Among events which had an enhanced form completed, 2.8% n=(7) had no date of form completion. Among those with an enhanced surveillance form and a date of completion, 2.3% (n=14) had a date of enhanced form completion before the date form was sent, including four from Saint James's hospital and three from Beaumont hospital.

Of the 609 (92%) reports with enhanced surveillance forms completed, 50 (8%) didn't have the key variables (CD4 counts and modes of transmission) documented. However we included the reports which did not have the key variables in the analysis.

Table 5. Distribution of 2012-2013 HIV notifications with no first HIV test, by HSE area

HSE area	No first HIV	/ test	Total
	number	%	
East	1	0.2	471
Midlands	1	5.6	18
Mid-West	34	85	40
North East	0	0	31
North West	0	0	10
South	41	80	51
South East	1	4	24
West	10	50	20
Total	88	14	665

Figure 6. Flow chart for the records exclusion from time intervals analyses



5.3.3. TIME INTERVALS

5.3.3.1. FROM FIRST HIV TEST TO HIV DIAGNOSIS CONFIRMATION AT NVRL (N=544)

The median time interval between the date of first HIV test and the date of HIV diagnosis confirmation was **10 days** (range 0 days - 8.2 years, Annex 4, table 7). St James's hospital, which accounts for 40% of the notified events, had the highest time interval of 13 days (range: 0 = 737 days, with a 90th percentile of 24 days).

Figure 7. Median, interquartile and range of number of days between the **first HIV positive test** and **HIV diagnosis confirmation**, by source hospital and for laboratories requiring two samples at NVRL for HIV confirmation, Ireland 2012-13*



* excluding Galway, Limerick and Cork source laboratories.

5.3.3.2. FROM HIV DIAGNOSIS CONFIRMATION TO NOTIFICATION TO CIDR (N=665)

The median time interval between **HIV diagnosis confirmation and notification to CIDR** was **9 days** (range: 0 days- 1.06 years, Annex 4, table 8). The median time interval was the highest in GUH with a median interval of 25 days⁵ (n=16, range:8-195 days). Notification coming from all other laboratories was below or equal to a median time interval of 12 days.

Figure 8. Median and interquartile range of number of days between HIV diagnosis confirmation and notification to CIDR, by source laboratory, Ireland 2012-13



⁵ Note: Special procedure in place in GUH, see methods and discussion for further information.

5.3.3.3. FROM NOTIFICATION TO CIDR TO EVENT CREATION, BY HSE AREA (N=648)

The median time interval between notification to CIDR and event creation by the Department of Public Health was 0 days (range: 0 - 129 days, Annex 4, table 9), 95% of events being created within 4 days after notification on CIDR. Delays above 14 days occurred only for 1% (n=7) of the records. Except for the South and South-East areas, all distributions of median delays are right-skewed, indicating that time intervals are above 0 or one day. For HSE West, 90% of the 19 events were created within 14 days.

Figure 9. Median and interquartile range of number of days between date of notification on CIDR and event creation at PH, by HSE area, Ireland 2012-13



5.3.3.4. FROM DIAGNOSIS CONFIRMATION TO THE SENDING OF ENHANCED FORM TO CLINICIANS, BY SOURCE HOSPITAL (N=665)

The median time interval between diagnosis confirmation and the sending of the enhanced surveillance form by NVRL was 8 days (range: 0 - 386 days, Annex 4, table 10). For cases diagnosed at GUH, the form was sent to clinician with a median time interval of four days (range: 1 to 59 days) prior to notification of cases to CIDR⁶.

Figure 10. Median (and interquartile range of) number of days between date of diagnosis confirmation and date the enhanced surveillance form was sent, by source hospital, Ireland 2012-13



⁶ ⁶ Note: Special procedure in place in GUH, see methods and discussion for further information.

5.3.3.5. FROM FORM SENT TO FORM COMPLETION BY CLINICIANS, BY SOURCE HOSPITAL(N=588)

The median time interval between the time the enhanced surveillance form was sent and its completion by clinician was 18 days (range: 0 days - 1.4 years, Annex 4, table 11). All source hospitals except the Mater showed a median time interval from 11 to 32 days to complete the form, with 75% of them being completed before 100 days (quartile). The Mater hospital which accounts for 16% of the events, reported a median time interval of 150 days for completing the form with 5% completed within 35 days.

Figure 11. Median (and interquartile range of) number of days between date the form is sent to clinician and date the enhanced surveillance form was completed, by source hospital, Ireland 2012-13



5.3.3.6. OVERALL DELAYS FROM FIRST HIV TEST OR DIAGNOSIS CONFIRMATION TO FORM COMPETED WITH CLINICAL INFORMATION, BY HSE AREA

From first HIV test to form competed

For 77% of the records included in the analysis of this time interval, the median time interval between the date of first HIV test and the form completion by clinician **was 44 days (range: 5 days - 8 years,** Annex 4, table 12).

Figure 12. Median (and interquartile range of) number of days between first HIV test and enhanced form completion, by HSE area, Ireland 2012-13 (n=510)



From diagnosis confirmation to form completion (regardless of the number of samples required) (n=589)

For 89% of the records included in the analysis of this time interval, the median lag between date of confirmation and form completion by clinician was 29 days (range: 4 days - 1.5 years, Annex 4, table 13.

Figure 13. Median (and interquartile range of) number of days between HIV diagnosis confirmation and the enhanced form completion, by HSE area, Ireland 2012-13 (n=92)



The highest mean time interval from diagnosis confirmation to the completion of the enhanced surveillance form was reported in the Midwest and in the South, where it took more than 40 days to get the enhanced form completed after HIV diagnosis confirmation (Figure 14).

Figure 14. Surveillance steps and median time intervals between DPH, Local laboratories, NVRL and Clinicians, HIV surveillance system in Ireland⁷



⁷ DPH: Department of Public Health, NVRL: National Virus Reference Laboratory, CIDR: Computerised Infectious Disease Reporting

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From diagnosis confirmation to form completion (for cases requiring only one-sample for notification by NVRL)(n=76)

For the three laboratories benefiting from the one-sample procedure for notification, the median lag between date of confirmation and form completion by clinician was 45 days (range: 4 days - 1.2 years, Annex 4, table 14).

Figure 15. Median (and interquartile range of) numbers of days between HIV diagnosis confirmation and the enhanced form completion, by local laboratory benefiting from one-sample notification procedure, Ireland 2012-13 (n=76)



The two-stages of data reporting: Identification of new diagnoses, availability of clinical information

The system is able to identify new diagnoses through CIDR notifications within approximately 19 days overall (delay from first positive test to confirmation to notification on CIDR). At the stage of notification on CIDR, clinical information, including the probable route of transmission (MSM, PWID, MTCT, Heterosexual), is not yet available automatically. This information becomes available once the

form is completed (and received). For 50% of cases, it was available approximately 30 days after diagnosis confirmation, and for 75% of cases it was available 75 days after diagnosis confirmation.

5.3.3.7. COMPARISON WITH GOLD STANDARDS AND IRISH STANDARDS

Enhanced surveillance form reported within 6 months of diagnosis (gold standard is 66% (12))

Among the records with the two documented tests (first test and confirmatory test) (n=563), 78% (n=439) had an enhanced form completed within six months after the first HIV positive test and 9.4% (n=53) had no form completed (Figure 12).

Among these 646 records⁸ with one documented test (HIV diagnosis confirmation), 81% (n=521) had an enhanced form completed within 6 months (183 days) after HIV diagnosis confirmation and 8.7% (n=56) had no form completed. The CDC gold standard is reached within two months (Figure 16).

Figure 16. Cumulative proportion of forms completed since first HIV test and since HIV diagnosis confirmation by number of months, HIV surveillance system in Ireland



Cumulative proportion of forms completed

⁸ Excluding those who had a form completed but no date of form completion or those for which the date of form completion was after the date of diagnosis confirmation

Comparison with Irish standards (NASC) (15)

- Events reported within a week, from HIV diagnosis confirmation to notification on CIDR

Out of 665 records, 250 (38%) were notified on CIDR within a week (less than 8 days) after HIV diagnosis confirmation. The distribution of diagnoses notified on CIDR within a week by source laboratories is the following: CUH: 45% of Cork diagnoses, UHL: 46%, St James's hospital's: 42%, Mater hospital: 21% NVRL: 65%, s, Beaumont: 15%, other laboratories: 36%.

- Events with clinical data reported within three month

Out of 644 records, 469 (73%) had a form completed within three months (less than 91.5 days) after the form was sent⁹. The distribution of records reported within three months by hospitals is the following: 84% of Beaumont's diagnoses, 25% of the Mater's, 67% of Cork's, 79% of Limerick's, 94% of St James's hospital, 100% of Galway's, 65% of those from other hospitals.

44

⁹ Excluding records with missing dates

6. DISCUSSION

6.1. DESCRIPTION OF THE SYSTEM

A process that has evolved over time, which needs to be formalised

Since its introduction in 2001 as a voluntary system, HIV case-based surveillance in Ireland has evolved over time with amendments and improvements made over the years on an ongoing basis, as issues were identified, all in an effort to improve the performance of the system. The most important change was the introduction of HIV as a notifiable disease with mandatory reporting in 2011, and inclusion of HIV within CIDR from 2012.

Describing the system has identified several issues for consideration. Firstly, although the HIV surveillance system is achieving what it aims to achieve, formal surveillance objectives have not been documented, and for the purposes of this evaluation temporary objectives were developed. Consideration needs to be given to reviewing and formally adopting system objectives which will set the strategic direction for HIV case based surveillance activities.

The central role of the NVRL

The central role of the NVRL in the design, operation and success of HIV surveillance is recognised. To date, confirmation of all new HIV diagnoses is performed at NVRL as a best practice initiative. The design of the system is dependent on all laboratories submitting samples to the NVRL for confirmation, which then initiates the notification and data collection process. With laboratory technologies improving and becoming more accessible, it is possible that at some stage in the future laboratories will not continue to confirm HIV diagnoses at NVRL. This will need to be monitored over time. The centralisation of laboratory confirmation and notification at the NVRL level ensures that duplicates can be identified in the NVRL in-house database. If confirmatory testing and notification were to be decentralised, this could lead to duplicate notifications, and increased work at Departments of Public Health and HPSC in removing them, as well as require a process at regional level to distribute and collate the enhanced surveillance forms.

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Despite the key role of the NVRL in the HIV surveillance system, the notification of HIV diagnoses on CIDR is person-dependant and relies on one surveillance scientist. At times of leave, the surveillance system can be interrupted as NVRL's capacity for ensuring adequate cover arrangements is limited. This is a weakness in the current system.

Finding the balance between flexibility and simplicity

The description of the HIV surveillance system identified several different ad hoc procedures for diagnosis and reporting by certain laboratories and hospitals. This is understandable as the system has developed incrementally over time and may provide great flexibility to the different participants. However, these different procedures may also make the system more complex.

Reporting formats, data quality and timeliness

The surveillance system uses both electronic and paper-based reporting formats. The CIDR electronic system is of great advantage both in terms of reducing the risk of introducing transcription errors and for timely reporting. However, the use of paper forms may introduce errors during transcription from paper to CIDR. Furthermore, the visit to the Department of Public Health in the East also identified that the speed of manual entry of data onto CIDR was not optimal and that it was time consuming. However in the absence of standardised electronic clinical information systems within the specialised HIV clinics, and a mechanism to upload this to CIDR; or alternatively a mechanism that enables clinicians to directly enter HIV information to CIDR securely, this poses a major challenge. The situation in GUH where diagnoses were reported by phone call to NVRL before they were uploaded on CIDR has provided considerable flexibility, however it raises some issues regarding traceability and data quality.

6.2. SENSITIVITY OF THE SYSTEM

The main cause of underreporting: the too specific nationally agreed current NVRL case definition for initiation of notification

For the detection of HIV events, the surveillance requirements and current nationally agreed NVRL laboratory requirements differ in terms of the number of samples needed for confirmation and notification of HIV cases. As the NVRL initiates the notification of all cases, all cases have to comply with these requirements first, rather than with the surveillance case definition. The current nationally agreed NVRL case definition being more specific than the surveillance one, this evaluation has shown that this has led to under-reporting.

The two sample requirement and the possible biased underreporting

A third of non-reported cases had only one sample tested at NVRL, and never had a confirmatory test sent to NVRL. No further information was available on their profile. They could have been anonymised diagnoses (through codes) which haven't been followed up or which haven't been linked to other diagnoses. The fact that some diagnoses were not followed up with a confirmatory test at NVRL also suggests that that some cases may not have accessed care or may have moved outside Ireland after their first diagnosis in Ireland.

Also, given that most of the non-reported cases were from a hospital which reports with a median interval of approximately two weeks between first test and diagnosis confirmation, it is unlikely that all these 2013 cases will be reported in the future.

Most of the cases that were not reported had two samples tested at NVRL, but their viral loads were undetectable, as patients were likely to be on treatment already. Serological testing on the subsequent samples could have confirmed these diagnoses and made them notifiable; however NVRL performed tests as per clinician requests. Most of these diagnoses were people who had previously been diagnosed positive in another country. Cases from abroad may be managed differently by clinicians in terms of requesting confirmatory tests, as they are confident of the diagnosis based on clinical history, and/or there may be a lack of awareness of the finer details of laboratory tests required for notification in these circumstances (two sample requirement for serology if virally supressed). Nevertheless, assessing the consistency of clinician practices with regard to laboratory testing and reporting could remain an important area to investigate in terms of sensitivity analysis of the system, particularly if the two samples requirement remains.

Should we be more sensitive to cases diagnosed abroad? Monitoring the burden of disease versus the trends in new infections occurring in Ireland

Inclusion of cases diagnosed abroad depends on the objectives of the system, which need to be formalised. Their inclusion would be helpful in order to monitor the burden of disease in Ireland, the needs in terms of treatment and care, and by extension the risk of infection posed to the population in Ireland. In 2014, 17% of notified diagnoses were from people already diagnosed abroad, and moving to one sample for notification is likely to increase this figure again. Including or not including the cases diagnosed abroad may also give a different epidemiological picture in terms of access to early diagnosis and treatment. The use of CD4 counts to monitor access to early diagnosis and treatment may have to be interpreted differently and may have to take into account the access to early diagnosis and treatment of the country where the cases have come from. Cases already on treatment but newly diagnosed in Ireland may have a higher CD4 count compared with cases previously (and possibly at a late stage) diagnosed abroad but with low access to treatment: these latter will be "re-diagnosed" as late presenters in Ireland although they would not have had an opportunity to engage with the Irish healthcare service. Nevertheless, the surveillance of these cases is not directly relevant for detecting trends in incident infections or increases in new infections occurring in Ireland.

Moving to one sample to increase the sensitivity: anticipating the possible impacts on data completeness and timeliness

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The sensitivity of the system would be increased if there was a national agreement to move to a one sample requirement for notification by NVRL. This would have practical implications however which need to be considered.

Moving to one sample may lead to difficulties in identifying the clinician to whom the enhanced surveillance form will be sent, as patients may not have been consulting at specialised HIV/STI clinics for their first test. One option to address this is that the enhanced surveillance form would be sent to the HIV/STI specialised clinic following the referral of the case and the confirmation of the diagnosis on a second sample by the NVRL. Other possible consequences of moving to one sample may be an increasing number of notifications, an increase in the delay between notification and form completion, and a lower overall level of completeness of the enhanced surveillance form, as some cases may not get a confirmatory test and therefore may not get their enhanced form completed. In these circumstances, it might be prudent to include a procedure whereby, in the absence of a second sample within one month, the form is sent to the person who ordered the first test for completion by him/her, or for him/her to direct it to the specialised clinic where the patient had been referred.

The use of one sample for notification threshold would also be more efficient in the context of an outbreak. Coincidentally, at the same time as the HIV evaluation, an outbreak of recent HIV diagnoses in PWID in Dublin 2015 has aided evaluating the implications of moving to one sample (19). In the outbreak, in order to improve the timeliness of the reporting of HIV cases in PWID, it has been agreed to change the laboratory threshold for notification in Dublin to one HIV test positive. The use of one sample for surveillance in this outbreak has proved to be more practical and compatible with early notification of diagnoses.

6.3. TIMELINESS OF THE SYSTEM

Dates' data quality

Very few events appeared in the CIDR database but not in NVRL database, and the majority of dates were consistent and coherent. One exception was the date of diagnosis confirmation that was different between the NVRL and CIDR databases for almost a third of the events. However, discrepancies between these two dates were small (with a mean time difference of two days). These findings may suggest either data quality issues in the NVRL database, or when Public Health enters the NVRL date of diagnosis in CIDR, or issues with compliance with NVRL's protocol.

From first positive to diagnosis confirmation

The time required for HIV diagnosis (from the first HIV positive test to diagnosis confirmation) was short overall. However, some sporadic events were confirmed over a long timeframe. Furthermore, the analysis of intervals between these two dates did not include laboratories that benefited from exceptional procedures and also did not include the number of HIV tests which could have been performed by the local laboratory prior to sending the first sample to the NVRL. Therefore, this delay in diagnosis could have been underestimated. Moving to one positive serology sample for notification would reduce the delay prior to notification.

From diagnosis confirmation to notification on CIDR

However, overall the results are coherent with i) the procedure in place at NVRL (batch notification at the beginning of each week), ii) the experience shared by the NVRL surveillance scientists who reported three to eight days for notification after confirmation and iii) with the 2012 HIV notification document for professionals requiring a weekly notification by the laboratories. Considering that notification at NVRL was carried out by one surveillance scientist and was person-dependant, the delays above a week could be explained by periods during which the scientist was absent from work. Despite the low proportion of cases that are notified within seven days as required in the Irish national standards, the median delay remains close to a week (eight days). Also, the notification date includes the step when local laboratories authorise the event on CIDR, which may few days. Furthermore, the step from upload on CIDR to authorisation is electronic, so probably at its optimum speed.

For GUH, the delay from diagnosis confirmation to notification on CIDR is much higher compared to diagnoses coming from other laboratories, even when compared with laboratories not requiring two samples for confirmation at NVRL. The main difference may reside in the particular arrangements GUH has with NVRL for confirmation and notification of diagnoses. GUH sends its first sample for

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confirmation to NVRL instead of the second one. This first sample may be considered as the confirmatory sample by NVRL. Meanwhile, GUH requests a second sample and calls NVRL to notify the diagnosis once they have confirmed it.

From notification on CIDR to event creation

From notification to event creation, very few events were identified with a long delay and overall, there is almost no delay, which is expected considering that this step is performed electronically. However it requires mainly an electronic validation and manipulation of data on CIDR by the DPH and may therefore depend on the human resources available at the DPH.

From diagnosis confirmation to sending of the form

The NVRL procedure consists of sending the enhanced surveillance form after diagnosis confirmation, and usually occurs between one to three days after uploading the event on CIDR. Therefore, this time interval calculation estimates the time required from diagnosis confirmation, the uploading of the diagnosis on CIDR, and also the sending of the form which may require additional time if the name of the clinician is not easily available on the initial laboratory request form.

For GUH, results showed that the delay in sending the form to the clinician after diagnosis confirmation was higher than for other hospitals. This relates to the same assumption mentioned above, which is that confirmatory test reported by NVRL corresponds to the date of the first test and the notification and the sending of the form is done after GUH laboratory informs NVRL that they had a second confirmatory sample.

Form completion (among records with a form completed)

Some forms seemed to have been completed at the same time they had been sent to clinicians; however this represents only a very small proportion of events. This could also be due to data entry errors either in CIDR (when documenting the field "date form completed") or in the NVRL database (date the form is sent). For the majority of the records, form completion remained timely and in accordance with the request for clinicians to provide data on quarterly basis, as it is the case for most of the notified cases. However, the delay is particularly long for one hospital (close to five months) and above what is agreed in the procedure; only a small proportion of those diagnoses are provided with clinical information within three months. In addition, for the analysis of this time interval, we didn't include the records which did not have a form completed as they wouldn't have any date to calculate the interval. At the time of the analysis, there were still 56 events from 2012 and 2013 with no completed enhanced form. Even though they represent a small proportion of all events reported during these two years, they would increase this reported delay had they been included in the analysis.

The date when the form is entered on CIDR is not currently collected, and the visit to the East identified potential additional long delays between the date the form was completed by the clinician and the date it was sent to HSE department for entry on CIDR. These additional potential delays could not be documented in this analysis.

An overall timely system

Overall, for those records where a date of first positive test was available, the median time interval between first diagnosis and form completion was approximately one and a half months. When looking at the median time interval from the confirmatory diagnosis to form completion, this was just below a month. These two time intervals are low and in accordance with the national requirements for reporting and CDC standards, indicating that the surveillance system is timely overall. However, these calculations were only based on those records with a form completed and good data quality with regard to dates recorded.

HPSC technical reports in 2010, 2009 and 2008 estimated the median time interval from when the form was sent from the NVRL to clinicians for completion to when it was returned to HPSC (4-6). At that time, HIV notifications were not mandatory. Based on these estimates, we could estimate the time required from form completion to access to the form at HPSC (which is a step that we could not evaluate in our report), which was almost two and a half months. Therefore, the overall time interval required from first test at NVRL to access to enhanced form completion for surveillance purpose was low, remaining below four months.

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With regard to CDC gold standard for timeliness, the HIV surveillance system in Ireland is efficient in terms of timely reporting of diagnosed HIV cases, both for time intervals involving two samples and those involving one sample. The overall time interval calculation from diagnosis confirmation to form completion may however not be able to fully predict the possible delay if a one-sample notification strategy is implemented, considering that it is unclear how the delay in collecting clinical data will be impacted by this recommendation. The time interval calculation for laboratories benefiting from the one-sample procedure for notification varied across laboratories and relied on a small proportion of events. In addition, these laboratories may also have other arrangements with the NVRL for sending the form or notifying the event which may as well have an impact on their time intervals. Also, we had no access to local laboratories procedures and possible time delays prior to sending the first sample to NVRL. Therefore, these results do not take into account these possible delays.

The CDC gold standards date back to 1999, a time when access to the Internet and electronic notification were not comparable with the current situation. Therefore, these gold standards would need to be revised in light of current available technologies. A six month delay from diagnosis to reporting may be acceptable for monitoring trends over time as mentioned in the first objective of the surveillance system, and also for fulfilling the current international reporting requirements to ECDC and WHO in terms of delay. They may not however allow early identification of increases in new diagnoses in any particular subgroup in a timely manner or enable early public health intervention in the context of an outbreak.

Also, the overall analysis of timeliness from diagnosis to reporting of clinical information was only based on the records for which the form was completed, not looking at the completeness and quality of the data collected. Recent evaluations focusing on the completeness of the reported data in 2012 and 2013 showed that data completeness for key surveillance variables such as probable route of transmission and CD4 count was greater than 90% and 80% respectively (3). Usually, most of the data is provided through the form and a small amount of additional information might be provided or updated at a later time if there are some data quality issues.

Accounting for delay variations in the analysis of trends

Considering the wide variations across areas, source laboratories, and hospitals, these need to be taken into consideration when monitoring of trends at national level. However, we identified that at six months, 81% of the forms have been returned and the percentage of forms completed does not increase greatly after that time. Therefore interpreting the trends six months in arrears may be accurate enough and avoid the need to adjust for delay variations by site, or area.

For reporting at the European level through TESSy, analysis is performed based on the "date of diagnosis" instead of the date of notification. ECDC considers the "reporting delays" as the time between diagnosis and the report of the event at the national level and adjusts the analysis of trends with the reporting delays in order to better inform HIV trends. Based on this definition, there are almost no reporting delays for Irish data as the definition does not take into account the first test but consider only the second confirmatory test. Therefore, the adjustment performed for the Irish data at European level is not based on the true reporting delay and should adjust for the delay between diagnosis confirmation and form completion (20).

6.4. LIMITATIONS OF THE EVALUATION

The evaluation of the HIV case-based surveillance system faced several limitations.

Usually, an assessment of the sensitivity of a system is not only based on underreporting but also on under-ascertainment relating to under-diagnosed/non-detected cases. This was beyond the scope and the objectives of this study; however this would need to be considered in order to have a comprehensive picture of the sensitivity of the HIV surveillance system in Ireland.

Interviewing clinicians to gain a better understanding of their approach towards cases that are new to Ireland but known to have HIV and who have transferred care from abroad wasn't feasible during this evaluation.

The analysis of the time interval between diagnosis confirmation and notification to CIDR could have been more accurate if we had had access to the date when NVRL uploads the diagnosis on CIDR (this information is available in CIDR only to the CIDR administrator). We would have been able to distinguish the time interval from diagnosis confirmation to uploading on CIDR, and from upload on CIDR to authorisation by the local laboratory.

7. CONCLUSIONS AND RECOMMENDATIONS

The HIV surveillance system in Ireland is unique in the sense that it relies largely on a great partnership between the NVRL, HPSC and the other laboratory and clinical stakeholders. This partnership and the central role played by NVRL, although strong and reliable, would benefit from the development of updated formal standard operating procedures for the HIV case based surveillance system overall and NVRL's role in it. This would provide a solid foundation for the surveillance of a disease which has such a public health importance for Ireland and worldwide. The flexibility of the system and in particular the specific arrangements in place between some laboratories and the NVRL may challenge the efficiency of the surveillance system with regard to timely notification. A move to a more standardised approach would be beneficial.

In terms of sensitivity, the underreporting that we could analyse using the NVRL database was mainly related to the notification threshold of two positive samples. As the current nationally agreed NVRL case definition that requires two positive samples was more specific than the surveillance one, this has led to some under-reporting. These results identified two challenges: further investigation is required at clinician level in terms of their testing and reporting practices regarding cases previously diagnosed abroad, and the need to consider the whether or not cases transferred from abroad should be included in the Irish surveillance system. This reinforces the need for clear objectives for the system.

Overall, based on the available data, HIV surveillance in Ireland is timely for monitoring of trends and fits within the CDC standards and the Irish guidelines on timeliness. The interval between the first and second sample could be eliminated if the system moves to a one-sample threshold for notification. This recommendation will improve the sensitivity of the system, but in terms of timeliness, the overall gains may depend on the next steps: the possibility to identify the clinicians to whom the form will be sent and from whom it will be completed and returned in a timely way. The steps carried out at NVRL from confirmation of diagnosis to uploading on CIDR, and then those consisting of authorising the event by local laboratories and creation the event at the DPH are very timely overall. The timeliness of these steps is supported by the fact that they rely on an electronic system. If feasible, the extension of the electronic system to the steps of collecting clinical

information would increase the overall timeliness of the system until the collection of enhanced information.

There are wide variations in the delays depending on the source laboratories, hospitals and areas, which will need to be taken into account when monitoring trends. However, there are no specific gold standards outlining a time interval within which increases in new diagnoses should be detected. Although the surveillance system could detect increasing trends based on the timely notifications of new diagnoses, it is not timely enough to detect increasing trends in specific risk groups quickly, as enhanced clinical information which includes the routes of transmission is received at the end of the process. It is worth noting that active review of a cluster of P24 positive cases in early 2015 did lead to the detection of the PWID outbreak in Dublin. In this outbreak, thanks to active monitoring of p24 positive new diagnoses and identification of the cluster, and the DPH actively seeking clinical information from clinicians rather than waiting for the forms to be submitted, the outbreak was detected and the affected risk group was identified quickly, enabling a timely response to be initiated. A possible solution would be to get the information on the route of transmission at the time of notification, if feasible.

Recommendations in the short term:

- The objectives for HIV surveillance should be reviewed by the concerned stakeholders and adopted for the system.
- Standard operating procedures for HIV case based surveillance, including the key role of NVRL should be documented
- We recommend that the current ad hoc arrangements regarding sampling between the NVRL and local laboratories are amended so that one common procedure for diagnosis confirmation and notification of diagnoses on CIDR is applied to all laboratories
- We recommend moving to notification of HIV for surveillance on CIDR based on a single sample testing positive (serology testing) to decrease the delay from initial diagnosis to notification and to increase the sensitivity of the system. Moving to one sample for notification of HIV will have to be discussed with NVRL. Other potential difficulties discussed above will have to be considered and tackled in this new strategy.

- The notification procedure at NVRL relies on one surveillance scientist and is therefore person-dependant, with an impact on the surveillance data and on time lag. Considering the key role of NVRL in HIV surveillance and notification of HIV cases, mechanisms to support NVRL so that it can guarantee continuity in the notification of HIV cases need to be explored.
- Further investigation of the reasons for longer intervals in some sites, and the development of strategies to assist more timely completion of forms from some hospital sites should be explored.
- Considering the key role of the Department of Public Health in ensuring timely and complete surveillance data, and the potential impact of moving to one sample notification in terms of workloads at the Department of Public Health level (follow up of missing forms), human resources need to be allocated accordingly, particularly in the East where the majority of cases are reported.
- Analysis of trends can be performed within 6 months of first notification. We recommend recording within CIDR the date the form has been received at the Public Health department. This would monitor the additional potential delay that has been reported by HSE East, and could provide evidence at HSE department level to encourage clinicians to send in completed enhanced surveillance forms quickly.

Recommendations in the longer term:

- The computerisation of the notification procedure from diagnosis at clinician level to clinical data collection would improve the overall delays, the burden of data entry in CIDR and data quality. Exploratory work should be undertaken to investigate the clinical systems in place in the specialised clinics, and examine the feasibility of electronic extraction of a set of standardised enhanced data that could be incorporated into CIDR.
- Investigate the possibilities of systematically obtaining information on the route of transmission at the time of notification, which could be uploaded to CIDR by NVRL.
- Timeliness is part of data quality and should be monitored on a regular basis.

8. ACKNOWLEDGMENTS

A sincere thank you to all who participated in the HIV surveillance evaluation: the stakeholder groups which includes the Association of Medical Laboratory Scientists (AMLS), the Health Protection Surveillance Centre, the Infectious Disease Society of Ireland (IDSI), the National Virus Reference Laboratory, the Faculty of Public Health Medicine, the Public Health STI/HIV Special Interest Group, the HPSC HIVSTI operational surveillance group and the Society for the study of Sexually Transmitted Diseases in Ireland (SSSTDI).

Special thanks to Joanne Moran, Cillian de Gascun and Jeff Connell (NVRL), Fionnuala Cooney, Orla Ennis, Jackie McElhinney, Bernie Clarke, and Sinead Dooner (Department of Public Health, HSE East) and Gillian Cullen (HPSC).

I would also like to express my appreciation to Kostas Danis (EPIET coordinator) for his great support, guidance and inputs and Alicia Barrasa (EPIET coordinator) for her advice in the initial protocol for the evaluation.

ANNEX 1: European HIV reporting system, European Centre for the Epidemiological Monitoring of AIDS (CESES).

Project Summary, Pilot phase, February 1999.

Objectives of the European HIV reporting system

Primary objectives:

- To maintain a sound surveillance of HIV infection in Europe, in the era of wide diffusion of effective pre-AIDS treatments. More specifically:
- To make recent HIV epidemics rapidly visible
- To compare the characteristics of the HIV epidemic(s) across European countries;
- To describe diagnosed HIV infected individuals, including those recently infected;
- To assess HIV incidence trends
- To quantify the needs of HIV infected individuals in terms of treatment and access to care
- Secondary objectives;
- To estimate past HIV incidence using indicators of the time of HIV infection;
- To describe the moment of HIV diagnosis in the history of infection in order to describe access to HIV diagnosis;
- To monitor progression to AIDS and death among individuals diagnosed with HIV before AIDS;
- To obtain minimum estimates of HIV prevalence

ANNEX 2: EU Case definition

Laboratory Criteria (HIV)

Adults, adolescents and children aged = 18 months

At least one of the following three:

- Positive result of a HIV screening antibody test or a combined screening test (HIV antibody and HIV p24 antigen) confirmed by a more specific antibody test (e.g. Western blot)
- Positive result of 2 EIA antibody test confirmed by a positive result of a further EIA test
- Positive results on two separate specimens from at least one of the following three:
 - Detection of HIV nucleic acid (HIV-RNA, HIV-DNA)
 - Demonstration of HIV by HIV p24 antigen test, including neutralization assay
 - o Isolation of HIV

Children aged <18 months

Positive results on two separate specimens (excluding cord blood) from at least one of the following three:

- Isolation of HIV
- Detection of HIV nucleic acid (HIV-RNA, HIV-DNA)
- Demonstration of HIV by HIV p24 antigen test, including neutralisation assay in a child =1 month of age (11).

ANNEX 3: HIV notification on CIDR: list of core variables

Event

Disease^{*} Organism Case classification Health Board^{*} County^{*} CCA Interpreted Overall Lab Result^{*}

Patient Record

Title, First name, Surname^{*}, Former Surname Date of birth Gender Ethnicity Country of birth Address line 1, Address line 2, Suburb, Town, Postcode, County^{*}, CCA, Health Board of residence^{*}

Laboratory record

Date of notification*

Specimen ID*, Reference Lab Specimen ID Specimen type, Specimen site, Specimen site qualifier Specimen collected date, Specimen received date, Reference Lab Specimen received date Reported date* Organism* Lab test, Lab test result Patient title, First name, Surname*, Former Surname Date of birth Patient age (if date of birth not known) Gender Address line 1, Address line 2, Suburb, Town, Postcode County *, CCA, Health Board of residence* Reference Lab Comments Source Lab Comments Patient type Hospital, Hospital Ward **Hospital Number** Referring Clinician* Notifying clinician

Clinical Record Date of notification*

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Case classification Patient age Country of infection County*, CCA, Health Board* Comments Patient type Hospital Hospital Number Date of admission Clinical description Diagnosis date Onset date Outcome Cause of death Date of death

*Mandatory field

Annex 4: TABLES

Table 6. Distribution of HIV notifications by laboratory among the "others" laboratory category

Other laboratories	Freq.	Percent
Bon Secours, Cork	2	3.1
Cavan General Hospital	1	1.5
Connolly Hospital Blanchardstown	3	4.6
Coombe Women and Infants University Hospital	2	3.1
Letterkenny General	2	3.1
Mercy Hospital, Cork	2	3.1
Midland Regional Hospital at Mullingar	4	6.2
Midland Regional Hospital at Portlaoise	1	1.5
Midland Regional Hospital at Tullamore	3	4.6
Naas General Hospital	2	3.1
National Maternity Hospital	2	3.1
OLL Drogheda	4	6.2
Our Lady's, Navan	3	4.6
Sligo General Hospital	1	1.5
St. Vincent's University Hospital	11	16.9
Tallaght Hospital / AMNCH	6	9.2
Waterford Regional	16	24.6
Total	65	100

Table 7. Time intervals in days between the first HIV positive test and diagnosis confirmation, by source hospital and for events requiring two samples at NVRL for HIV confirmation, Ireland 2012-13*

	Time interval (days) from							
	HIV first	t HIV positiv	e test to	o diagno	sis confi	rmation		
Source hospital	n	median	q25	q75	min	max		
St James's hospital	262	13	5	24	0	737		
Mater hospital	111	7	3	19	0	357		
Other hospitals	110	5	3	11	0	2,996		
Beaumont hospital	61	9	3	13	0	27		
Total	544	10	4	19	0	2,996		

* i.e excluding Galway, Limerick and Cork source laboratories

Table 8. Time interval in days between HIV diagnosis confirmation and notification to CIDR, by source laboratory, Ireland 2012-13

	Time interval (days) from HIV diagnosis confirmation to notification to CIDR						
Source laboratories	n	median	q25	q75	min	max	
St James's hospital	266	8	6	13	0	156	
Mater	103	12	8	18	7	76	
NVRL	71	7	5	9	0	43	
Other laboratories	64	9.5	6	14	2	69	
Beaumont hospital	62	11.5	8	17	2	73	
CUH	44	8	6	13	2	386	
UHL	39	8	5	12	1	220	
GUH	16	25	16	56	8	195	
Total	665	9	6	14	0	386	

Table 9. Time interval in days from date of notification to event creation, by HSE area, Ireland 2012-13

	Time interval (days) from notification to CIDR to event creation							
HSE area	n	median	q25	q75	min	max		
East	465	0	0	1	0	129		
South	50	0.5	0	1	0	3		
Midwest	40	0	0	1	0	16		
North east	28	1	0	3.5	0	14		
South East	21	1	0	1	0	10		
West	19	0	0	6	0	66		
Midlands	17	0	0	1	0	52		
North west	8	1	1	3	0	5		
Total	648	0	0	1	0	129		

Table 10. Time interval in days between the date of diagnosis confirmation to date enhanced surveillance form was sent to clinicians, by source hospital, Ireland 2012-13

	diagno	Time interval (days) from diagnosis confirmation to surveillance sent form to clinicians						
Source hospital	n	median	q25	q75	min	max		
St James's hospital	266	8	6	11	0	51		
Other hospitals	131	7	5	12	1	68		
Mater hospital	120	9	6	13	2	39		
Beaumont	62	9	7	13	1	43		
UHL	38	8.5	6	12	2	221		
CUH	32	8	6	12	1	386		
GUH	16	14	8	52	4	196		
Total	665	8	6	12	0	386		

Table 11. Time interval in days from form sent to completion by clinicians, by source hospital, Ireland2012-13

	Time interval (days) from							
	su	surveillance form sent to completion by clinicians						
Source hospital	n	median	q25	q75	min	max		
St James's hospital	255	11	6	19	1	361		
Mater	94	150	78	213	2	523		
Other hospitals	104	20.5	8.5	53.5	0	447		
Beaumont	56	21	8.5	42	3	241		
CUH	29	28	9	99	2	407		
UHL	37	32	18	81	2	226		
GUH	13	11	8	29	2	29		
Total	588	18	8	60	0	523		

Table 12. Time interval in days from first HIV positive test to form competed, by HSE area, Ireland 2012-13

HSE area

Time interval (days) from

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	First HIV positive test to form completed					
	n	median	q25	q75	min	max
East	418	133	36	266	17	421
North east	23	39	26	83	15	306
South East	22	48	22	149	10	380
Midlands	13	35	24	128	5	242
South	10	35	24	128	5	242
West	9	38	30	55	18	532
North west	9	42	23	85	20	229
Midwest	6	105	30	202	28	258
Total	510	44	28	90	5	3029

Table 13. Time interval in days from HIV diagnosis confirmation to form competed, by HSE area, Ireland 2012-13

	Time interval (days) from						
		HIV diagnosis confirmation to form completed					
HSE area	n	median	q25	q75	min	max	
East	416	28	17	59	5	454	
South	47	43	19	194	4	453	
Midwest	40	49	27	125	12	252	
North east	23	34	20	62	10	299	
South East	23	34	20	149	9	367	
West	18	29	19	45	13	531	
Midlands	13	20	14	117	11	239	
North west	9	39	21	84	12	161	
Total	589	29	17	75	4	531	

Table 14. Time interval in days from HIV diagnosis confirmation to form competed for laboratory benefiting from one-sample procedure for notification, by source laboratory, Ireland 2012-13

	Time interval (days) from HIV diagnosis confirmation to form completed					
Source laboratories	n	median	q25	q75	min	max
Cork University hospital	32	39	16	131	4	453
Galway university hospital	10	34	25	45	13	94
UHL	34	49	25	108	12	232
Total	76	45	24	103	4	453

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