Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

hpsc

An evaluation of the completeness of national HIV surveillance data in CIDR in 2012 and 2013

Technical Report

Report prepared by:
Kate O'Donnell, Cathal Ryan, Derval Igoe, Health Protection Surveillance Centre
August 2014

1.0 Introduction

HIV is an important public health issue, and warrants prioritisation for surveillance. Accurate and complete surveillance information on new HIV diagnoses is essential, in order to monitor the epidemiology of HIV over time, and evaluate the effect of prevention strategies and interventions.

This report describes the completeness of the HIV enhanced surveillance system in Ireland over a two year period from January 1st 2012 to December 31st 2013. It is the first report to examine the completeness of HIV reporting since it became a notifiable disease in Ireland, and was included in the national Computerised Infectious Disease Reporting System, CIDR.

Data were extracted from CIDR on 23rd July 2014 and were correct at the time of publication.

2.0 Background

HIV was made a notifiable disease in Ireland in September 2011. Since January 2012 onwards, all newly confirmed cases of HIV are notified via CIDR. CIDR is Ireland's secure national web-based electronic reporting system that can only be accessed through the Government VPN.

2.1 HIV surveillance system

All HIV positive cases detected in laboratories in Ireland are confirmed in the National Virus Reference Laboratory (NVRL). The NVRL's case definition for HIV requires confirmation of HIV on a second sample (serology or HIV viral load >200 copies per ml) prior to notification for surveillance (Appendix 1). NVRL also reviews its in-house database to determine that this person is newly diagnosed.

On confirmation with the second sample, the NVRL enters the case into CIDR, and it is sent securely within CIDR to the Department of Public Health in the area where the clinician who requested the test is based. If the HIV sample has come to the NVRL from a laboratory, the result on CIDR is sent to Public Health via the laboratory. Public Health then creates an event of HIV on CIDR, and epidemiological reports are based on these HIV events.

The NVRL also sends an enhanced surveillance form to the clinician who requested the confirmatory HIV test. The clinician completes the form and returns it to the relevant Department of Public Health who update the HIV event on CIDR with the enhanced data received. In situations where a completed form is not received by Departments, or where a submitted form is very incomplete, Department personnel actively liaise with the relevant clinicians to facilitate provision of the required surveillance data. The current HIV surveillance form is shown in Appendix 2.

Anonymised data are analysed at a national level by HPSC. With the use of CIDR, HIV data can now be analysed in real time and are included in the weekly HPSC infectious disease (ID) report and the weekly HIV&STI report (see http://www.hpsc.ie/hpsc/NotifiableDiseases/WeeklyIDReports/).

2.2 HIV Paediatric reporting

In relation to newly diagnosed paediatric HIV cases, a separate process for notification is undertaken. All paediatric cases are referred for management to Dr Karina Butler, Consultant Physician in Paediatric Infectious Diseases, Our Lady's Children's Hospital, Crumlin. A surveillance form on each confirmed paediatric HIV infection is sent to the British Paediatric Surveillance Unit (BPSU) in the United Kingdom (UK), and a copy of each form is sent to the relevant Department of Public Health in Ireland. Public Health then creates a new clinical notification of HIV and enters the relevant enhanced information into CIDR. A copy of the BPSU HIV paediatric form can be seen at http://www.ucl.ac.uk/nshpc/documents/forms/blue-form-color.pdf

3.0 Return of HIV surveillance report forms

Between January 1st 2012 and December 31th 2013, 674 adult cases of HIV were newly confirmed by the NVRL and an enhanced surveillance form on each case was sent to the clinician who requested the confirmatory HIV test.

Table 1 below provides a breakdown of forms which were sent by NVRL to clinicians by the HSE area where the clinicians are based. This table is based on a variable in CIDR called "Primary Lab Referral Source" which is completed by the NVRL and represents the clinician/clinic who requested the confirmatory HIV test. The majority of forms were sent to clinicians in HSE-East while the least were sent to HSE-Northwest.

Table 1: Forms sent to clinicians by HSE area of clinician (2012 and 2013)

HSE Area	2012		2013		Total	
	Number	%	Number	%	Number	%
East	273	81.5	254	74.9	527	78.2
Midlands	5	1.5	3	0.9	8	1.2
Midwest	18	5.4	22	6.5	40	5.9
Northeast	3	0.9	5	1.5	8	1.2
Northwest	1	0.3	2	0.6	3	0.4
South	21	6.3	33	9.7	54	8.0
Southeast	6	1.8	10	2.9	16	2.4
West	8	2.4	10	2.9	18	2.7
Total	**335**	**100.0**	**339**	**100.0**	**674**	**100.0**

A further eight paediatric cases were notified by the Rainbow Clinic directly to Departments of Public Health in 2012 and 2013 (five in 2012 and three in 2013) and were entered onto CIDR as clinical notifications.

Table 2 provides a breakdown of the forms returned by year. In 2012, 89% of enhanced forms were returned while in 2013, 93% of enhanced forms were returned.

Table 3 provides a detailed breakdown of form returns for each HSE area, plus each Hospital/G.P./Clinic in that area (based on the field "Primary Lab Referral Source" in CIDR). The percentage of forms returned by HSE areas ranged from 75-100%.

Table 2: Enhanced forms completed and returned (2012 and 2013)

Enhanced form returned	2012		2013		Total	
	No.	%	No.	%	No.	%
Yes	299	89.3	315	92.9	614	91.1
No	36	10.7	24	7.1	60	8.9
Total	**335**	**100.0**	**339**	**100.0**	**674**	**100.0**

Table 3: Return of enhanced surveillance form by HSE area and by hospital/G.P./Clinic[1]

Area	Hospital/Clinic/GP	Number of forms sent	Number of forms returned	% of forms returned
HSE East	Baggot Street Clinic	2	2	100.0
	Beaumont Hospital	62	60	96.8
	Catherine McAuley Clinic	15	8	53.3
	Connolly Hospital	3	1	33.3
	Coombe Women's Hospital	2	1	50.0
	Gay Men's Health Clinic	14	12	85.7
	Mater Hospital	91	74	81.3
	Naas General Hospital	2	2	100.0
	National Maternity Hospital, Holles St	2	2	100.0
	Rotunda Hospital	14	13	92.9
	St. James's (incl. GUIDE)	259	254	98.1
	St. Vincent's Hospital	11	6	54.5
	Tallaght Hospital	6	3	50.0
	G.P.'s/Clinics	44	36	81.8
	Total	**527**	**474**	**89.9**
Midlands	Midlands Regional Hospital, Mullingar	4	4	100.0
	Midlands Regional Hospital, Portlaoise	1	1	100.0
	Midlands Regional Hospital, Tullamore	3	3	100.0
	Total	**8**	**8**	**100.0**
Midwest	Midwestern Regional Hospital, Limerick	40	38	95.0
	Total	**40**	**38**	**95.0**
Northeast	Cavan General Hospital	1	0	0.0
	Our Lady of Lourdes Hospital, Drogheda	4	3	75.0
	Our Lady's Hospital, Navan	3	3	100.0
	Total	**8**	**6**	**75.0**
Northwest	GP	1	1	100.0
	Letterkenny General Hospital - GUM	1	1	100.0
	Sligo General Hospital	1	1	100.0
	Total	**3**	**3**	**100.0**
Southeast	St Luke's Kilkenny	2	2	100.0
	GPs	6	6	100.0
	Waterford Regional Hospital	7	7	100.0
	Wexford General Hospital	1	1	100.0
	Total	**16**	**16**	**100.0**
West	Galway University Hospital	18	17	94.4
	Total	**18**	**17**	**94.4**
South	Bon Secours Hospital, Cork	2	2	100.0
	Bon Secours Hospital, Tralee	1	1	100.0
	Cork University Hospital	21	20	95.2
	GPs/Clinics	20	19	95.0
	Mercy Hospital	2	2	100.0
	STI Clinic, Victoria Hospital	4	4	100.0
	Tralee General Hospital	4	4	100.0
	Total	**54**	**52**	**96.3**
Ireland	**Total**	**674**	**614**	**91.1**

[1] This table reflects the area/hospital of the clinician/clinic which has requested the confirmatory HIV test – the "primary lab referral source" in CIDR.

4.0 Completeness of HIV data

The completeness of data items on CIDR are detailed in table 4. Some of the data items (i.e. DOB, gender) are provided by the NVRL and/or source laboratory in the initial notification to Public Health. Most of the remaining data items are then provided by clinicians on the HIV enhanced surveillance form. However, the NVRL also provide additional information in CIDR, where available, including probable route of transmission, date of last negative test, result of P24 antigen test and HIV type. Because data items can be completed from clinical and/or laboratory data, the percentage complete is reported as a percentage of total cases. Appendix 3 describes the completeness of the data in cases where enhanced forms were returned.

Data on county reflects the county of residence of the patient, if address information is available. If address information is not available, the county will reflect the county of the laboratory or the county of the treating clinician.

There was huge variation in the completeness of individual variables ranging from 21-100%. Overall data completeness for key fields for HIV surveillance during this time period was good. Probable route of transmission was provided for more than 90% of cases in both 2012 and 2013. An improvement in data completeness between 2012 and 2013 was noted for CD4 count at diagnoses (from 80% to 89%), country of birth (from 86% to 92%) and probable country of infection (from 66% to 71%).

Overall data completeness for some fields was low, namely, previously tested negative for HIV (64% in 2013), duration of drug use if drug user (44% in 2013), stage of hepatitis B infection if co-infected with hepatitis B (44% in 2013), gestational age if pregnant (43% in 2013) and stage of hepatitis C infection if co-infected with hepatitis C (21% in 2013).

Table 4: Completeness of HIV data items, 2012 and 2013 (cells with less than 80% are highlighted in red)

Section	Question	% complete in 2012	% complete in 2013
Patient Details	DOB	100.0	100.0
	Sex	100.0	100.0
	County of residence	100.0	100.0
	Date of diagnosis	99.4	100.0
	Country of Birth	86.2	92.1
	Ethnicity	72.9	76.3
	Probable Country of Infection	66.2	71.9
	Sexual Orientation	89.7	91.5
	Pregnant (% of females)	81.4	76.7
	Gestational age (% of those pregnant)	76.2	42.9
	Reason for test	81.8	84.8
Probable route of HIV infection	Probable route of transmission	94.4	92.7
	> Hetero subcategory (% of hetero cases)	81.2	75.9
	> Mother to Child subcategory (% of MTCT cases)	100.0	100.0
	> Duration of drug use (% of IDUs)	69.2	44.4
Laboratory information	CD4 count at diagnosis	80.0	88.9
	CD4 % at diagnosis	67.4	71.3
	Viral load at diagnosis	71.5	77.2
	Date of initial NVRL test	87.1	88.3
	HIV type	99.1	99.4
	P24 antigen[1]	na	na
Testing history	Previously tested positive for HIV	75.9	78.7
	> Country of test (% of those who tested positive previously)	92.8	93.5
	> Year of test (% of those who tested positive previously)	85.5	87.1
	Previously tested negative for HIV	62.6	63.5
	> Country of test (% of those who tested negative previously)	91.8	90.0
	> Year of test (% of these who tested negative previously)	95.1	90.8
Co-infections	Co-infected with syphilis	82.4	87.4
	Co-infected with chlamydia	79.4	85.1
	Co-infected with gonorrhoea	79.7	85.4
	Co-infected with hepatitis B	82.6	90.9
	Co-Infected with hepatitis C	83.2	88.3
	> Stage of hepatitis B infection (% of those with hep B)	58.8	44.4
	> Stage of hepatitis C infection (% of those with hep C)	23.1	20.7
Clinical Stage and AIDS	Clinical Stage	87.1	85.4
	> Date of AIDS diagnosis (% of those with AIDS defining illness)	82.4	78.6
	> AIDS-defining illness (% of those with AIDS defining illness)	97.1	96.4
	ART indicated	63.8	71.9
	ART initiated	60.6	71.3
	> Date ART initiated (% of those with ART initiated)	87.2	87.6

[1]P24 antigen test is not carried out on all new diagnoses therefore is not given as a percentage of total cases

4.1 Mother-to-Child transmission

For cases where the route of transmission is reported as mother-to-child, an additional six data items are collected. The questions relate to the source of maternal infection, timing of the mothers diagnosis (before, during or after birth) and whether the mother and/or baby received anti-retroviral therapy (before/during or after birth).

Eight cases where the probable route of transmission was mother-to-child were notified in 2012 and 2013 (5 in 2012 and 3 in 2013). Data completeness for the additional items ranged from 38-100% (see table 5). However, it is important to note that all of the MTCT cases diagnosed in 2012 and 2013 were born in sub-Saharan Africa and therefore clinical information relating to their birth may not be readily available.

Table 5: Completeness of HIV enhanced questions – MTCT, 2012 and 2013 data

Item	Number complete	% complete of MTCT cases
Subcategory of Mother	8	100.0
Timing of HIV diagnosis	3	37.5
ART for Mother/Baby	3	37.5
ART given ante-natally	4	50.0
ART given intra-partum	4	50.0
ART given post-partum	3	37.5

4.2 Acute/Sero-conversion illness

From January 1st 2012, it was agreed with surveillance partners to gather additional information relating to contact tracing and sexual networks for cases where the clinician has indicated that the stage of infection is “acute, sero-conversion illness”.

There were 27 cases in 2012 and 2013, where the clinician indicated that the infection was an “acute, sero-conversion illness”. Table 6 describes the completeness of additional data collected for these cases.

Table 6: Completeness of HIV enhanced questions – Acute/Sero-conversion cases, 2012 and 2013 cases

Item	Number complete	% complete
Has contact tracing taken place	9	33.3
Number of sexual contacts in the last 3 months - total (of those where contact tracing took place)	6	66.7
Any social/sexual networks identified?	9	33.3
If network identified, has public health been informed? (none identified)	na	na

4.3 Completeness by HSE area

Table 7 describes the completeness of key surveillance variables by HSE area for 2012 and 2013.

Table 7: Completeness of key surveillance variables by HSE area, 2012 and 2013 data

	% Complete in 2012					
HSE Area	**Probable route of transmission**	**CD4 count**	**Country of birth**	**Probable county of infection**	**Clinical Stage**	**Total cases 2012**
East	94.6	82.6	86.0	73.6	88.0	242
Midlands	90.0	80.0	100.0	80.0	100.0	10
Midwest	95.0	90.0	95.0	55.0	75.0	20
Northeast	94.1	52.9	64.7	52.9	64.7	17
Northwest	100.0	83.3	83.3	50.0	100.0	6
Southeast	100.0	78.6	100.0	78.6	100.0	14
South	90.5	61.9	85.7	14.3	90.5	21
West	90.0	80.0	80.0	20.0	80.0	10
Total	**94.4**	**80.0**	**86.2**	**66.2**	**87.1**	**340**

	% Complete in 2013					
HSE Area	**Probable route of transmission**	**CD4 count**	**Country of birth**	**Probable county of infection**	**Clinical Stage**	**Total cases 2013**
East	92.8	91.9	91.1	75.3	86.0	235
Midlands	90.0	80.0	100.0	100.0	100.0	10
Midwest	90.9	81.8	95.5	54.5	77.3	22
Northeast	92.9	85.7	100.0	50.0	78.6	14
Northwest	80.0	100.0	100.0	100.0	100.0	5
Southeast	91.7	75.0	66.7	66.7	91.7	12
South	93.9	81.8	100.0	66.7	78.8	33
West	100.0	81.8	90.9	45.5	90.9	11
Total	**92.7**	**88.9**	**92.1**	**71.9**	**85.4**	**342**

5.0 Discussion

HIV enhanced surveillance in Ireland involves collaboration with many partners and requires significant commitment and effort by all to ensure the quality and usefulness of the data. The purpose of this report is to review and report on the completeness and quality of the first two years of HIV surveillance data in CIDR.

Of the new HIV infections diagnosed in 2012 and 2013, 89% and 93% respectively of HIV enhanced surveillance forms were completed by clinicians and returned to Public Health (as of 23rd July 2014). This is similar to the percentages returned in recent years; 86% in 2011 and 89% in 2010. While the review highlighted excellent rate of returns from many clinics/locations, the evaluation also identified some areas where improvements in surveillance are needed.

It is important to obtain data on key variables for all new HIV diagnoses in order to monitor the spread of the HIV epidemic in Ireland. In addition to return of forms, Public Health have actively sought information from clinicians on key surveillance variables and data completeness for these variables such as probable route of transmission and CD4 count was greater than 90% and 80% respectively during this time period, indicating good quality surveillance. Comparing to a European perspective, data on probable route of transmission is available for 88% of new diagnoses and CD4 count at diagnosis for 55% of new diagnoses in European Union/European Economic Area (EU/EEA) countries in 2012.[1]

Some of the data items have not been included in national HIV reports and are not required for reporting to ECDC, namely sexual orientation, country of previous negative test and CD4%. From January 2015 onwards, it is proposed to remove these three data items from the HIV surveillance form. The usefulness and value of other data items on the HIV surveillance form will also be considered following the outcome of an EPIET project which is commencing in autumn 2014 and will evaluate HIV surveillance in Ireland. The usefulness and value of the additional data items collected on acute cases only will also be reviewed following the evaluation and once the results of the planned Recent Infection Testing Project are available. It is proposed that some additional data items, including date of CD4 test, date of viral load test, ART history and year of arrival in Ireland will be added to the HIV surveillance report form from January 2015 onwards.

Currently, anonymised HIV data are reported to ECDC annually and 31 data items are included in the dataset provided. HIV surveillance in Europe is currently under review, and ECDC has commissioned Public Health England to work with them to develop a new integrated HIV and AIDS dataset. The revised dataset consists of 34 fields which relate to patient demographics, clinical markers and death. The objectives of the revised dataset are to

- Integrate HIV and AIDS surveillance into a single data return
- Expand the focus of HIV surveillance to the monitoring of all those living with HIV (not just new diagnoses)
- Simplify reporting of HIV exposure
- Improve the quality and clarity of data relating to migrants

- Include additional biomedical markers such as viral load and recent infection
- Monitor the extent that patients diagnosed with HIV are linked into HIV care, treated and obtain an undetectable viral load (the “continuum of care”).

While not all countries can provide all the items in the new dataset, the aim is that over the medium-term, increasing numbers of countries will be able to design and enhance national surveillance systems so that they can provide the full set of variables in the future. In order to assess the feasibility of collecting the additional variables, the revised dataset has been piloted across EU member states and Ireland was part of this pilot. A report on the pilot will be produced and circulated in the coming months. A copy of the current dataset provided to ECDC and the proposed dataset can be seen in Appendix 4.

6.0 References

1. European Centre for Disease Prevention and Control; 2012. European Centre for Disease Prevention and Control/WHO Regional Office for Europe. HIV/AIDS surveillance in Europe 2011. Stockholm

Acknowledgements

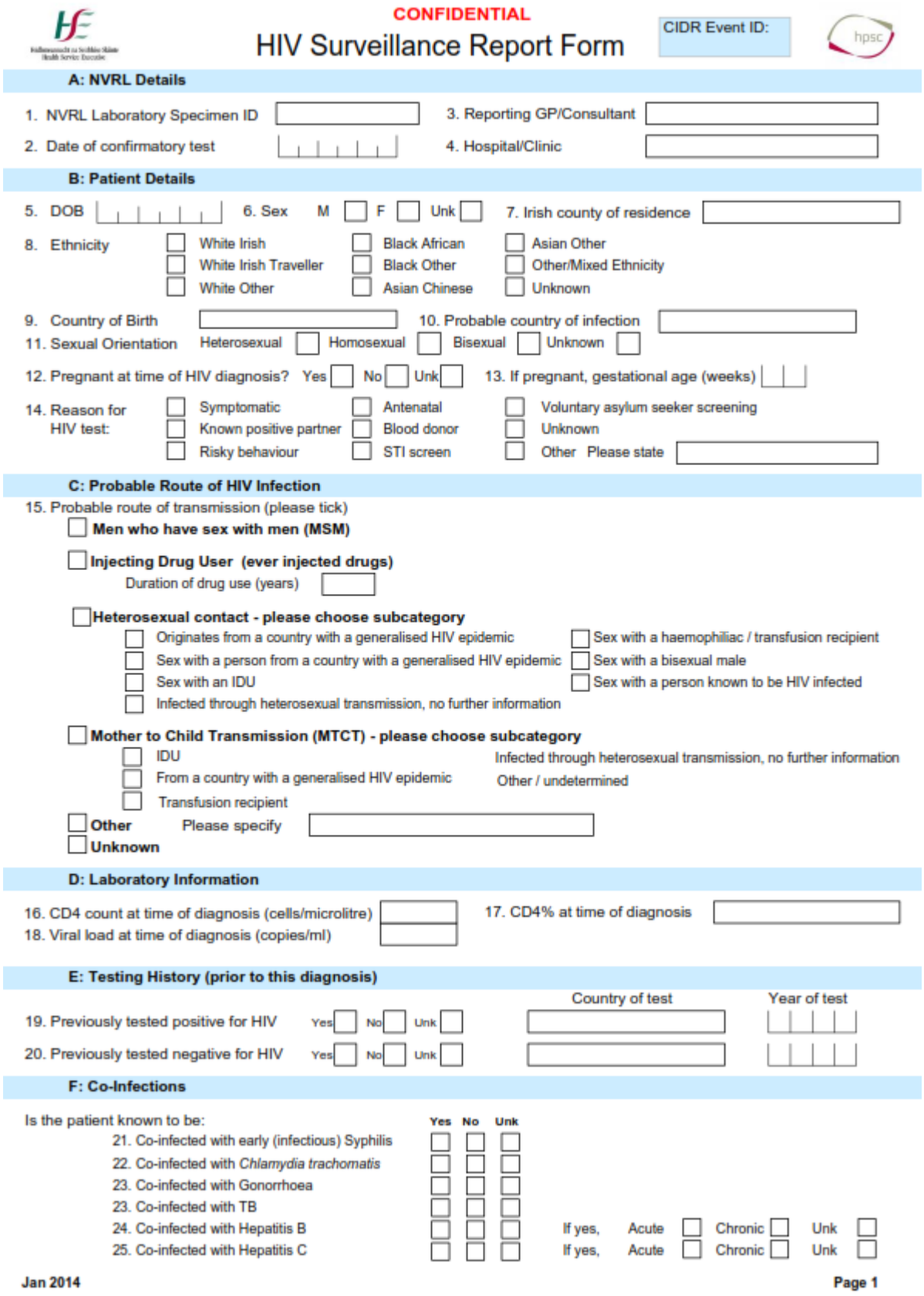
We wish to acknowledge the support, help and cooperation of all those involved in HIV Surveillance namely the National Virus Reference Laboratory, Clinical Microbiologists, Laboratory Surveillance Scientists, Consultants in Infectious Disease and Genitourinary Medicine and other participating clinicians and colleagues in Departments of Public Health.

Appendix 1: Working case definition for HIV surveillance (NVRL)

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.

Appendix 2: Current HIV Surveillance form, 2014



CONFIDENTIAL

HIV Surveillance Report Form

CIDR Event ID:

A: NVRL Details

1. NVRL Laboratory Specimen ID
2. Date of confirmatory test
3. Reporting GP/Consultant
4. Hospital/Clinic

B: Patient Details

5. DOB
6. Sex M F Unk
7. Irish county of residence
8. Ethnicity
   - White Irish
   - White Irish Traveller
   - White Other
   - Black African
   - Black Other
   - Asian Chinese
   - Asian Other
   - Other/Mixed Ethnicity
   - Unknown
9. Country of Birth
10. Probable country of infection
11. Sexual Orientation: Heterosexual Homosexual Bisexual Unknown
12. Pregnant at time of HIV diagnosis? Yes No Unk
13. If pregnant, gestational age (weeks)
14. Reason for HIV test:
    - Symptomatic
    - Known positive partner
    - Risky behaviour
    - Antenatal
    - Blood donor
    - STI screen
    - Voluntary asylum seeker screening
    - Unknown
    - Other Please state

C: Probable Route of HIV Infection

15. Probable route of transmission (please tick)
    - **Men who have sex with men (MSM)**
    - **Injecting Drug User (ever injected drugs)**
      Duration of drug use (years)
    - **Heterosexual contact - please choose subcategory**
      - Originates from a country with a generalised HIV epidemic
      - Sex with a person from a country with a generalised HIV epidemic
      - Sex with an IDU
      - Infected through heterosexual transmission, no further information
      - Sex with a haemophiliac / transfusion recipient
      - Sex with a bisexual male
      - Sex with a person known to be HIV infected
    - **Mother to Child Transmission (MTCT) - please choose subcategory**
      - IDU
      - From a country with a generalised HIV epidemic
      - Transfusion recipient
      - Infected through heterosexual transmission, no further information
      - Other / undetermined
    - **Other** Please specify
    - **Unknown**

D: Laboratory Information

16. CD4 count at time of diagnosis (cells/microlitre)
17. CD4% at time of diagnosis
18. Viral load at time of diagnosis (copies/ml)

E: Testing History (prior to this diagnosis)

		Country of test	Year of test
19. Previously tested positive for HIV	Yes No Unk		
20. Previously tested negative for HIV	Yes No Unk		

F: Co-Infections

Is the patient known to be:

	Yes	No	Unk	
21. Co-infected with early (infectious) Syphilis				
22. Co-infected with *Chlamydia trachomatis*				
23. Co-infected with Gonorrhoea				
23. Co-infected with TB				
24. Co-infected with Hepatitis B				If yes, Acute Chronic Unk
25. Co-infected with Hepatitis C				If yes, Acute Chronic Unk

Jan 2014

Page 1

CONFIDENTIAL

HIV Surveillance Report Form

G: Clinical Stage and AIDS

26. Clinical presentation at time of HIV diagnosis (please tick one)

- ☐ Asymptomatic
- ☐ Acute, Seroconversion illness (please complete section I)
- ☐ Symptomatic, non-AIDS
- ☐ AIDS defining (see questions 27-31)
- ☐ Non-AIDS, not further specified
- ☐ Unknown

27. Date of AIDS diagnosis ☐☐/☐☐/☐☐☐☐

Please state AIDS defining illnesses (see list on page 3)

28. AIDS defining illness 1 ☐
29. AIDS defining illness 2 ☐
30. AIDS defining illness 3 ☐
31. AIDS defining illness 4 ☐

32. Anti-retroviral (ART) treatment indicated Yes ☐ No ☐ Unk ☐
33. ART initiated Yes ☐ No ☐ Unk ☐
34. Date ART initiated D D M M Y Y

H: Deaths

35. Has the patient died Yes ☐ No ☐ Unk ☐
36. If yes, date of death D D M M Y Y
37. Cause of death (if known) AIDS ☐ Non-AIDS ☐ Unk ☐

If the patient subsequently dies, please inform your local Department of Public Health

I: Contact Tracing & Sexual Networks - PLEASE COMPLETE FOR ACUTE SEROCONVERSION CASES ONLY

38. Has contact tracing taken place? Yes ☐ No ☐ Patient declined ☐ Unknown ☐

39. Number of sexual contacts in the last 3 months (prior to diagnosis)
Total: ☐☐☐ Traceable: ☐☐☐ Untraceable: ☐☐☐ Unknown: ☐☐☐

40. Any social/sexual networks identified? Yes ☐ No ☐ Unk ☐

41. If you have identified a social/sexual network, have Public Health been informed? Yes ☐ No ☐

Form Completed By

Form completed by ☐ Date completed ☐☐/☐☐/☐☐☐☐

Comment: Please give relevant details not covered elsewhere

Please return this form in strictest medical confidence to your local Department of Public Health. For who to notify, see http://www.hpsc.ie/hpsc/NotifiableDiseases/Whotonotify/.
If the patient has been referred elsewhere for HIV care and you are unable to complete the form, please forward this form to the clinician they have been referred to.

Version: Jan 2014 **Page 2**

HIV Surveillance Report Form

Guidelines for completing the HIV Surveillance form:

Please complete all relevant sections of this form and return in strictest medical confidence to the Department of Public Health where the patient resides. For a list of who to notify, please see http://www.hpsc.ie/hpsc/NotifiableDiseases/Whotonotify/ .

If the patient has been referred elsewhere for HIV care and you are unable to complete the form, **please forward this form to the clinician they have been referred to.**

Section A: NVRL details
This section will be completed by the National Virus Reference Laboratory at time of confirmatory HIV diagnosis. The NVRL laboratory ID will be used to as an identifier on the paper form

Section B: Patient details

Section C: Probable Route of HIV Infection
Reliable information about probable route of HIV infection and of the patient's exposure within that risk category is especially important.
IDU should be ticked if the patient ever injected drugs. Heterosexual contact is used for cases for which heterosexual transmission is highly probable and do not fit into another category. It is important that the source of infection for heterosexual cases is provided.

Section D: Laboratory Information
CD4 count, CD4% and Viral load should be provided at the time of diagnosis

Section E: Testing History
This seeks where possible to define the period during which infection occurred.

Section F: Co-infections
This seeks to determine if the patient has any other co-infections at the time of HIV diagnosis

Section G: Clinical Stage and AIDS
This information asked for in this section will be used to establish the stage of disease progression at which the HIV diagnosis has been made. In the case of an AIDS defining illness, at least one (and a maximum of four) AIDS defining illnesses should be stated. A full list of AIDS defining illnesses is shown in the table below.

Section H: Deaths
This section should be completed for all cases. If a patient subsequently dies, please inform your local Department of Public Health

Section I: Contact tracing and sexual networks
This section is to be completed for **acute seroconversion cases only.**

List of AIDS Defining Illnesses

1. Bacterial infections, multiple or recurrent in a child under 13 years of age
2. Candidiasis of bronchi, trachea, or lungs
3. Candidiasis, oesophageal
4. Coccidioidomycosis, disseminated or extrapulmonary
5. Cryptococcosis, extrapulmonary
6. Cryptosporidiosis, intestinal with diarrhoea (>1 months duration)
7. Cytomegalovirus disease (other than liver, spleen, or nodes) in a patient over one month of age
8. Cytomegalovirus retinitis (with loss of vision)
9. Herpes simplex: chronic ulcer(s) (>1 months duration); or bronchitis, pneumonitis, or oesophagitis in a patient over one month of age
10. Histoplasmosis, disseminated or extrapulmonary
11. Isosporiasis, intestinal with diarrhoea (>1 months duration)
12. Mycobacterium avium complex or M. kansasii, disseminated or extrapulmonary
13. Mycobacterium tuberculosis, pulmonary in an adult or an adolescent (aged 13 years or over)
14. Mycobacterium tuberculosis, extrapulmonary
15. Mycobacterium, other species or unidentified species, disseminated or extrapulmonary
16. Pneumocystis carinii pneumonia
17. Pneumonia, recurrent in an adult or an adolescent (aged 13 years or over)
18. Progressive multifocal leukoencephalopathy
19. Salmonella (non typhoid) septicaemia, recurrent
20. Toxoplasmosis of brain in a patient over one month of age
21. Cervical cancer, invasive in an adult or an adolescent (aged 13 years or over)
22. Encephalopathy, HIV-related
23. Kaposi s sarcoma
24. Lymphoid interstitial pneumonia in a child under 13 years of age
25. Lymphoma, Burkitt s (or equivalent term)
26. Lymphoma, immunoblastic (or equivalent term)
27. Lymphoma, primary, of brain
28. Wasting syndrome due to HIV
30. Opportunistic infection(s), not specified
31. Lymphoma(s), not specified

Thank you very much for your help completing this form.
Further information on HIV surveillance can be obtained from www.hpsc.ie

Appendix 3: Data completeness only where forms are returned (n=622), 2012 and 2013 (cells with less than 80% are highlighted in red)

Section	Question	Number with information completed	% of total cases with information completed
Patient Details	DOB	622	100.0
	Sex	622	100.0
	County of residence	622	100.0
	Date of diagnosis	620	99.7
	Country of Birth	600	96.5
	Ethnicity	505	81.2
	Probable Country of Infection	469	75.4
	Sexual Orientation	594	95.5
	Pregnant (% of females)	143	85.1
	Gestational age (% of those pregnant)	22	66.7
	Reason for test	564	90.7
Probable route of HIV infection	Probable route of transmission	609	97.9
	> Hetero subcategory (of 257 hetero cases)	207	80.5
	> Duration of drug use (of 28 PWID)	17	60.7
Laboratory information	CD4 count at diagnosis	566	91.0
	CD4 % at diagnosis	472	75.9
	Viral load at diagnosis	494	79.4
	Date of initial NVRL test	545	87.6
	HIV type	617	99.2
	P24 antigen[1]	27	na
Testing history	Previously tested positive for HIV	526	84.6
	> Country of test (of 131 who previously tested positive)	122	93.1
	> Year of test (of 131 who previously tested positive)	113	86.3
	Previously tested negative for HIV	428	68.8
	> Country of test (of 250 who previously tested negative)	230	92.0
	> Year of test (of 179 who previously tested negative)	232	92.8
Co-infections	Co-infected with syphilis	577	92.8
	Co-infected with chlamydia	560	90.0
	Co-infected with gonorrhoea	562	90.4
	Co-infected with hepatitis B	588	94.5
	> Stage of hepatitis B infection (of 33 co-infected with hepB)	17	51.5
	Co-Infected with hepatitis C	582	93.6
	> Stage of hepatitis C infection (of 54 co-infected with hepC)	12	22.2
Clinical Stage and AIDS	Clinical Stage	586	94.2
	> Date of AIDS diagnosis (of 62 with AIDS)	50	80.6
	> AIDS-defining illness (of 62 with AIDS)	60	96.8
	ART indicated	463	74.4
	ART initiated	450	72.3
	> Date ART initiated (of 230 where ART was initiated)	201	87.4

Appendix 4: Overview of the current and revised set of variables for HIV/AIDS surveillance

Current European HIV dataset	Proposed European HIV dataset (pilot)
Common set of variables	**TESSy System Related Variables**
1. RecordID	1. RecordID
2. RecordType	2. RecordType
3. RecordTypeVersion	3. RecordTypeVersion
4. Subject	4. Subject
5. Status	5. Status
6. DataSource	6. DataSource
7. ReportingCountry	7. ReportingCountry
8. DateUsedForStatistics	8. DateUsedForStatistics
9. Age	**Diagnosis Information**
10. Gender	9. DateOfDiagnosis
11. Outcome	10. DateOfNotification
12. DateOfOnset	11. HIVType
13. DateOfDiagnosis	12. Transmission
14. DateOfNotification	13. TransmissionPartner
15. Classification	14. ProbableCountryOfInfection
16. ClinicalCriteria	15. FirstCD4Count
17. LaboratoryResult	16. FirstCD4Date
18. EpiLinked	17. RecentInfectionAssay
	18. RecentInfectionScore
	19. RecentInfectionSampleDate
Disease Specific Variables	**Demographics**
19. HIVType	21. Age
20. Stage	22. Gender
21. Transmission	23. CountryOfBirth
22. TransmissionHetero	24. YearOfArrival
23. TransmissionMTCT	25. LastAttendanceDate
24. HIVStatus	**Clinical Information**
25. DateOfAIDSDiagnosis	26. ART
26. DateOfDeath	27. CD4Latest
27. CountryOfBirth	28. CD4LatestDate
28. CountryOfNationality	29. VLLatest
29. RegionOfOrigin	30. VLLatestDate
30. CD4Cells	31. DateOfAIDSDiagnosis
31. ProbableCountryOfInfection	32. AIDSIndicatorDisease
	Death
	33. DateOfDeath
	34. DeathCause