



HIV Surveillance Protocol

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Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
CHI	Children's Health Ireland
CIDR	Computerised Infectious Disease Reporting
CDCN	Communicable Disease Control Nurse
CPHM	Consultant in Public Health Medicine
DOB	Date of Birth
ESF	Enhanced Surveillance Form
GP	General Practitioner
GUH	Galway University Hospital
HIV	Human Immunodeficiency Virus
HPSC	Health Protection Surveillance Centre
ICN	Infection Control Nurse
LIMS	Laboratory Information Management System
MOH	Medical Officer of Health
MRH	Midlands Regional Hospital
NVRL	National Virus Reference Laboratory
PH	Public Health
RDPH	Regional Department of Public Health
SJH	St. James' Hospital
SMO	Senior Medical Officer
STI	Sexually Transmitted Infection
TESSy	The European Surveillance System
UHW	University Hospital Waterford

1.0 Background

HIV remains an important public health issue in Ireland. HIV became a notifiable disease in Ireland in September 2011. The [case definition](#) has been developed in line with the [EU case definition](#). HPSC is responsible for maintaining, updating and circulating case definitions.

All medical practitioners, including clinical directors of diagnostic laboratories, are required to notify the Medical Officer of Health (MOH)/Director of Public Health (DPH) of certain diseases (see [section 5.0](#) for more information on how HIV is notified). The list of diseases (and their respective causative pathogens) that are notifiable is contained in the [Infectious Diseases Regulations 1981 and subsequent amendments](#).

It is essential that all cases of HIV infection are notified in a timely manner to ensure that surveillance data is accurate and complete; prevention activities are effective; incidents and outbreaks are identified early and managed promptly to prevent secondary transmission and consequent health harms. This reporting requirement includes everyone with a diagnosis of HIV made in Ireland regardless of whether they have been previously diagnosed with HIV in another country prior to testing here.

Notifications of HIV are made to the Medical Officer of Health (MOH) in the health region where the patient resides. Contact details for the MOH and the counties they cover are available [on the HPSC website](#). In 2012, HIV was included in the national Computerised Infectious Disease Reporting (CIDR) system. Access to confidential patient information on CIDR is restricted to named individuals as designated by the MOH in each regional Department of Public Health.

2.0 Purpose

To describe the roles and responsibilities of those involved in HIV Surveillance in Ireland.

This protocol sets out a nationally agreed process for notification of HIV in Ireland, and by complying with it, laboratories and clinicians are fulfilling their statutory obligations to notify to the MOH as per the [Infectious Diseases Regulations 1981](#) and subsequent amendments.

3.0 Governance arrangements

This protocol was prepared by a sub-group of the National Hep-HIV-STI Surveillance group in 2024 (see Appendix A for membership of sub-group). The sub-group had representation from the Health Protection Surveillance Centre (HPSC), Public Health (PH) and the National Virus Reference Laboratory (NVRL). Input to relevant sections of the protocol was also provided by the Rainbow Clinic at Children's Health Ireland (CHI) and surveillance staff in the laboratory in St James's Hospital (SJH).

The National Hep-HIV-STI Surveillance group has representation from HPSC, National Health Protection Office (NHPO), NVRL, Surveillance Staff in the laboratory in SJH, National Gonococcal Reference Laboratory (NGRL) and the HSE Sexual Health Programme (SHP). The group reports to the National All Hazards group chaired by the HPSC.

The protocol was reviewed by the Area Directors of Public Health and approved by the National Director of Health Protection.

The protocol will be reviewed in three years, or sooner if required.

4.0 Related Documentation

Case definition for Ireland	https://www.hpsc.ie/a-z/hivandaids/casedefinitions/
EU Case Definition	https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32018D0945&from=EN#page=23
Who to notify	https://www.hpsc.ie/notifiablediseases/whotonotify/
HIV enhanced surveillance form (ESF)	https://www.hpsc.ie/a-z/hivandaids/surveillancedocuments/
National ID Hub	https://notifiabledisease.hpsc.ie/

5.0 Protocol

The role of each surveillance partner is described in the relevant sections below. Schematic diagrams are included in [Appendix B](#) (Notification of HIV cases from NVRL and SJH (aged 18 months and older)) and [Appendix C](#) (Notification of paediatric HIV cases from CHI).

5.1 Laboratories

All samples testing positive for HIV require confirmatory testing and confirmed positives only are notified to PH. As of July 2024, the NVRL and SJH carry out confirmatory HIV testing in Ireland and other laboratories which test for HIV send positive samples to NVRL or SJH for confirmatory testing.

When NVRL or SJH have a newly confirmed HIV diagnosis (not previously reported in Ireland), they initiate a process of notification to PH (as below).

- If the test request has come from a source laboratory to NVRL or SJH, the result is returned to the source laboratory within CIDR for authorisation and notification to PH.¹
- If the test request has come directly to NVRL or SJH (i.e. not from another laboratory), the result is notified directly by NVRL or SJH to PH within CIDR.

As both NVRL and SJH are notifying new diagnoses to CIDR, it is possible for some duplication to occur if patients have a test in both places. New notifications should be thoroughly checked on CIDR by PH before creating new events.

¹ Source laboratories are responsible for authorising these notifications to PH within CIDR but do not need to upload new positives to CIDR

5.1.1 National Reference Virus Laboratory (NVRL)

Initial notification to CIDR

At the NVRL, data is extracted weekly for all new HIV diagnoses (aged 18 months and older) for upload to CIDR.²

Before each HIV case is notified, results are carefully cross-checked against the record of previous NVRL notifications to ensure that duplicate notifications are not sent to PH.

For each new notification, the referral form from the source is checked for any clinical details and any information in relation to country and probable country of infection. In addition, there may be information that may aid in completing section C, Routes of HIV infection on the HIV Enhanced Surveillance Form (ESF).

All newly confirmed cases are uploaded to CIDR which is the formal notification to PH. If the test request comes from a source laboratory, the result is returned to the source laboratory within CIDR for authorisation and notification to PH; if the test request comes directly to NVRL (e.g. from GP), the result is sent back directly to PH via CIDR.

Notifications to CIDR are accompanied by a comment, which includes the following: Date case reported; HIV type: HIV-1 or HIV-2; P24 positive result if available

A manual comment is added to CIDR providing additional information on risk group and country of birth (if available). If no risk group is indicated, then “No details” is entered in the comments field. Once uploaded to CIDR the internal NVRL HIV database is updated for future reference.

In addition, if there is a p24 antigen positive result, an email is sent to the relevant regional Department of Public Health (cc-ing HPSC) using the NVRL Surveillance Healthmail account.³

Please Note: For any new diagnosis from Galway University Hospital (GUH), the consultant microbiologist in GUH first reviews the results from NVRL and the surveillance scientist returns a list of the corresponding NVRL specimen ID numbers, confirming the new cases for upload to CIDR by the NVRL. As of July 2024, these processes are currently performed monthly.

² Cases from SJH are **not** notified by the NVRL as these will be notified by SJH

³ See here for a list of organisations who are connected to healthmail

<https://www.ehealthireland.ie/ehealth-functions/access-to-information-a2i/healthmail1/>

Sending HIV Enhanced Surveillance Forms (ESF)

An ESF (paper form or Excel file – see below) is sent from NVRL to the clinician or the source who requested the confirmed HIV test. HIV ESFs are sent every two weeks, to ensure the timeliness of HIV data.

Names are included on the ESF to enable the clinician and PH to identify the patient in combination with other data points (e.g. DOB, sex).

The following information is also included in the ESF (paper form or excel file):

- Full name or initials;
- DOB;
- Sex;
- Reporting doctor;
- NVRL Laboratory specimen number;
- Viral load and date of viral load if available;
- Date of confirmatory test and the reported date;
- Hospital or clinic

The remainder of the ESF is to be completed by the clinician.

As of July 2024, ESFs are sent as follows

- For all notifications (excepting those from: HSE Southwest, Midlands Regional Hospitals (MRH) Mullingar and Portlaoise, Mater Misericordiae University Hospital, Rotunda Hospital, and University Hospital Waterford (UHW), sections of the paper form are partially completed by the NVRL with information available in the LIMS or on the test request form. Once all the ESFs and the accompanying letters (which provides guidance on how to complete the form) have been printed, they are placed into envelopes marked 'PRIVATE AND CONFIDENTIAL' and addressed to the clinician and hospital indicated on the request form and posted.
- For all new notifications from HSE Southwest, Midlands Regional Hospitals (MRH) Mullingar and Portlaoise, Mater Misericordiae University Hospital, Rotunda Hospital, and University Hospital Waterford (UHW), an excel file containing information on each new diagnosis, is created and sent electronically and securely to the clinician/source who requested the confirmatory HIV test or to PH, using NVRL Surveillance Healthmail account. The excel file is utilised by the recipient to complete the ESF.

5.1.2 St James's Hospital

Initial notification to CIDR

In SJH, data are extracted weekly from the LIMS to enable notification of all new HIV diagnoses to PH via CIDR. SJH maintain an up-to-date internal database listing previously diagnosed HIV patients. The patient's Medical Record Number (MRN) is cross referenced in this database to identify newly diagnosed patients who require notification.

All newly confirmed cases (aged 18 months and older) are uploaded to CIDR which is the formal notification to PH. Notifications are made to the area in which the patient is resident. The result interpretation field for each record notified in the CIDR upload details whether the HIV case is Anti-HIV-1 positive or Anti-HIV-2 positive and indicates when HIV-1 p24 antigen is positive. For cases which are P24 antigen positive, an email is sent to the relevant regional Department of Public Health (cc-ing HPSC).

New HIV diagnoses determined from samples referred to SJH by a private facility are emailed to the area in which the patient is resident.

Sending HIV Enhanced Surveillance Forms

Following notification, new HIV diagnosis cases are added to a HIV Enhanced Surveillance excel file which exists on a shared drive that both the Surveillance department and the GUIDE department at SJH can access, update and complete. Names are included with each notification to enable the clinician and PH to identify the patient in combination with other identifiers (e.g. DOB, sex).

5.2 Clinicians/Clinical Staff

By completing an ESF for each new HIV diagnosis and returning it to PH, clinicians fulfil their statutory obligation regarding notification of HIV.

If necessary, the diagnosing clinician should ensure referral of a new case of HIV to tertiary level care for management of their HIV. If the patient is being referred elsewhere for care, the diagnosing clinician is asked to complete as much of the HIV ESF as possible and return to the regional Department of Public Health where the patient is resident, indicating to who the patient has been referred.⁴

Within the HIV service, the treating clinician and team manage the clinical needs of their patient, undertake contact tracing and offer infection control advice. They also complete the HIV ESF and return it to the regional Department of Public Health where the patient is resident (if this is not possible, will help to ensure that the process is facilitated).⁴

If the patient is on holidays in Ireland and/or is attending for HIV care in another jurisdiction (i.e. outside Ireland), this is indicated on the ESF, and returned to the regional Department of Public Health so the event can be de-notified from CIDR.

For cases seen in CHI, notifications are made directly to PH (see [section 5.3](#) on paediatric cases).

Please note: ESFs should ideally be completed electronically and emailed securely to the regional Department of Public Health (editable version available on [HPSC](#)

⁴ For HIV treatment centres in Dublin, the return of HIV ESFs has been agreed as follows: Mater Misericordiae University Hospital and Beaumont Hospital return to PH Area – HSE Dublin and North East; St James’s Hospital return to PH Area – HSE Dublin and Midlands; St Vincents University Hospital return to PH Area – HSE Dublin and South East

5.3 Paediatric notifications

All HIV exposed infants identified from antenatal screening and all new diagnoses of HIV in children <16 years old identified in Ireland are referred to the Rainbow Clinic at CHI for HIV care.

- New HIV diagnoses confirmed by CHI, are notified in a timely way to PH in the area where the child is resident. This is done by completion and return of the HIV ESF to the appropriate regional Department of Public Health. If the child is no longer resident in that region, the ESF should be forwarded to the appropriate regional Department of Public Health.
- Data from the ESF are entered into CIDR by PH if there is an existing event on CIDR or a new clinical notification created if there is not an existing event.
- All new diagnoses in children aged 18 months and older are notified by NVRL and SJH to PH via CIDR.
- HIV ESFs on all children aged 16 years and older are sent by NVRL and SJH to the requesting clinician (ESFs on those aged 0-15 years are completed and returned by CHI).

Please note: ESFs should ideally be completed electronically and emailed securely to the regional Department of Public Health (editable version available on [HPSC website](#)).

5.4 Regional Departments of Public Health

Note: While actions may be modified by each department to reflect local work practices, it is intended that this protocol provides guidance on actions to be taken on receipt of HIV notifications so that the duty of the MOH can be properly discharged.

In this regard the role of Public Health in relation to HIV is as follows:

- Surveillance, monitoring of trends and detection of outbreaks.
- Recommending referral of cases to specialist services for treatment and contact tracing.
- Preparedness to respond to increased number of infections in line with the STI Outbreak Guidelines.
- Management of an incident or outbreak, in conjunction with the clinician(s) and/or other appropriate personnel.
- Risk reduction/disease prevention/health promotion measures, in particular in relation to a possible/definite outbreak.

5.4.1 Initial notification on CIDR

When a notification of HIV is received, the designated person/s (e.g. Epidemiologist/Surveillance Scientist, Surveillance Assistant, Senior Medical Officer (SMO), Communicable Disease Control Nurse (CDCN), Infection Control Nurse (ICN)) manage the notification as follows:

- Check on CIDR to confirm it is a new notification (CIDR has records since 2012). If previously diagnosed in Ireland between 2003 and 2011, check with HPSC if previously reported on 2003-2011 database. If diagnosed in Ireland pre-2003 (before case-based reporting started), it can be assumed it was previously notified by NVRL to the Department of Health (DOH).
- Any additional data supplied by the NVRL or SJH (in the comments field in the laboratory record) are entered into corresponding enhanced fields, namely
 - HIV type
 - P24 status
 - Date of confirmatory test
 - Risk group/Route of transmission
 - Month and year of last negative test
 - Hep B/Hep C co-infection status
- Note: Where a case has moved to an area (this especially applies to International Protection Applicants), then the following applies:
 - If it is less than 3 months since the original notification, then event should be re-assigned to the region where the patient is now resident.

- If is more than 3 months since the original notification, then all subsequent lab results should be linked to the original event (i.e reassign to the region where the patient was formally resident)

5.4.2 Paediatric notifications (see also section 5.3)

All cases aged 18 months and older are notified from NVRL and SJH to PH via CIDR.

For new diagnoses in children seen to the Rainbow Clinic (CHI), HIV ESFs are sent by CHI to the relevant Department of Public Health. A new event of HIV is created on CIDR by PH or the data from the HIV ESF are added to an existing event on CIDR.

5.4.3 Enhanced Surveillance forms

- Completed HIV ESFs are returned by clinicians to PH, either by post or by email.
- The data from the HIV ESF are entered onto CIDR.
 - Note: A report on CIDR (HIV lab ID search v1.0 in corporate documents) can return event IDs based on laboratory specimen ID
- Where there is insufficient information on the notification, the notifying team who requested the confirmatory test are contacted by PH, by phone, to request that they provide further information.
- If it is indicated on the ESF that the person was on holidays in Ireland and attends for care elsewhere, the event is de-notified from CIDR.
- If the ESF is returned incomplete by a non STI/ID service clinician (they may not have all the relevant information), it is forwarded by PH to the specialist service to which the case was referred with a request to complete it.
- If more than one ESF is received, discrepant data is discussed with a designate of the CPHM who can, in turn clarify data with the clinician/health advisor if necessary.
- Follow up of all ESFs which have not been returned to PH is carried out and should be completed within 6 months from time of notification.
- No contact with the case by PH unless deemed necessary following discussion with the clinician.
- Notes of all communication and referrals are to be kept in a secure place, as well as copies of letters and the ESF. Where possible, all efforts should be made to send and receive ESFs and correspondence via secure email rather than hard copies by post.

5.5 Health Protection Surveillance Centre

5.5.1 Data validation

Quarterly validations are carried out (one quarter in arrears) by HPSC in partnership with PH using standard validation reports and additional validation checks.

Validation with CHI is carried out every six months to ensure that all new cases attending CHI have been notified on CIDR.

5.5.2 Data analysis and reporting

HPSC are responsible for reviewing the epidemiology of national HIV data to identify trends in demographic characteristics, route of transmission and stage of infection.

HIV data are published weekly on the [National Notifiable Disease Hub](#) with two sections available: a weekly summary of HIV cases and a selection of time-series dashboards. A [report with the latest trends in HIV and STIs](#) is published at the start of every month.

A detailed annual epidemiological report is published in Quarter 3 or Quarter 4 each year.

5.5.3 International reporting

An anonymised line listing of all cases are reported to TESSy annually (usually in Quarter 2). The previous year and three earlier years are usually provided by HPSC to TESSy (e.g. in 2024, 2023 data will be provided along with 2022, 2021 and 2020 data). This is to ensure that updates to earlier data are captured. Additional validations are sometimes required at this stage to ensure the data are accepted by TESSy.

5.5.4 CIDR User Guidelines

For CIDR users, more detailed guidelines are available within CIDR Business Objects - *HIV – Guidelines for Laboratories and Public Health Users* when notifying on CIDR (HPSC, 2023)

Appendix A: Membership of HIV Surveillance Protocol sub-group

Mary Archibald, Surveillance Officer, HPSC

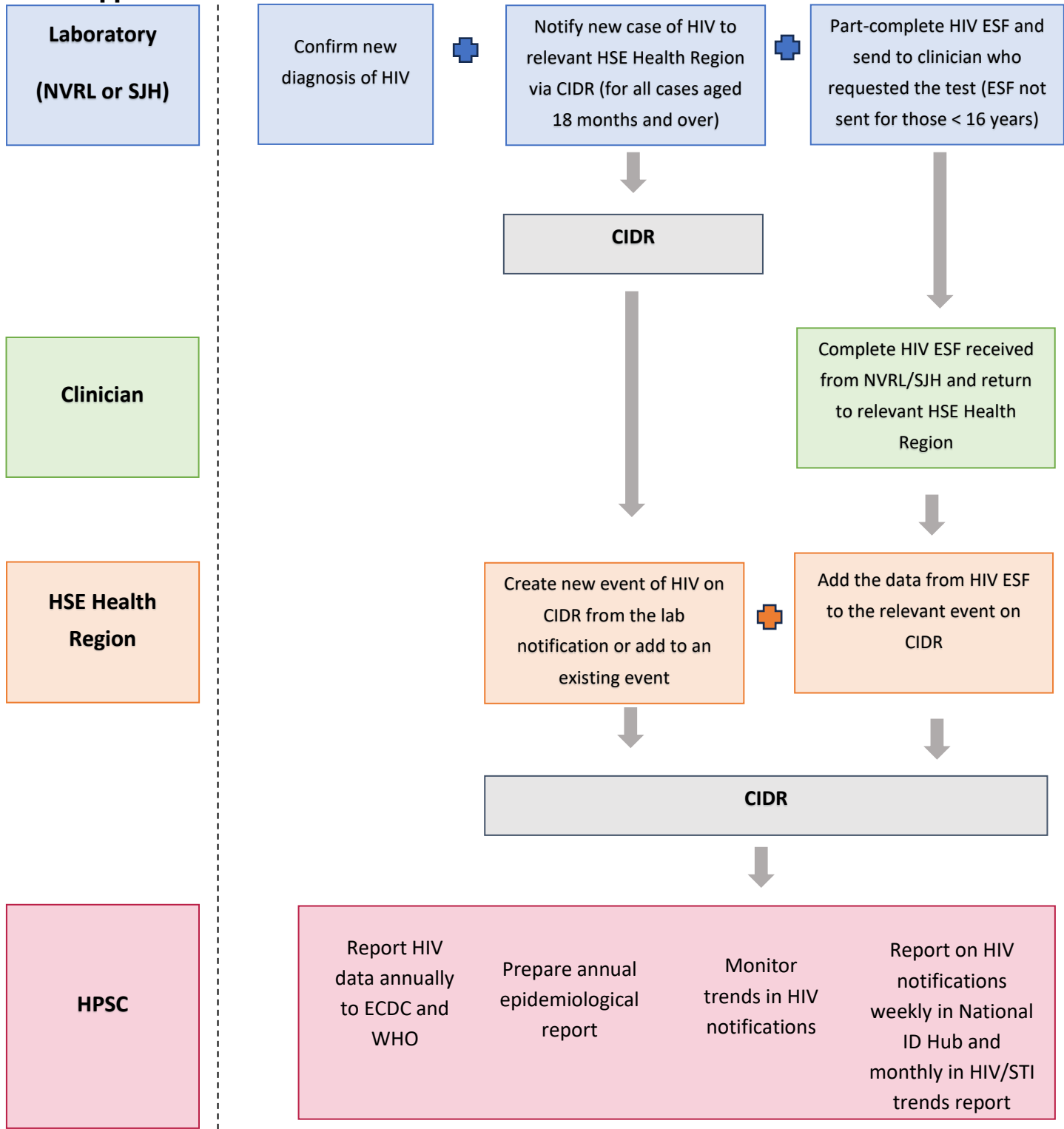
Phil Downes, Principal Epidemiologist, HPSC

Kate O'Donnell, Senior Epidemiologist, HPSC

Orla Bruton, Senior Epidemiologist, HSE South West

Chantale Lecours, Surveillance Scientist, NVRL

Evonne McCabe, Surveillance Scientist, NVRL

Appendix B: Notification of HIV cases from NVRL and SJH⁵⁵ aged 18 months and older

Appendix C: Notification of paediatric HIV cases from CHI

