Surveillance, Evaluation and Research Program Standard Operating Procedures
National HIV/AIDS Case Reporting

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Contents

1. Statement of accuracy of Surveillance, Evaluation & Research Program for Public Health Standard Operating Procedures (National HIV/AIDS Case Reporting)

This document accurately reports the activities conducted by the Kirby Institute Surveillance, Evaluation and Research Program, in collaboration with the National Blood-borne Virus (BBV) and Sexually Transmissible Infections (STI) Surveillance Subcommittee for the collection, analysis and dissemination of information on diagnoses of HIV infection and AIDS in Australia.

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2. Background

Under Australia's federal system of government, reports of new diagnoses of designated communicable diseases are made to state and territory health authorities. When acquired immunodeficiency syndrome (AIDS) was first diagnosed in Australia in late 1982, state and territory governments enacted laws that required doctors to notify the health authority of newly diagnosed cases of AIDS. The need for national coordination of surveillance for newly diagnosed cases of AIDS in Australia led to the establishment of the National Health and Medical Research Council Working Party on AIDS (1983-1984) and the AIDS Coordinating Unit within the Commonwealth Health Department (1985) (Whyte et al 1987, Whyte and Cooper 1988).

Following identification of the human immunodeficiency virus (HIV) as the cause of AIDS and the development of antibody tests to detect HIV infection in 1985, surveillance for AIDS was expanded to include surveillance for newly diagnosed HIV infection in some health jurisdictions. In others, specific laws were enacted requiring laboratory notification of cases of newly diagnosed HIV infection.

The NHMRC Special Unit in AIDS Epidemiology and Clinical Research was established at the University of New South Wales (UNSW Sydney) in 1986 with funding from the Australian Government and assigned responsibility for coordination of national surveillance activities related to HIV and AIDS, in collaboration with the Commonwealth and State and Territory Governments. It was renamed the National Centre in HIV Epidemiology and Clinical Research in 1990 and the Kirby Institute for infection and immunity in society (Kirby Institute) in 2011. The role of national coordination of surveillance for HIV infection and AIDS is specified as part of the terms of reference that accompany the contract between the Department of Health and UNSW Sydney, through the Kirby Institute.

These Standard Operating Procedures describe the activities that are carried out by the Kirby Institute in fulfilling its responsibilities in the national surveillance of HIV.

3. Objectives of case surveillance for HIV infection in Australia

To monitor the extent and characteristics of new diagnoses of HIV in order to inform governments and communities about

(a) trends in HIV transmission

(b) behavioural, geographic and demographic factors associated with HIV transmission

(c) the numbers and demographic characteristics of people living with HIV

(d) the morbidity and mortality due to HIV infection

(e) the impact of public health and clinical interventions on the occurrence of HIV

4. Roles and responsibilities

4.1 Role of the Kirby Institute

The Kirby Institute is administered as an organisational unit of the Faculty of Medicine at UNSW Sydney. It derives its responsibilities in national surveillance from the terms of reference associated with the contract between the Australian Government and UNSW Sydney to manage the Kirby Institute. Within the Kirby Institute, surveillance activities are conducted by individuals appointed within specialised Programs.

Specific positions at the Kirby Institute related to surveillance for HIV infection and AIDS are:

(a) Head, Surveillance, Evaluation and Research Program: Oversees conduct of all surveillance activities.

(b) Epidemiologist, National HIV/AIDS Surveillance: Coordinates national surveillance activities for HIV in Australia, including the development and implementation of new procedures and new initiatives in HIV/AIDS surveillance, quality control studies, analysis and interpretation of national data for publication in surveillance reports and peer reviewed journals.

(c) Program Coordinator: provision of secretariat support for the National BBV and STI Surveillance Subcommittee, administrative and management support for the Surveillance, Evaluation and Research Program.

(d) Epidemiologist/Statistician: Undertakes statistical analyses of relevant surveillance data.

(e) Database programmer: Develops and maintains databases for national case surveillance for HIV and AIDS.

See Appendix A for the names of the current holders of these positions.

4.2 Governance of surveillance procedures

Surveillance activities coordinated by the Kirby Institute involve a range of activities, including case reporting, reporting of routine testing at clinical sites, and regular cross-sectional surveys. This document describes the procedures adopted by the Kirby Institute in its role as the coordinator of national case reporting, or passive surveillance for new diagnoses of HIV. The procedures are developed by the Kirby Institute in consultation with the National BBV and STI Surveillance Subcommittee. This committee is made up of representatives of the Australian Government Department of Health, the State and Territory Departments of Health, and representatives of other relevant organisations, including those of affected communities. It is a subcommittee of the Communicable Diseases Network of Australia, which in turn is a subcommittee of the Australian Health Protection Committee.

This procedures document is updated as necessary. Changes to procedures must be agreed by a decision of the National BBV and STI Surveillance Subcommittee. All agreed changes must be documented in committee minutes, and reflected in updated versions of this

procedures document. Each update must be signed by the Head of the Kirby Institute Surveillance, Evaluation and Research Program.

5. Regulatory environment

5.1 Confidentiality

Confidentiality of information on cases of newly diagnosed HIV infection is vital to ongoing national HIV/AIDS surveillance activities. Notification of cases of newly diagnosed HIV infection to the Kirby Institute is made using the namecode, defined by the first two letters of person's family name and the first two letters of person's first given name and date of birth, to maintain confidentiality while minimising duplicate notification. Information on reported cases of diagnosed HIV infection must NOT be disclosed to anyone under any circumstances, except for the purpose of fulfilling national surveillance responsibilities.

On appointment to the Kirby Institute, staff sign a confidentiality form (see Appendix B) in regard to the handling of any personal or private information that they may gain access to in the context of their employment. This document is kept in individual personnel files. Before a person can begin work on surveillance data related to HIV infection, the Epidemiologist, National HIV/AIDS Surveillance receives written advice from the Kirby Institute Human Resources Advisor to confirm that the undertaking has been signed. This advice is then kept on file by the Program Coordinator, Surveillance, Evaluation and Research Program.

Only the Epidemiologist, National HIV/AIDS Surveillance, the Epidemiologist/Statistician, and the data programmer responsible for the database have access to line records involving namecode and date of birth. Other staff members can be authorised to have access to national HIV/AIDS case surveillance data, including line records containing personal data, by the Head of the Kirby Institute Surveillance, Evaluation and Research Program, for specific purposes, after signing confidentiality undertakings.

5.2 Legislation and regulations

The notification of new diagnoses of HIV is mandated by public health legislation in each state and territory. The reporting of new diagnoses to the Kirby Institute is performed by agreement between the jurisdictional health authorities and the Kirby Institute.

As an organisation established with the support of the Australian Government, the Kirby Institute is bound by the provisions of the Federal Privacy Act 1988, which deals with personal information privacy protection, as set out in 11 Information Privacy Principles. These principles set standards for the collection, storage, use and disclosure of, and access to, personal information.

In addition to the Privacy Act 1988, other legislation requires the Kirby Institute to protect privacy, such as the Health Records and Information Privacy Act 2002 (NSW). This Act regulates the collection and handling of health information by public and private sector organisations in NSW. It applies to every organisation that is a health service provider or collects, holds or uses health information. The Act contains 15 Health Privacy Principles, which describe what organisations must do when they collect, store, use or disclose health information.

5.3 Access to registry records for research purposes

Access to national surveillance data for HIV infection and AIDS for research purposes can be granted subject to:

(a) the approval of the Head of the Kirby Institute Surveillance, Evaluation and Research Program
(b) the approval of the jurisdictions via the Communicable Diseases Network of Australia (CDNA).

Researchers seek access by submitting a concept sheet or protocol for the study. The protocol must specify who is conducting the research, its purpose, the data being sought, the methods to be used, the intended outcome of the research and the publication plan. It must be accompanied by documentation of any ethics committee approvals that are required. These documents are then circulated to the CDNA members together with a copy of the standard data request form for approval (see Appendix C). Upon conditional approval from CDNA members, the data are forward individually to each jurisdiction for approval or comment, as appropriate (see Appendix D for jurisdictional surveillance contacts). Once conditions (a), (b) and (c) are fulfilled, the Kirby Institute provides the researcher with the requested data from those jurisdictions that have individually approved release by the return of the signed request form to the Kirby Institute, via CDNA.

Line record data are not provided with namecodes or dates of birth, except when they are required to conduct studies that involve record linkage. For such studies, line record data including namecodes and dates of birth are only provided to the organisation conducting the linkage.

6. Defining eligibility for national notification of HIV infection

To be eligible for inclusion on the National HIV Registry (NHR) cases of HIV must be diagnosed in Australia and meet the inclusion and exclusion criteria listed below. Once a case is determined as eligible and entered on the registry, it is assigned a unique number.

6.1 Case definitions

In Australia case definitions for nationally notifiable diseases are determined by the Communicable Diseases Network Australia (CDNA). Case definitions for HIV infection (newly acquired), HIV infection (unspecified), HIV infection (child aged less than 18 months at the time of blood sample collection) and AIDS (see Appendix E) were approved for use by the CDNA from 1 January 2004 (CDNA 2004).

6.2 Minimum data required for entry onto the NHR

6.2.1 HIV infection

A notification of newly diagnosed HIV infection must contain the following core information for inclusion on the NHR (see Appendix F for HIV notification forms).

(a) date of birth

(b) date of HIV diagnosis

(c) namecode (family namecode, given namecode)

(d) sex

(e) state/territory of notification

(f) details on other data variables routinely requested are included in Appendix G

6.2.2 Death following HIV infection

A notification of death following HIV infection for an existing HIV notification must contain the following information for inclusion on the NHR.

(a) family namecode, given namecode

(b) date of birth

(c) the day, month and year of death

6.3 Exclusion of previously notified cases of HIV infection

By agreement with the Kirby Institute, jurisdictions forward reports of all new diagnoses of HIV infection that are made in residents of their jurisdiction. Some of these cases may have been previously diagnosed elsewhere, either in another jurisdiction or outside Australia.

Each case of newly diagnosed HIV infection reported to the Kirby Institute is reviewed prior to data entry to determine whether it had been previously diagnosed in another jurisdiction and reported to the Kirby Institute.

A search of the database is first carried out to identify if there is a previously recorded diagnosis in Australia for the case as follows:

A search is made for exact and near-exact matches on namecode and date of birth. If no match is found, a new record is created for the case. If the case exactly matches an existing case, or matches closely (e.g. cases with an abbreviated first name or an estimated date of birth), further data fields are checked. Based on an assessment of the degree of concordance with all of the fields examined, in consultation with jurisdictions, the Kirby Institute makes a determination that the case is either new to Australia, or a repeat notification of a case that has already been reported. In the latter circumstance, this decision is communicated to the jurisdiction that submitted the more recent of the two reports. Unless further information is provided that confirms that the second report is a distinct individual, a new entry is not created.

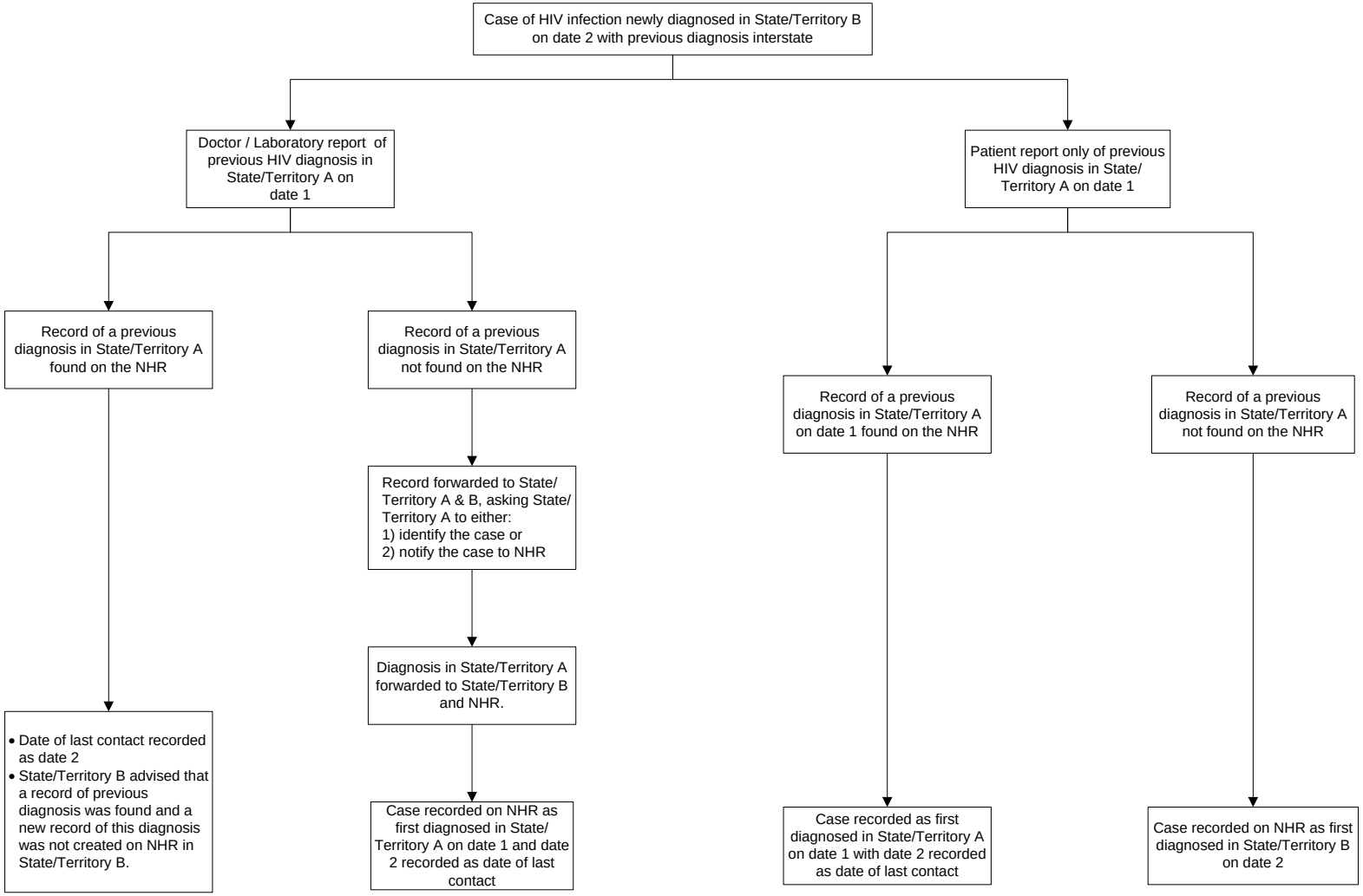
(a) If a case is reported by a state/territory as previously diagnosed in another state/territory

If a state/territory health authority (State/Territory B) notifies the National HIV Registry (NHR) of a case of HIV infection as newly diagnosed in its jurisdiction on date 2 and has clear evidence of a previous HIV/AIDS diagnosis interstate such as a laboratory or doctor report of previous HIV/AIDS diagnosis on a specified date (date 1) in a specified state/territory (State/Territory A), and the record of previous HIV/AIDS diagnosis

(i) can be found on the National HIV Registry in State/Territory A record, the date of HIV/AIDS diagnosis in State/Territory B (date 2) is entered into the “date of last contact” field of the original notification in State/Territory A. The Kirby Institute Surveillance, Evaluation and Research Program confirms with State/Territory B that the case was previously diagnosed interstate and a new record of the case in its jurisdiction was not created.

(ii) cannot be found on the National HIV Registry, State/Territory B will advise State/Territory A and the Kirby Institute Surveillance, Evaluation and Research Program of the date and available laboratory or doctor evidence of the previous HIV/AIDS diagnosis on date 1. State/Territory A will either confirm with State/Territory B and the Kirby Institute Surveillance, Evaluation and Research Program, of the notification of first HIV/AIDS diagnosis for the case in its jurisdiction on date 1 or will include the case as newly diagnosed in their jurisdiction using the date of laboratory or doctor confirmed date of previous HIV/AIDS diagnosis reported by State/Territory B (date 1).

Figure 1: HIV/AIDS cases previously diagnosed interstate



NHR=National HIV Registry

Date 1 is earlier than Date 2.

(b) If a case is reported by a state/territory as previously diagnosed overseas:

If a state or territory health authority (State/Territory B) notifies the National HIV Registry of a case of HIV infection as newly diagnosed in its jurisdiction on a specified date (date 2) and the case was known to have been previously diagnosed in a specified country other than Australia ("Country of previous HIV diagnosis" field) on date 1, the specified country and date of previous diagnosis overseas (date 1) is entered into the "Country of previous HIV diagnosis" field and the "Date of previous diagnosis overseas" field, respectively. The date of previous HIV diagnosis overseas must precede the date that a case commences living in Australia. The date of first HIV diagnosis in Australia in State/Territory B on date 2 is entered into "Date of specimen collection for this HIV diagnosis", in the State/Territory B record. Cases of HIV previously diagnosed overseas are not included in annual reporting of new cases, however are included in calculations of the number of people estimated to be living with HIV in Australia.

6.4 Jurisdiction of notification

The jurisdiction of notification for cases recorded on the NHR is the jurisdiction of residence, **based on postcode of residence at diagnosis**, at the time of the earliest reported diagnosis of HIV infection or AIDS in Australia. In line with the CDNA cross-border notification protocol, the jurisdiction of residence of a case has the responsibility of reporting the notification to the Kirby Institute.[1]

6.5 Duration of stay in Australia

A diagnosis of HIV infection made in Australia in a person born in a country other than Australia **is recorded** on the NHR if the person

(a) has lived in Australia for at least three months prior to diagnosis of HIV infection, and

(b) intends to reside in the notifying State/Territory.

A diagnosis made in Australia in a person born in a country other than Australia **is not included** on the NHR if:

(a) the person reports to the notifying clinician that he or she is visiting Australia and intends to return to the country of origin.

(b) the person reported to the notifying clinician that he or she was visiting Australia and intended to return to the country of origin but died in Australia.

(c) the person came to Australia specifically for HIV treatment or prevention of mother-to-child transmission.

The Kirby Institute makes the assumption that a case diagnosed in Australia in a person born outside Australia and reported to the NHR has been confirmed at the jurisdictional level as satisfying criteria (a) and (b) and not satisfying criteria (c), (d) or (e). Specific documentation to this effect is not required to be made available to the Kirby Institute.

7. Data transfer, entry and updating

7.1 Data transfer

HIV data transfer systems are the subject of ongoing review, with the long term aim of facilitating the direct electronic transfer of data into the National HIV Registry. The current process is described below.

7.1.1 HIV infection

HIV infection is a notifiable condition in all Australian States and Territories. Each state or territory health authority forwards an electronic file of notifications of new HIV diagnoses to the NHR at the Kirby Institute for national collation and analysis.

New case notifications are sent to the Kirby Institute quarterly in Excel format. Data should be forwarded to the Kirby Institute within four weeks of the end of each quarter. These records are sent as zipped, password protected files attached to an email or via a secure online portal (where available), and their receipt is acknowledged by return email. Jurisdictions with smaller numbers of cases may return completed password protected forms electronically to the Surveillance, Evaluation and Research Program. State or territory health authorities can use the national surveillance form (see Appendix F) or forms of their own design. The password is conveyed by telephone. Immediately upon receipt, these records are transferred to a directory on the Kirby Institute network and the file password protection is retained.

From time to time state and territory health authorities will update or query existing notifications (as discussed in more detail below). In this instance, password protected Excel files will be sent to the Kirby Institute for cross checking, or by phone when it involves a smaller number of cases. **Namecodes and dates of birth are never included in the text of an email.**

7.1.2 AIDS

AIDS was de-notified in October 2016. Jurisdictions may still report an AIDS diagnosis at time of HIV diagnosis.

A list of diseases considered AIDS defining illnesses can be found in Appendix E.

7.1.3 Death following HIV infection

Deaths in people with HIV infection are reported to state and territory health authorities by clinicians using standard notification forms. These password protected forms (Appendix F) are then electronically forwarded to the NHR for national collation and analysis.

7.2 Data entry

7.2.1 Data fields collected

The information collected at a national level for cases of newly diagnosed HIV infection and death in a person with HIV infection is summarised in Tables 1 and 2 respectively. Detailed information about codes and coding rules is provided in Appendix G.

Table 1: Newly diagnosed HIV

Data type	Description of fields
Case identification	State/Territory of diagnosis, State/Territory case number, family namecode, given namecode
Demographic characteristics	Date of birth, sex, country of birth, year of arrival in Australia if born overseas, Aboriginal and Torres Strait Islander status, language mostly spoken at home, postcode of usual place of residence at HIV diagnosis
Diagnosis	Date of first HIV diagnosis in Australia, HIV type, prior HIV antibody testing history, State/Territory, date of previous HIV diagnosis and source of information on the previous diagnosis if previously diagnosed in Australia, country and date of HIV diagnosis if previously diagnosed overseas
Clinical history	Clinical status at this HIV diagnosis, reason for HIV antibody testing, CD4+ cell count result and date, date of last contact/death, HIV subtype, HIV genotype
Exposure history	Person's report of their exposure to HIV through sexual contact, injecting drug use, mother-to-child transmission, receipt of blood/tissue, treatment for haemophilia/ coagulation disorder, other documented exposure and undetermined exposure, HIV infection was most likely to have been acquired either in Australia or overseas. Details on determination of exposure risk can be found at Appendix I.

Table 2: Death following HIV infection

Data type	Description of fields
Case identification	State/Territory of diagnosis, notifying officer, date of notification to State/Territory, source of information on death, State/Territory case number, family namecode, given namecode
Demographic characteristics	Date of birth, sex
Information on death	Date of death, cause of death

7.2.2 Validation at data entry

Once a reported case is determined to be a new notification at the national level it is entered into the NHR. The database applies standard range and validity checks to the data entered (Appendix G).

If the data being entered for cases of newly diagnosed HIV infection fall outside the standard responses or reference ranges, the surveillance officer in the state or territory of notification is personally contacted to validate the information on the notification; if the data are revised, a note is made on the notification and the data on the NHR are revised accordingly.

7.3 Data updating

7.3.1 Corrections requiring changes or removal of records

When a notification is determined to be a repeat of an existing case through the procedure outlined in section 6.3, it is reviewed to see if it contains any additional information or a more recent date of last contact and residential postcode. The NHR is then updated with this information.

Occasionally, it is necessary to remove a case from the NHR. Removal of a case is performed by the responsible Kirby Institute officer only after agreement between the Program Head, the Epidemiologist, National HIV/AIDS Surveillance and the surveillance officer in the relevant state or territory.

All data alterations, updates and deletions are recorded electronically and manually either as notes on or with the notification forms, with the date of action. A log of NHR changes is maintained in a password protected Excel file.

7.3.2 Recording notifications of death following HIV infection

Prior to 2013, Australia maintained separate registries for HIV and AIDS cases, but the two registries were merged in early 2013. From 31 December 2012 cases of newly diagnosed AIDS were no longer entered into the National AIDS Registry (NAR). After this date, all cases of AIDS and death following HIV infection are only recorded on the NHR.

A search is made for exact and near-exact matches on namecode and date of birth, using the similar methods for excluding previously notified cases of HIV infection. To be matched, cases must also be consistent with respect to timing of HIV diagnosis and death following HIV infection. If the Kirby Institute determines that a death matches an existing HIV notification, the information from the death notification is added to the NHR. If the Kirby Institute is unable to identify a match on the NHR, the Kirby Institute will contact the notifying jurisdiction and request they submit a HIV notification for the case as well.

The HIV record may be updated based on additional or revised information received with a death notification. Changes will be noted in the comment section of the record.

7.3.3 Confirming new HIV diagnoses, and deaths following HIV infection with States and Territories

Annually, lists of new HIV diagnoses, and deaths following HIV infection reported to the Kirby Institute in the quarter, are generated and sent to the notifying jurisdiction. The list includes each case for which a notification was received, and indicates whether or not the case or death was included as a new entry on the NHR and the reason why each case was or was not included. **Jurisdictions are provided with the national HIV number and the State/Territory case number for case identification at this time.**

Further clarification of information on individual cases, by either state or territory health authorities or the Kirby Institute Surveillance, Evaluation and Research Program, occurs on an ongoing basis.

8. Data management

The Kirby Institute Surveillance, Evaluation and Research Program maintains the NHR, the current registry that combines both HIV and AIDS notifications. The database uses Oracle software. The NAR, the former independent AIDS registry is securely archived at the Kirby Institute.

The Kirby Institute Surveillance, Evaluation and Research Program stores both electronic and hard copy records of HIV and AIDS case notifications from the states and territories.

8.1 Electronic records

The NHR and the NAR are stored on a password protected file server within the Kirby Institute. The file server is only accessible through three users' computers at the Kirby Institute. The file server is physically located within the secure Kirby Institute Information Technology Unit. The registry files themselves are also password protected. All electronic files held on the Kirby Institute servers are backed up every evening; in addition, once a month, an additional full back-up procedure is performed and the resultant back-up disc is stored in a secure off-site location.

National registry records are never transferred to any other computer within the Kirby Institute.

8.2 Hard copy (paper) records

Historical hard copy records are stored in locked filing cabinets only accessible to the Program Coordinator and the Epidemiologist, National HIV/AIDS Surveillance. The filing cabinets remain locked unless records are being filed or retrieved; new case notification records awaiting data entry are also stored in these cabinets upon receipt.

Filing of new case notification forms is performed immediately after data entry. Single hard copy case notification forms are filed by state/territory of notification and within a jurisdiction by reverse national number, that is, the most recent document is placed at the front of the file for each jurisdiction. Detailed information on the procedures for identifying previously notified cases is given in section 6.3. Case notification forms that are identical to an existing form are shredded and securely disposed of. A duplicate notification form that contains additional information about a previously notified case is filed with the original case notification form(s).

9. Routine reporting

The Kirby Institute Surveillance, Evaluation and Research Program produces a number of reports from HIV/AIDS surveillance data, on a routine basis.

9.1 HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report

9.1.1 National surveillance for HIV diagnoses

Tables and figures based on national HIV surveillance data are produced for the Annual Surveillance Report each year. The outputs are based on tabulations of newly diagnosed cases of HIV diagnosed to 31 December the preceding year received by 31 March in the year of publication. Examples of these tabulations can be found in Appendix H.

The report also includes national estimates of the proportion of people with HIV in Australia who are under care, receiving treatment and having undetectable levels of HIV. The methodology used to calculate these estimates are detailed in the report.

9.2 Bloodborne viral and sexually transmitted infections in Aboriginal and Torres Strait Islander people: Surveillance and Evaluation Report

Tables and figures based on national HIV/AIDS surveillance data are produced for the Bloodborne viral and sexually transmitted infections in Aboriginal and Torres Strait Islander people: Surveillance and Evaluation Report. These outputs are based on tabulations of newly diagnosed cases of HIV diagnosed to 31 December the preceding year received by 31 March in the year of publication. Examples of these tabulations can be found in Appendix H.

9.3 National BBV & STI Surveillance and Monitoring Report

Tables and figures based on national HIV/AIDS surveillance data are produced for the National BBV & STI Surveillance and Monitoring Report. This report provides an annual account of progress against the objectives of Australia's National blood-borne virus BBV and STIs Strategies. These outputs are based on tabulations of newly diagnosed cases of HIV diagnosed to 31 December the preceding year received by 31 March in the year of publication, and are largely a repeat of information presented in the HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report.

10. Use of National HIV/AIDS Surveillance Data

Requests for access to national HIV data have been integrated into national guidelines. The full National Notifiable Diseases Surveillance System data release policy can be found at Appendix J.

10.1 Guidelines for the release of national surveillance data and authorship of papers and reports

The Kirby Institute depends on collaboration with state and territory health authorities and other organisations for the collection of data on cases of newly diagnosed HIV infection, viral hepatitis and sexually transmissible infections. Issues of data ownership and joint authorship of reports and publications are likely to arise in any collaborative research arrangement and pre-determined guidelines are useful for attributing appropriate credit.

Analyses of national case surveillance data may be classified as either primary or secondary. Primary analyses are those that identify risk factors or describe trends and patterns of new diagnoses. Secondary analyses are those designed to support or address a specific research question or hypothesis, or make use of case surveillance data that has been enhanced through extended mathematical or statistical analyses or linkage to other datasets.

Primary analyses are usually carried out by representatives to the National BBV and STI Surveillance Subcommittee, whereas secondary analyses may be carried out by researchers with expertise in other areas such as cancer epidemiology, mathematical modelling or statistics. Proposals for both primary and secondary analyses of national surveillance data are to adhere to the below data request process.

10.1.1 Access and publication of HIV data

HIV data are published annually in the *HIV, viral hepatitis and sexually transmissible infections in Australia: Annual Surveillance Report*, and the *Bloodborne viral and sexually transmissible infections in Aboriginal and Torres Strait Islander people: Annual Surveillance Report*. Data are also used to track progress against indicators in the *National Blood-borne Virus and Sexually Transmissible Infections Surveillance and Monitoring Report*.

Data are also available online in a de-identified public data set, with a number of variables collapsed into categories.[1]

However, not all needs for data are met by the routinely published or publicly available data. Requests are regularly made by third parties for access to HIV data. These requests may require approval of the CDNA JEG (Jurisdictional Executive Group) members before being released.

[1] https://kirby.unsw.edu.au/surveillance/Australian-HIV-Public-Access-Dataset

10.1.2 Historical process for data requests

In the past, when a third party has wanted access to HIV data, a request has been submitted to the Kirby Institute, including data shells and ethical approval, as relevant. This information has then been forwarded by the Kirby Institute to the CDNA National BBV and STI Surveillance Subcommittee representatives in each state and territory for review and if appropriate, approval. This approach was not consistent with processes for National Notifiable Diseases Surveillance System (NNDSS) data requests, and the new process for HIV data as detailed below ensures a more consistent approach. These procedures should be read in line with the *Data release policy for communicable disease-related data held by the Department of Health* (Appendix J).

10.1.3 General principles governing data release

In consultation with the States and Territories and CDNA, the Kirby Institute will communicate to data requestors the conditions with which data may be used or released.

CDNA JEG approval aims to ensure protection of privacy and appropriate use of the data. Data may be requested for use in public presentations, intended publications, research, media articles, policy development and other general enquiries related to health care planning, program evaluation, health surveillance and/or quality assurance analysis.

Only those data fields essential to the applicant's purpose will be released ('fit for purpose'). 'Fit for purpose' refers to the closeness of correspondence between the characteristics of the data provided and its intended purpose. Poor fit means that the data are unlikely to meet the needs of those requesting the data.[2]

The risk of disclosing data which could be re-identified or linked through "data mining" and other techniques will be minimised by not releasing unique identification numbers and limiting the disclosure of date of birth. Additionally, those requesting the data are obliged to take all steps to ensure that no individual, organisation or community can be identified from provided data.

Combinations of data fields that may enable the potential identification of individuals will not be released unless the release is properly authorised through the appropriate jurisdictional approval and Human Research Ethics Committee (HREC) process if necessary.

Conditions of data provision

The release of data from the NNDSS varies according to the degree of detail that is being requested.

a. Publicly available data

Requests for publicly available data may be released to third parties via a 'fast-tracked' process without the approval of CDNA JEG members. This includes data published in the *CDI, the HIV, viral hepatitis and sexually transmissible infections in Australia: Annual*

[2] Department of Health and Ageing Data Reporting and Release Policy, Economic and Statistical Analysis Branch, Portfolio Strategies Division, Department of Health and Ageing, March 2009, Version 4.0, page 4.

Surveillance Report, the *Bloodborne viral and sexually transmissible infections in Aboriginal and Torres Strait Islander people: Annual Surveillance Report*, and the *National Blood-borne Virus and Sexually Transmissible Infections Surveillance and Monitoring Report*.

This includes:

- Notifications (by diagnosis date) by State and Territory and Australia, by month and year (counts and crude rates)
- Notifications (by diagnosis date) by sex for Australia by year (counts and crude rates)
- Notifications (by diagnosis date) by Indigenous status for Australia by year
- Information stating that no cases have occurred

b. National HIV aggregate data requested by internal parties for the specific purpose of informing policy and practice

Requests for NHR data at the national level and national data by state and territory may be released to internal parties such as DoHA, AHPPC and CDNA committees and working groups for the specific purpose of informing policy and practice without specific CDNA JEG approval following internal clearance with the Kirby Institute. Conditions may apply to the release of this data, i.e. the data must be destroyed after use, are not published and are not used for any other purposes.

c. Requests for aggregated data by third parties that have been deemed low-risk[3].

- Such requests may include aggregate requests for fields including:
  - Total number of cases
  - Age (which may be in five-year age groups)
  - Sex
  - Year of diagnosis and/or year of notification
  - State and Territory, Australian Statistical Geography Standard (ASGS)[4] Statistical Local Areas (SLA) 2, 3 or 4[5]
  - Place of acquisition[6]
  - Organism serogroup/subtype[7]

[3] A request for data will be deemed low-risk by CDNA JEG when the combination of requested fields has a low chance of re-identifying individuals. For example, when a combination of demographic data fields that distinguishes groups has an estimated resident population of greater than 1,000. The '1,000 denominator population rule' is an example of the 'data reduction' principle described in Appendix 4 of the National Statistical Service Handbook. The population group are defined using any demographic information that is relevant (in the sense that the combinations of the demographic data items may enable individuals in the community to be identified) and for which resident population estimates are available from the Australian Bureau of Statistics (ABS). Hence the populations may be defined on the basis of geography (e.g. postcode or region of residence), age, sex, country of birth, Indigenous status, or marital status.

[4] From July 2011, the Australia Bureau of Statistics replaced the Australian Standard Geographical Classification (ASGC) with the ASGS. The ASGS is broken down into Statistical Local Areas 4 through to 1. More information can be found here http://www.abs.gov.au/websitedbs/D3310114.nsf/home/Australian+Statistical+Geography+Standard+(ASGS).

[5] SLA 4 contains 106 regions with populations in the range of 100,000 to 500,000, SLA 3 contains 351 regions with populations in the range of 30,000 to 130,000 and SLA 2 contains 2,214 regions with populations in the range of 3,000 to 25,000.

[6] May only be released as aggregate data.

[7] As the data quality and completeness for specific variables may vary the process of extracting and manipulating data, assessing data quality and completeness, and developing appropriate caveats can take considerable time. In addition, as state and territory data release processes and/or legislation varies the time it takes for individual states and territories to approve the data for release can vary.

- Indigenous status[7]

- All requests for aggregated communicable disease data are delegated to the Kirby Institute for approval, unless the request contains a combination of fields that Department of Health has assessed may increase the risk of an individual being potentially re-identified (e.g. a request that includes Indigenous status, age/age-group and sex). In this circumstance, CDNA JEG will be informed of the request at the next fortnightly teleconference, at which time they can decide if it requires CDNA JEG approval or if the request can be delegated to Department of Health for approval.

d. National HIV data not publicly available to third parties which require approval from CDNA JEG

NHR data that are not in the public domain may be released to third parties and trusted stakeholders as aggregate or unit record data; this requires prior approval by CDNA JEG.

Where data are of particularly poor quality or are too incomplete to be meaningful these data may not be released. The decision to release such data will be made by CDNA JEG members on a case by case basis. As data quality and completeness for specific variables may vary, caveats (e.g. explaining data limitations) may be provided with released data.[8]

Requests will be raised by the Kirby Institute as an agenda item for CDNA meetings, and the data request form and where relevant populated data shells will be forwarded prior to the call.

Requests for data not publicly available may be subject to review by expert CDNA working groups to ensure that the data being released are of the highest standard before being sent to CDNA JEG members for approval. This process is to take no longer than two weeks.

e. Requests for similar data by third parties

Where a request from a third party, including a commercial entity (such as a vaccine company), for communicable disease data is very similar to one made by another party, which has already had CDNA JEG approval, and the data request is 'fit-for-purpose', the subsequent request(s) may not need to be re-approved by CDNA JEG.

In these circumstances CDNA JEG will be asked to delegate the request to the Kirby Institute for approval at the next appropriate CDNA meeting.

[8] As the data quality and completeness for specific variables may vary the process of extracting and manipulating data, assessing data quality and completeness, and developing appropriate caveats can take considerable time. In addition, as state and territory data release processes and/or legislation varies the time it takes for individual states and territories to approve the data for release can vary.

f. Ethics approval

For a request that seeks data that are potentially identifiable for research purposes, the applicant is required to have their research proposal cleared by an approved HREC that reports annually to the National Health and Medical Research Council. A copy of HREC approval and a summary of the project proposal submitted to HREC must be provided, unless an exception is stated.

Approval of an application by HREC does not constitute authority to the release of data; it is a prerequisite for an authorisation to occur. The release of any potentially identifiable data from the NHR for research purposes requires a HREC approval in conjunction with authorisation from the Department of Health and CDNA JEG members.

g. Roles and responsibilities

The Kirby Institute, UNSW Sydney

The Kirby Institute acts as a custodian and data steward of the NHR data and Kirby Institute employees share the responsibility for maintaining and securing data and information as per the *Privacy Act 1988*.

The Kirby Institute will monitor applicants to ensure that they abide by the conditions under which the data was released to them, (e.g. where CDNA JEG have requested the right of comment on the use and interpretation of the data prior to publication, secure storage of the data, and destruction of the data when no longer required by the applicant).

The Kirby Institute will keep a record of all requests for NHR data and will provide an annual report on these and the outcomes to the NBBVSTI Subcommittee and CDNA JEG.

Jurisdictions (CDNA JEG)

Jurisdictions are legally authorised to collect personal information on specified communicable diseases data under their relevant public health legislation.

A jurisdiction via their CDNA JEG member receiving a request for that state or territory's HIV data will follow their respective state or territory data release policy(ies) and/or legislation in agreeing to release the data to a third party.

On receipt of a request for data release via the Kirby Institute, jurisdictions will provide the Kirby Institute with a response, in which they may agree to the supply of data as requested (with or without a caveat(s)), reject the request or seek additional information about the request. Should the jurisdiction wish to reject the request, detailed reasons should be given to enable the applicant to reconsider their request, and resubmit their application for reconsideration by the jurisdictions. Where there is a divergence of views amongst jurisdictions the Kirby Institute will inform CDNA JEG and seek a resolution.

Applicants ('third parties')

It is the applicant's responsibility to determine if the data they require are already publicly available from the Kirby Institute and/or CDNA websites, and other published reports. If not, the applicant should complete the 'Release of NHR data form'; providing full details, and return it by email to surveillance@kirby.unsw.edu.au or by fax on 02 9385 0920. To avoid a delay in the processing of the form applicants replying by fax should advise the Kirby Institute of this in an email to surveillance@kirby.unsw.edu.au at the time the fax is sent. Where appropriate the requestor must provide a copy of ethics approval for their project at the time the form is submitted. The applicant must be willing to communicate by email and telephone further details about the nature of their request with the Kirby Institute Epidemiologist handling their request.

The data that are provided to the applicant must be used for the intended purpose as stated in the completed "Release of NHR form" (see Appendix C). If the applicant wishes to vary the use or reporting of the data they must complete another "Release of NHR form" and this will be treated as a completely new request.

If a CDNA JEG member in any jurisdiction has approved the release of data on the condition that a manuscript intended for publication be reviewed by that jurisdiction prior to publication, a draft copy of the publication materials/manuscript must be provided to the Kirby Institute prior to submission for publication. Publishable data that may require state and territory approval refers to NHR data that are not already available in the public domain from the Department of Health and CDNA websites or from other published sources. This may include data being published in a report, a peer-reviewed journal, or presented at a conference as a presentation, abstract or poster, by the media or to public groups.

It is the responsibility of the applicant to ensure that they will protect the security and integrity of data released into their care. Data supplied to the applicant:

- Must be stored securely.
- Must be destroyed when no longer required by the applicant.
- Must not be accessed or used by a third party.

Data supplied to the applicant must meet the requirements for data storage and disposal as set out in the *National statement on Ethical Conduct in Human Research.*

Expert CDNA subcommittees/working groups

Expert CDNA subcommittee/ working groups may review requests for enhanced data to ensure that the data being released are of the highest standard before being sent to CDNA JEG members for approval. This process is to take no longer than two weeks.

h. Accuracy of data

The data quality and completeness for HIV may be variable over time and should be interpreted with caution. The numbers reported may represent an underestimate of the true absolute number and incidence rate of cases in states and territories. Changes in surveillance practices, diagnostic techniques and reporting may contribute to different

case ascertainment between and within states and territories over time. The data specifications (Appendix G) provide further details of when various variables where added to HIV notification forms, and give an indication of completeness.

The provision of data is to be accompanied by a standard quality statement which reflects the above.

i. Data transfer requirements

All data pertaining to data requests will be sent to applicants by secure means, such as emailed electronically as a password protected WinZip file. The password is provided to the applicant by telephone when they receive the data.

j. Review of potential publications

Requestors will send any potential publications to the Data Request Coordinator for review prior to publication. All potential publications will be sent to CDNA JEG for noting.

If the request is assessed by the Kirby Institute as requiring CDNA JEG approval or at the request of a CDNA JEG member, the potential publication will be sent to CDNA JEG for comment.

CDNA JEG reserves the right of approval or veto of data and interpretations prior to publication.

k. Data retention period

By default, all data sent to the applicant(s) must be destroyed after twelve months from the date the data were received. If the applicant(s) wish to retain the data for a period longer than this, they must indicate and justify the retention period required on the data request form.

l. Appeals

If applicants wish to appeal the decision of a state or territory to not release data, they will be provided details for an appropriate contact person in that state or territory to correspond with.

m. Further information

If you require further assistance, have questions about data availability, the request process or on data interpretation, please contact surveillance@kirby.unsw.edu.au.

11. References

Australian Bureau of Statistics. Standard Australian Classification of Countries. Canberra: Australian Bureau of Statistics, 1998.

Australian Bureau of Statistics. Standard Australian Classification of Languages. Canberra: Australian Bureau of Statistics, 2005.

Australia's notifiable diseases status, 2009: Annual Report of the National Notifiable Diseases Surveillance System - Notes. *Communicable Diseases Intelligence* 2011;35(2).

Communicable Diseases Network Australia 2004. Surveillance Case Definitions for the Australian National Notifiable Diseases Surveillance System. Communicable Diseases Australia, Australian Government Department of Health and Ageing, Canberra ACT 2004. http://www.health.gov.au/casedefinitions

Whyte BM, Gold J, Dobson AJ and Cooper DA. Epidemiology of acquired immunodeficiency syndrome in Australia. *Medical Journal of Australis* 1987; 147: 65-59.

Whyte BM and Cooper DA. The surveillance definition of the acquired immunodeficiency syndrome and the clinical classification of infection with the human immunodeficiency virus type 1. *Medical Journal of Australia* 1988; 149: 368-373.

12. Appendices

Appendix A – Kirby Institute staff members with responsibility for national HIV/AIDS case surveillance

Position title	Incumbent
Head, Surveillance and Evaluation Program for Public Health	Associate Professor Rebecca Guy
Epidemiologist	Dr Skye McGregor
Epidemiologist/Statistician	Dr Hamish McManus
Computer Systems Officer	Mr Noorul Absar
Program Coordinator	Ms Jane Costello

Appendix B – Kirby Institute confidentiality form

The Kirby Institute for Infection and Immunity in Society

CONFIDENTIALITY UNDERTAKING

I, (name) _____understand that, while I am employed at the Kirby Institute, I will have access to confidential data collected for research and surveillance purposes. The confidential data may include the identity of, and personal and medical information on, individual persons.

I undertake strictly to preserve the confidentiality of these data and will not divulge any identifiable, personal or medical information on individual persons, except to authorised staff of the Kirby Institute who require such information to carry out the functions of the Institute, or to individuals or organisations whose collaborations have been approved by appropriate management bodies of the Institute.

I will ensure that confidential information, whether in the form of paper documents or computerised data, is stored in a secure and orderly manner which prevents unauthorised access.

I understand that if I cause a breach of confidentiality, it is possible that my employment at the Kirby Institute will be terminated.

Signed by	in the presence of
_____	_____
(Name)	(Name)
_____	_____
(Signature)	(Signature)
_____	_____
(Position)	(Position)

Date _____ / _____ / _____

Level 6, Wallace Wurth Building, The University of New South Wales, Sydney NSW 2052

PH: (02)9385-0900; FAX:(02)9385-0920

Appendix C – Standard data request forms

See next page

Communicable Diseases Network Australia

National HIV Registry data request form

IMPORTANT: Please discuss your data request with an Epidemiologist at the Kirby Institute before submitting this form to ensure that the data you want is available. The relevant person can be contacted at surveillance@kirby.unsw.edu.au or on 02 9385 0900.

Once completed by the applicant it should be returned by email to surveillance@kirby.unsw.edu.au. Please provide as much detail as possible.

Project and contact details

1. **Person and/or agency making the request**	
Principal Investigator	
Contact officer *(if different)*	
Position	
Organisation	
Postal address	
Phone	Work: Mobile:
Email	

2. **Details of data requested**	
Please specify the data fields, time period and whether you are requesting aggregated or linelisted data. The applicant may also attach a 'mock up' table of the data required, providing column and row headings, to further clarify their request. ☐ 'Mock up' table attached	
Date data requested by? *The Kirby Institute undertakes data release activities within the context of other work priories. As such, it may take several months to process your request.*	

3.	**Please state the aims of the research / project and the research question and / or hypotheses, the benefits and outcomes.**
If applicable, please specify if the request is conducted on behalf of an Institution or Organisation/Company project/study or if the research is funded.	

4.	**Describe the methodology used in the research project**

5.	**Human Research Ethics Committee (HREC) Approval** *All research that is the basis of a data request must comply with the National Statement on Ethical Conduct in Human Research (2007).* *Has your research proposal been reviewed by a HREC?*
☐ No	*Please specify why HREC approval is not required*
☐ Yes	*Please provide evidence as an attachment that the research proposal has been reviewed by a HREC.*

6.	**What (if any) publication of data is intended?**
When do you expect the results to be disseminated? *(Please provide a date)*	

Maintaining privacy and confidentiality

7.	**Please list all others who, for the purpose of this project, will have authority to use or have access to the data and describe the nature of the use/access** *(If this exceeds one person, please attach a full list at the end of this form)*
Name	
Position	
Organisation	
Phone	Work: Mobile:
Postal address	
Email	
Nature of access	

8.	**Please specify the measures to be taken to ensure the security of data from misuse, loss or unauthorised access while the data are stored with your organisation?** *(e.g. how the data will be securely sored, how long will it be stored for and how will it be destroyed after completion of the project)*

9.	**Person taking responsibility for use of the data** *(e.g. Principal Investigator)*
Name	
Organisation	
Position	
Phone	Work: Mobile:
Email	

	Contact officer *(if different)*
Name	
Organisation	
Position	
Phone	Work: Mobile:
Email	

The undertaking

Note: This application must be signed by a responsible officer with the authority or delegation to commit the organisation to the terms and conditions of this undertaking. This would usually be the Chief Financial Officer for an organisation or Business Manager for a unit within an organisation.

Please note this should be not be signed by the applicant, or any other member of the research team.

I, _____

Full name and position of Responsible Officer

in the _____

Name of the Department or Organisation

HEREBY UNDERTAKE that the above mentioned organisation will use the information in accordance with the following conditions.

1. No attempt will be made to match linelisted data (if provided), in whole or in part, with any other information for the purposes of attempting to identify individuals, nor will any attempt to identify an individual be made.
2. The person/organisation will not disclose or release the data to any other person or organisation, except as statistical information that does not risk identifying an individual.
3. The Principal Investigator will be responsible for securing the data from misuse, loss or unauthorised access and the destruction of data at the completion of the project. The Principal Investigator will explain to any employees granted access to the data that the information is not to be released to unauthorised users.
4. Access to the data will not be granted to any other organisation without specific approval from CDNA JEG.
5. The information will be used for the purposes for which it was approved to be released.
6. The recipient will cooperate with any monitoring procedures established by the Kirby Institute and CDNA JEG and advised to the recipient in writing.
7. The recipient will abide by any conditions attached to the release of the data by CDNA JEG such as i) right of comment on the use and interpretation of the data prior to publication, ii) right of approval or veto of data and interpretations prior to publication, and iii) other specified conditions.
8. The Kirby Institute and CDNA will be acknowledged in all reports and publications resulting from this project and will be provided with a copy of all such reports and publications.
9. Copyright in all data is vested in the Commonwealth and contributing States and Territories.

Signature of responsible officer: _____

Witness _____

Position: _____

Organisation/Unit: _____

Signature: _____

Date: _____

All employees of the above organisation who will be granted access to the information must be listed and must agree to comply with the conditions included in the undertaking.

For internal use:

Date received: _____

Request number: _____

Communicable Diseases Network Australia

Request for Release of
National HIV notifications Data

Email to: CDNA.Secretariat@health.gov.au

Name of requestor & request subject: _____

Request number _____

To be completed by State/Territory officer with authority to approve data release.
(Please choose one of the three options below by ticking the appropriate box(es).

☐ The release of data from this jurisdiction as requested above is approved

OR

☐ The release of data from this jurisdiction as requested above is approved subject to:

- ☐ right of comment on use of data and interpretation prior to publication
- ☐ right of approval or veto of data and interpretations prior to publication
- ☐ other conditions, please specify: _____

_____

_____

_____

_____

_____

OR

☐ Release of data as requested above is not approved, please specify:

_____

_____

_____

_____

Name of Officer: _____

Position of Officer: _____

State/Territory: _____

Signature: _____

Date: _____

Appendix D - Jurisdictional HIV surveillance contacts of the National BBV and STI Surveillance Committee

State/Territory	Primary contact	Number	Email
ACT	Ms Rebecca Hundy, ACT Health	(02) 6205 2052	Rebecca.Hundy@act.gov.au
NSW	Dr Christine Selvey, NSW Health Department	(02) 9391 9675	CSELV@doh.health.nsw.gov.au
NT	Mr Matthew O'Dwyer, Department of Health and Community Services	(08) 8922 8606	m.odwyer@nt.gov.au
QLD	Dr Carolyn Lang, Queensland Department of Health	(07) 3224 5526	Carolyn.Lang@health.qld.gov.au
SA	Dr Russell Waddell, SA Health Commission	(08) 8226 6025	Russell.Waddell@health.sa.gov.au
TAS	Dr Mark Veitch, Department of Health and Human Services	(03) 6166 0697	cameron.sault@dhhs.tas.gov.au
VIC	Ms Nasra Higgins	(03) 9096 2202	Nasra.Higgins@health.vic.gov.au
	Ms Carol El-Hayek, Burnet Institute	(03) 9282 2290	carol@burnet.edu.au
WA	Ms Carolien Giele, WA Department of Health	(08) 9388 4844	Carolien.Giele@health.wa.gov.au

Appendix E – Case definitions

Australian case definitions are also available at: http://www.health.gov.au/casedefinitions

Australian national notifiable diseases case definitions – Human immunodeficiency virus (HIV) – newly acquired

Newly acquired HIV infection may be diagnosed in individuals aged 18 months or older at the time of blood sample collection. A diagnosis of newly acquired HIV infection excludes a diagnosis of HIV infection (unspecified).

Reporting

Both confirmed cases and probable cases should be notified.

Confirmed case

A confirmed case requires laboratory definitive evidence only.

Laboratory definitive evidence

Repeatedly reactive result on a screening test for HIV antibody followed by a positive result on a western blot AND laboratory evidence of a negative or indeterminate HIV antibody result in the 12 months prior to blood sample collection.

OR

A group IV indeterminate western blot AND detection of HIV by at least one of the following virologic assays (nucleic acid testing for proviral DNA; HIV p24 antigen, with neutralization; virus isolation). A group IV indeterminate western blot is defined by the presence of a glycoprotein band (gp41, gp120 or gp160) and one or two other HIV specific bands.

Probable case

A probable case requires laboratory suggestive evidence and clinical evidence.

Laboratory suggestive evidence

Detection of HIV by at least one of the following virologic assays (nucleic acid testing for proviral DNA; HIV p24 antigen, with neutralization; virus isolation).

OR

Repeatedly reactive result on a screening test for HIV antibody followed by a positive result on a western blot.

Clinical evidence

HIV seroconversion illness within the 12 months prior to blood sample collection.

Australian national notifiable diseases case definitions – Human immunodeficiency virus (HIV) – unspecified

HIV infection (unspecified) is diagnosed in individuals aged 18 months or older at the time of blood sample collection, who do not have evidence of HIV acquisition in the previous 12 months. A diagnosis of HIV infection (unspecified) excludes a diagnosis of newly acquired HIV infection.

Reporting

Both confirmed cases and probable cases should be notified.

Confirmed case

A confirmed case requires laboratory definitive evidence only AND that the case does not meet any of the criteria for a newly acquired case.

Laboratory definitive evidence

Repeatedly reactive result on a screening test for HIV antibody followed by a positive result on a western blot. A positive result on a western blot is defined by the presence of a glycoprotein band (gp41, gp120 or gp160) and at least three other HIV-specific bands

OR

Detection of HIV by at least two virologic assays (nucleic acid testing for proviral DNA; HIV p24 antigen, with neutralization; virus isolation) performed on at least two separate blood samples.

Probable case

A probable case requires laboratory suggestive evidence only.

Laboratory suggestive evidence

Detection of HIV by at least one of the following virologic assays (nucleic acid testing for proviral DNA; HIV p24 antigen, with neutralization; virus isolation) in one blood sample.

Australian national notifiable diseases case definitions – Human immunodeficiency virus (HIV) – child aged less than 18 months at the time of blood sample collection

Reporting

Both confirmed cases and probable cases should be notified.

Confirmed case

A confirmed case requires laboratory definitive evidence only.

Laboratory definitive evidence

Detection of HIV by at least two virologic assays (nucleic acid testing for proviral DNA; HIV p24 antigen, with neutralization; virus isolation) on at least two separate blood samples (excluding cord blood).

Probable case

A probable case requires laboratory suggestive evidence only.

Laboratory suggestive evidence

Detection of HIV by one of the following virologic assays (nucleic acid testing for proviral DNA; HIV p24 antigen, with neutralization; virus isolation) in one blood sample (excluding cord blood) and no subsequent negative HIV virologic or antibody tests.

Definition of AIDS-defining illnesses

Candidiasis of the bronchi, trachea or lungs – definitive diagnosis only

Gross inspection by endoscopy or autopsy or by microscopy (histology or cytology) on a specimen obtained directly from the tissues affected (including scrapings from the mucosal surface), not from a culture.

Oesophageal candidiasis – definitive or presumptive diagnosis

Definitive diagnosis:

(i) As for candidiasis of the bronchi, trachea or lungs.

Presumptive diagnosis:

(i) Recent onset of retrosternal pain on swallowing;

AND

(ii) Oral candidiasis diagnosed by the gross appearance of white patches or plaques on an erythematous base or by the microscopic appearance of fungal mycelial filaments in an uncultured specimen scraped from the oral mucosa.

Invasive cervical cancer – definitive diagnosis only

Histological evidence of cancer.

Coccidioidomycosis, disseminated or extrapulmonary – definitive diagnosis only

Microscopy (histology or cytology), culture or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

Cryptococcosis, extrapulmonary – definitive diagnosis only

Microscopy (histology or cytology), culture or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

Cryptosporidiosis, of more than one month's duration – definitive diagnosis only

Microscopy (histology or cytology), culture or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

Cytomegalovirus disease, other than liver, spleen or lymph nodes – definitive diagnosis only

Microscopy (histology or cytology), culture or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

Cytomegalovirus retinitis, with loss of vision – definitive or presumptive diagnosis

Definitive diagnosis:

(i) As for cytomegalovirus disease, other than liver, spleen or lymph nodes.

Presumptive diagnosis:

(ii) A characteristic appearance on serial opthalmoscopic examinations, for example discrete patches of retinal whitening with distinct borders, spreading in a centrifugal manner along the paths of blood vessels, progressing over several months, and frequently associated with retinal vasculitis, haemorrhage, and necrosis. Resolution of active disease leaves retinal scarring and atrophy with retinal pigment epithelial mottling.

Encephalopathy, HIV related – definitive diagnosis only

Clinical findings of disabling cognitive or motor dysfunction interfering with occupation or activities of daily living, progressing over weeks to months, in the absence of a concurrent illness or condition other than HIV infection that could explain the findings. Methods to rule out such concurrent illness and conditions must include cerebrospinal fluid examination and either brain imaging (computed tomography or magnetic resonance) or autopsy.

Herpes simplex: chronic ulcer(s) of more than one month's duration, bronchitis, pneumonitis or oesophagitis – definitive diagnosis only

Microscopy (histology or cytology), culture or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

Histoplasmosis, disseminated or extrapulmonary – definitive diagnosis only

Microscopy (histology or cytology), culture or detection of antigen in a specimen obtained directly from the tissues affected or a fluid from those tissues.

Isosporiasis, chronic intestinal, of more than one month's duration – definitive diagnosis only

Microscopy (histology or cytology).

Kaposi's sarcoma – definitive or presumptive diagnosis

Definitive diagnosis:

(i) Microscopy (histology or cytology).

Presumptive diagnosis:

(i) A characteristic gross appearance of an erythematous or violaceous plaque-like lesion on skin or mucous membrane. Note: Presumptive diagnosis of Kaposi's sarcoma should not be made by clinicians who have seen few cases of it.

Lymphoma, Burkitt's – definitive diagnosis only

Microscopy (histology or cytology).

Lymphoma, immunoblastic – definitive diagnosis only

Microscopy (histology or cytology).

Lymphoma, primary, of brain – definitive diagnosis only

Microscopy (histology or cytology).

***Mycobacterium tuberculosis* complex, any site, pulmonary or extrapulmonary – definitive or presumptive diagnosis**

Definitive diagnosis:

(i) Isolation (or culture if preferred terminology) of Mycobacterium tuberculosis, Mycobacterium bovis or Mycobacterium africanum from a clinical specimen.

Presumptive diagnosis:

(i) Demonstration of acid-fast bacilli in a clinical specimen or in a histopathological lesion when a culture is not available, in a person with signs or symptoms compatible with tuberculosis; or evidence of resolution of disease where treatment with two or more antituberculosis medications have been prescribed and follow-up has been instigated.

Non-tuberculosis mycobacterial disease, disseminated or extrapulmonary – definitive or presumptive diagnosis

Definitive diagnosis:

(i) Culture

Presumptive diagnosis:

(i) Microscopy of a specimen from normally sterile body fluids, or tissue from a site other than lungs, skin or cervical or hilar lymph nodes that shows acid-fast bacilli of a species not identifiable by culture, in a person with signs, symptoms or immunological profile compatible with disseminated disease.

Pneumocystis jirovecii (formerly Pneumocystis carinii) pneumonia – definitive or presumptive diagnosis

Definitive diagnosis:

(i) Microscopy (histology).

Presumptive diagnosis:

(i) a history of dyspnoea on exertion or non-productive cough of recent onset (with in the past three months);

AND

(ii) Chest x-ray evidence of diffuse bilateral interstitial infiltrates or evidence by gallium scan of diffuse bilateral pulmonary disease;

AND

(iii) Arterial blood gas analysis showing an arterial pO2 of <70mm Hg or a low respiratory diffusing capacity (<80% of predicted values) or an increase in the alveolar-arterial oxygen tension gradient;

AND

(iv) No evidence of a bacterial pneumonia.

Pneumonia, recurrent bacterial – definitive or presumptive

Definitive diagnosis:

(a) Two or more episodes occurring within a 12 month interval, of acute (new x-ray evidence, not present earlier) pneumonia. Both episodes must have culture (or other organism specific diagnostic method) proven infection with a pathogen that typically causes pneumonia (other than Pneumocystis carinii or Mycobacterium tuberculosis) and radiological evidence of pneumonia.

Presumptive diagnosis:

(i) Two or more episodes occurring within a 12 month interval of acute (new symptoms, signs or x-ray evidence not present earlier) pneumonia, based on clinical or radiological evidence.

Progressive multifocal leukoencephalopathy – definitive diagnosis only

Microscopy (histology or cytology).

Salmonella septicemia, recurrent – definitive diagnosis only

Culture proven infection with Salmonella species.

Toxoplasmosis – definitive or presumptive diagnosis

Definitive diagnosis:

(i) Microscopy (histology or cytology).

Presumptive diagnosis:

Toxoplasmosis of brain

(i) Recent onset of a focal neurological abnormality consistent with intracranial disease or a reduced level of consciousness;

AND

(ii) Evidence by brain imaging (computed tomography or nuclear magnetic resonance) of a lesion having a mass effect or the radiographical appearance of which is enhanced by injection of contrast medium;

AND

(iii) Serum antibody to toxoplasmosis or successful response to therapy for toxoplasmosis.

Wasting syndrome due to HIV infection – definitive diagnosis only

Findings of profound involuntary weight loss of >10% of baseline body weight plus either chronic diarrhoea (at least two loose stools per day for ≥ 30 days), or chronic weakness and documented fever (for ≥ 30 days, intermittent or constant) in the absence of a concurrent illness or condition other than HIV infection that could explain the findings (for example cancer, tuberculosis, cryptosporidiosis or other specific enteritis).

Bacterial infection affecting a child less than 13 years of age – definitive diagnosis only

Laboratory diagnosis of multiple or recurrent bacterial infection (any combination of at least two within a two-year period) of the following types: septicaemia, pneumonia, meningitis, bone or joint infection, or abscess of an internal organ or body cavity (excluding otitis media or superficial skin or mucosal abscesses), caused by Haemophilus, Streptococcus (including Pneumococcus) or other pyogenic bacteria.

Lymphoid interstitial pneumonia and/or pulmonary lymphoid hyperplasia affecting a child less than 13 years of age – definitive or presumptive diagnosis

Definitive diagnosis:

(i) Microscopy (histology or cytology).

Presumptive diagnosis:

Lymphoid interstitial pneumonia – bilateral reticulonodular interstitial pulmonary infiltrates present on chest x-ray for two months or more, with no pathogen identified and no response to antibiotic treatment. Other causes of interstitial infiltrates should be excluded, such as tuberculosis, Pneumocystis carinii pneumonia, cytomegalovirus infection or other viral or parasitic infections.

Appendix F – HIV/AIDS notification forms

See next page

Kirby Institute | UNSW AUSTRALIA

Office use only

State number

National HIV number

Notification of laboratory confirmed HIV infection

Confidential form revised : April 2015

1 Notifying doctor

Name

Address

Telephone Facsimile

2 Identification of the person with newly diagnosed HIV infection

Family name (First two letters only)

Given name (First two letters only)

Date of birth / /
(DD/MM/YYYY)

Sex ◯ Male ◯ Female ◯ Transgender

Postcode of usual place of residence:

3 Laboratory diagnosis of HIV infection

3.1 Laboratory number:

3.2 Date of specimen collection for this diagnosis of HIV infection: / / (DD/MM/YYYY)

3.3 HIV type: ◯ HIV-1 ◯ HIV-2 ◯ HIV-1 & HIV-2

3.4 Laboratory evidence of newly acquired HIV infection?

◯ No ◯ Yes, proviral DNA/p24 antigen/virus
◯ Yes, evolving western blot[1]

3.5 CD4+ cell count:
(Measured within 3 months of HIV diagnosis) cells/µl

4 Other characteristics of the person with newly diagnosed HIV infection

4.1 Country of birth ◯ Australia ◯ Other (Specify)

If ***Other*** country, state year of arrival in Australia:

4.2 Is the person of Aboriginal or Torres Strait Islander origin?

◯ No ◯ Yes, Aboriginal ◯ Yes, Torres Strait Islander

For persons of ***both Aboriginal and Torres Strait Islander*** origin, mark both "Yes" circles.

What language does the person mostly speak at home?

◯ English ◯ Other (Specify)

5 Why was the person tested for HIV antibody?

(Tick as many circles as appropriate)

◯ Reported risk behaviour for HIV infection
◯ Investigation of clinical symptoms suggestive of HIV infection
◯ Confirmation of a previous diagnosis of HIV infection
◯ Partner with diagnosed HIV infection
◯ Screening for sexually transmissible infections
◯ Screening immigration
◯ Screening associated with pregnancy
◯ Other (Specify)

6 What was the clinical status of the person at the date of specimen collection for this HIV diagnosis?

(Tick the appropriate circles)

◯ Symptoms consistent with primary HIV infection (HIV seroconversion illness)[2]
◯ Asymptomatic
◯ AIDS
◯ Other symptoms (Specify)
◯ Deceased *(Please **complete question 10 overleaf**)*

Does the person report a history of symptoms consistent with primary HIV infection?

◯ Yes ◯ No

If ***Yes,*** date of onset of symptoms / /
(DD/MM/YYYY)

7 HIV antibody testing history

7.1 Has the person had a previous HIV antibody test?

◯ Yes ◯ No ◯ Not reported

If ***Yes,*** when was the last HIV antibody test?

Date of last test (DD/MM/YYYY) / /

What was the result of the last HIV antibody test?

◯ Negative ◯ Indeterminate ◯ Positive

Who reported the result of the last antibody test?

◯ Person ◯ Doctor ◯ Laboratory

7.2 If applicable, when was the first ever diagnosis of HIV infection in Australia? / /
(DD/MM/YYYY)

Specify the State/Territory of first ever HIV diagnosis in Australia:

7.3 If applicable, when was the first ever diagnosis of HIV infection overseas? / /
(DD/MM/YYYY)

Specify the country of first ever HIV diagnosis overseas:

(Continued over page…)

8 HIV exposure history

Please indicate the person's reported exposure history by ticking the appropriate circles

8.1 **Sexual exposure** (One circle must be ticked)

- ◯ Sexual contact with person of same sex
- ◯ Sexual contact with both sexes
- ◯ Sexual contact only with person of opposite sex *(Please **complete question 8.2**)*
- ◯ No sexual contact
- ◯ Sexual exposure not reported

8.2 Complete this question only if heterosexual contact was a potential source of exposure to HIV

Heterosexual contact with: (Tick all appropriate circles)

- ◯ Man who has had sex with men
- ◯ Injecting drug user
- ◯ Recipient of blood/tissue
- ◯ Person with haemophilia/coagulation disorder
- ◯ Person from a country other than Australia
  (Specify the country) _____

Date of most recent heterosexual contact with this person: ___/___/___
(DD/MM/YYYY)

Did heterosexual contact with this person occur in Australia?

◯ Yes ◯ No ◯ Not reported

- ◯ Person with diagnosed HIV infection
  (Specify the partner's exposure) _____
- ◯ Heterosexual contact, not further specified

8.3 **Blood exposure** (Tick all appropriate circles)

- ◯ Injecting drug use
- ◯ Receipt of blood/tissue – Year blood/tissue received : ☐☐☐☐ (YYYY)
- ◯ Haemophilia/coagulation disorder

8.4 **Mother-to-child transmission**

- ◯ Mother-to-child HIV transmission

8.5 Other source of exposure to HIV (Specify) _____

8.6 Undetermined exposure

- ◯ Source of exposure to HIV remains unclear or undetermined

(Detail) _____

Where was HIV infection most likely to have been acquired?

◯ Australia ◯ Overseas ◯ Not known

10 Current status of person

10.1 ◯ Person is alive
Date of most recent contact ___/___/___
(DD/MM/YYYY)

10.2 ◯ Person has died
Date of death ___/___/___
(DD/MM/YYYY)

What was the cause of death?

- ◯ AIDS defining illness
- ◯ Non-AIDS defining cancer
- ◯ Heart or vascular disease
- ◯ Suicide
- ◯ Accidental
- ◯ Drug overdose
- ◯ Liver disease
- ◯ Not reported
- ◯ Other cause (Specify) _____

Source of information on the death:

- ◯ Doctor
- ◯ State/Territory
- ◯ Other (Specify) _____

***If you require assistance** with contact tracing or any other aspect of public health management of the person with HIV infection, please contact your local Area Health Service or Sexual Health Clinic.*

Notification forms are available at www.kirby.unsw.edu.au

Footnotes

1 Evolving western blot: typical evolution of HIV specific antibodies detected by western blot in consecutive specimens consistent with primary HIV infection (incremental reactivity to gag, pol and envelope proteins of HIV-1).

2 Primary HIV infection occurs 2– 4 weeks following exposure to HIV, and is characterized by fever, lethargy, anorexia, pharyngitis, headaches, myalgias and arthralgias and lymphadenopathy.

State/Territory health authority use only

Date form forwarded to Doctor ___/___/___
(DD/MM/YYYY)

Date form received at State/Territory Health Authority ___/___/___
(DD/MM/YYYY)

Date forwarded to Kirby Institute ___/___/___
(DD/MM/YYYY)

Please return the completed form to the Area Health Service at the address below

Kirby Institute | UNSW AUSTRALIA

Notification of AIDS

Office use only

State number

National HIV number

National AIDS number

Confidential form revised : April 2015

1 Notifying doctor

Name

Address

Hospital/Clinic name
(If appropriate)

2 Identification of the person with AIDS

Family name (First two letters only)

Given name (First two letters only)

Date of birth / /
(DD/MM/YYYY)

Sex ◯ Male ◯ Female ◯ Transgender

3 Other characteristics of the person with AIDS

Country of birth ◯ Australia
◯ Other

If ***Other,*** state year of arrival in Australia

Is the person of Aboriginal or Torres Strait Islander origin?

◯ No ◯ Yes, Aboriginal ◯ Yes, Torres Strait Islander

For persons of ***both Aboriginal and Torres Strait Islander*** origin, mark both "Yes" circles.

What language does the person mostly speak at home?

◯ English ◯ Other (Specify)

Postcode of usual place of residence

Current status of person

◯ Person is alive
Date of most recent contact / /
(DD/MM/YYYY)

◯ Person has died
Date of death / /
(DD/MM/YYYY)

4 Laboratory tests

CD4+ count at AIDS diagnosis
cells/ µl

Date of specimen collection for measurement of CD4+ count / /
(DD/MM/YYYY)

HIV viral load at AIDS diagnosis
copies/ml

Date of specimen collection for measurement of viral load / /
(DD/MM/YYYY)

5 Antiretroviral therapy

Prior to AIDS, was the person treated with antiretroviral therapy?

◯ Yes ◯ No ◯ Not known

6 Diagnosis of AIDS in Australia

Date of AIDS[1] diagnosis in Australia / /
(DD/MM/YYYY)

Date of first diagnosis of HIV infection / /
(DD/MM/YYYY)

Has the person been previously diagnosed with AIDS elsewhere?

◯ Yes ◯ No ◯ Not known

If ***YES*** and diagnosis was in another State/Territory, specify

If ***YES*** and diagnosis was overseas, specify country

7 Diseases indicative of AIDS

(At least one must be ticked)

	Definitive	Presumptive
Pneumocystis jiroveci (carinii) pneumonia	◯	◯
Oesophageal candidiasis	◯	◯
Kaposi's sarcoma		
Site	◯	◯
Herpes simplex: chronic ulcer(s) of more than one month's duration, bronchitis, pneumonitis, oesophagitis		
Site	◯	
Cryptococcosis, extrapulmonary		
Site	◯	
Cryptosporidiosis, of more than one month's duration	◯	
Toxoplasmosis		
Site	◯	◯
Cytomegalovirus retinitis, with loss of vision		
Site	◯	◯
Mycobacterium tuberculosis complex		
– Pulmonary	◯	◯
– Extrapulmonary	◯	◯
Non-tuberculosis mycobacterial disease, disseminated or extrapulmonary	◯	◯

Question 7 continued next page

7 Diseases indicative of AIDS (Continued)

Definitive Presumptive

(At least one box for Question 7 must be ticked)

Non–Hodgkin's lymphoma, primary of brain/CNS ◯

Non–Hodgkin's lymphoma, other site ◯

(Type) ◯ Large cell/Immunoblastic

◯ Burkitt's

◯ Other (Specify) _____

HIV encephalopathy
(includes AIDS Dementia Complex) ◯

HIV wasting syndrome ◯

Invasive cervical cancer ◯

Recurrent bacterial pneumonia
(2 or more episodes in 1 year) ◯ ◯

Other _____

8 HIV exposure history

Please indicate the person's reported exposure history by ticking the appropriate circles

8.1 Sexual exposure (One circle must be ticked)

◯ Sexual contact with person of same sex

◯ Sexual contact with both sexes

◯ Sexual contact only with person of opposite sex
*(Please **complete question 8.2**)*

◯ No sexual contact

◯ Sexual exposure not reported

8.2 Complete this question only if heterosexual contact was a potential source of exposure to HIV

Heterosexual contact with: (Tick all appropriate circles)

◯ Man who has had sex with men

◯ Injecting drug user

◯ Recipient of blood/tissue

◯ Person with haemophilia/coagulation disorder

◯ Person from a country other than Australia
(Specify the country) _____

Date of most recent heterosexual contact with this person: / /
(DD/MM/YYYY)

Did heterosexual contact with this person occur in Australia?

◯ Yes ◯ No ◯ Not reported

◯ Person with diagnosed HIV infection
(Specify the partner's exposure) _____

◯ Heterosexual contact, not further specified

8.3 Blood exposure (Tick all appropriate circles)

◯ Injecting drug use

◯ Receipt of blood/tissue
– Year blood/tissue received : ☐☐☐☐
(YYYY)

◯ Haemophilia/coagulation disorder

8.4 Mother-to-child transmission

◯ Mother-to-child HIV transmission

8.5 Other source of exposure to HIV (Specify)

_____

8.6 Undetermined exposure

◯ Source of exposure to HIV remains unclear or undetermined

(Detail) _____

_____

_____

9 Where was HIV infection most likely to have been acquired?

◯ Australia ◯ Overseas ◯ Not known

Footnotes

1 Communicable Diseases Network Australia 2004. Interim surveillance case definitions for the Australian national notifiable diseases surveillance system. Communicable Diseases Australia, Australian Government Department of Health and Ageing, Canberra ACT 2004. http://www.health.gov.au/internet/wcms/publishing.nsf/Content/cda-surveil-nndss-casedefs-distype.htm

2 Notification forms are available at www.kirby.unsw.edu.au

State/Territory health authority use only

☐☐☐ State/Territory ☐☐ Initials of State/Territory Officer

Date notification received at State/Territory Health Authority / /
(DD/MM/YYYY)

Date forwarded to Kirby Institute / /
(DD/MM/YYYY)

Kirby Institute | UNSW AUSTRALIA

Office use only

☐☐☐
Kirby Institute number

Notification of blood donor with HIV infection

Confidential form revised : April 2015

1 Blood Bank information

State/Territory ☐☐☐

Contact person

Name

Address

Telephone Facsimile

2 Site of donation

Site of donation found to have HIV antibody

(Specify)

Postcode of site of donation (If available) ☐☐☐☐

◯ Tick if donation was at a mobile unit

3 Donor identification

Internal Blood Transfusion Service Code

☐☐☐☐☐☐☐☐☐☐☐☐

Date of birth / /

(DD/MM/YYYY)

Sex ◯Male ◯Female ◯Transgender

Place of residence at time of donation found to have HIV antibody

(Specify)

Postcode of residence at time of donation found to have HIV antibody (If available) ☐☐☐☐

4 Donation history

Date of first recorded donation

☐☐ ☐☐☐☐
Month Year

Date of first recorded donation since 1 May 1985

☐☐ ☐☐☐☐
Month Year

Years donated (Tick the appropriate year(s))

◯Prior to 2000 (Specify year of donation) ☐☐☐☐

◯2000 ◯2001 ◯2002 ◯2003 ◯2004

◯2005 ◯2006 ◯2007 ◯2008 ◯2009 ◯2010

Date of donation found to have HIV antibody / /

(DD/MM/YYYY)

Date of last donation prior to the one which had HIV antibody

☐☐ ☐☐☐☐
Month Year

5 Information on exposure

◯Elicited by interview with Blood Transfusion Service Personnel

◯Provided by doctor to whom donor was referred

◯Donor not interviewed

◯Donor could not be traced following last donation

◯Other

(Specify)

6 HIV exposure category*

More than one exposure category may be ticked.

◯Sexual contact with person of same sex (Male donors only)

◯Sexual contact with person of opposite sex**

(Detail)

◯Blood transfusion, blood components or tissue recipient

(Detail)

◯Injecting drug use

(Detail)

◯Person from a high prevalence country***

(Specify Country)

◯Donor interviewed with regard to exposure category, but none of the above apply

(Detail)

◯Donor not interviewed with regard to exposure category

(Detail)

Footnotes

* Where detail is requested, please supply available information that may be relevant. For example, under 6 – Blood transfusion, give date of transfusion or other procedure.

** Where donor reports SEXUAL CONTACT WITH PERSON OF OPPOSITE SEX only, specify any information that may be available on sexual partners with or at risk of HIV infection.

In particular, specify a sexual partner who was reported as bisexual, an injecting drug user, a person with haemophilia/coagulation disorder, a recipient of blood transfusion, blood components or tissue, or from a country where HIV is endemic (give country)***

*** Includes countries of sub–Saharan Africa, the Caribbean and Thailand, Cambodia and Myanmar.

Please return password protected completed forms to:

Skye McGregor
The Kirby Institute, UNSW
Email: smcgregor@kirby.unsw.edu.au
Telephone: (02) 9385 0900 Facsimile: (02) 9385 0920

Australian Paediatric Surveillance Unit and the

Kirby Institute | UNSW AUSTRALIA

Child with HIV infection or perinatal exposure to HIV

Office use only

State number | National number

Confidential form revised : April 2015

1 Notifying doctor

APSU code for notifying doctor

Name

Month/year of report to APSU (Month) (Year)

2 Identification of the child

5

Family name (First two letters only)

Given name (First two letters only)

Date of birth / /
(DD/MM/YYYY)

Sex ◯ Male ◯ Female

3 Other characteristics of the child

Country of birth ◯ Australia ◯ Other

If the child was ***born in Australia,*** in which State/Territory was the child born?

Birthweight: _____ grams Gestational age: _____ weeks

If the child was ***born overseas,*** state year of arrival in Australia

State/Territory of residence of the child

Is the child of Aboriginal or Torres Strait Islander descent?

◯ No ◯ Yes, Aboriginal ◯ Yes, Torres Strait Islander

For persons of ***both Aboriginal and Torres Strait Islander*** descent, tick both "Yes" circles.

What language does the child mostly speak at home?

◯ English ◯ Other (Specify):

4 Exposure to HIV

At least one box must be ticked

◯ Child was born to woman with diagnosed HIV infection

◯ Other exposure (Specify)

If the child ***is primarily cared for by another clinician who you believe will report the case and could provide additional details,*** please complete Questions 1, 2, 3 and 4 above and then write the primary clinician's name in the space below. Could you return the partially completed form to the National Centre in HIV Epidemiology and Clinical Research at the address given below.

Primary clinician caring for the child:

Name

Hospital

Perinatal exposure to HIV

To be completed only if the child was born to a woman with HIV infection

Was the child treated with antiretroviral therapy before her/his HIV infection status was known?

◯ Yes ◯ No ◯ Not known

If ***Yes,*** date of commencement of therapy
(DD/MM/YYYY) / /

Was the child treated with prophylactic therapy before her/his HIV infection status was known?

◯ Yes ◯ No ◯ Not known

If ***Yes,*** date of commencement of therapy
(DD/MM/YYYY) / /

6 Child's HIV infection status

When was the child last tested for HIV infection?
(DD/MM/YYYY) / /

What was the result of the last test?

◯ Not infected ◯ Undetermined
◯ Infected ◯ Not known

If the child has HIV infection:

When was the first diagnosis of HIV infection in Australia?
(DD/MM/YYYY) / /

What was the child's CD4+ count at first HIV diagnosis? (cells/μl)

What was the child's viral load at first HIV diagnosis? (RNA copies/ml)

7 Current status of the child

◯ Child is alive
Date of most recent contact (DD/MM/YYYY) / /

◯ Child has died
Date of death (DD/MM/YYYY) / /

Information is sought on the child's mother and her risk factors for perinatal HIV transmission.

Would you either:

Complete the enclosed questionnaire on the child's mother;
or Complete the section "Child born to the woman with HIV infection" of the enclosed questionnaire and forward to the doctor providing the mother's HIV care. **Thank you**

Footnotes

1 Communicable Diseases Network Australia. Interim surveillance case definitions for the Australian National Notifiable Diseases Surveillance System, Version 1, 1 January 2004. Australian Government Department of Health and Ageing, Canberra, ACT. 2004. Internet address: http://www.health.gov.au

Return completed password protected form to:

Skye McGregor
The Kirby Institute, UNSW
Tel: 02 9385 0900 Fax: 02 9385 0920
Email: smcgregor@kirby.unsw.edu.au Website: www.kirby.unsw.edu.au

Australian Paediatric Surveillance Unit and the

Kirby Institute | UNSW AUSTRALIA

Mother with perinatally exposed children

Office use only

State number | National number

Confidential form revised : April 2015

Information is sought on the mother with perinatally exposed children and her risk factors for perinatal HIV transmission

1 Identification of the mother with HIV infection

Family name (First two letters only)

Given name (First two letters only)

Date of birth / /
(DD/MM/YYYY)

Child born to the mother with HIV infection

The child indicated below was notified through the Australian Paediatric Surveillance Unit as having been born to the mother with HIV infection

Family name (First two letters only)

Given name (First two letters only)

Date of birth / /
(DD/MM/YYYY)

Sex ◯ Male ◯ Female

2 Other characteristics of the mother with HIV infection

Country of birth ◯ Australia
◯ Other

If ***Other,*** state year of arrival in Australia

Does the mother self-identify as Aboriginal or Torres Strait Islander?

◯ No ◯ Yes, Aboriginal ◯ Yes, Torres Strait Islander

Does the father self-identify as Aboriginal or Torres Strait Islander?

◯ No ◯ Yes, Aboriginal ◯ Yes, Torres Strait Islander

For person of ***both Aboriginal and Torres Strait Islander*** status, tick both "Yes" circles.

State/Territory of residence

Postcode of usual place of residence

What language does the mother mostly speak at home:

◯ English
◯ Other (Specify):

Current status of the mother

◯ Mother is alive
Date of most recent contact / /
(DD/MM/YYYY)

◯ Mother has died
Date of death / /
(DD/MM/YYYY)

3 Diagnosis of HIV infection

Date of first diagnosis of HIV infection in Australia
(DD/MM/YYYY) / /

CD4+ count at diagnosis of HIV infection
(cells/µl)

4 Exposure to HIV

◯ Injecting drug use
◯ Receipt of blood/tissue
Date of receipt (DD/MM/YYYY) / /

Heterosexual contact with:

◯ Man who has had sex with men
◯ Injecting drug user
◯ Recipient of blood/tissue
◯ Person with haemophilia/coagulation disorder
◯ Person from a country other than Australia
Specify the country:
◯ Person with diagnosed HIV infection
(Specify the person's exposure)
◯ Heterosexual contact, not further specified

◯ Other exposure
(Specify)

◯ Source of exposure to HIV remains unclear or undetermined
(Details)

Where was HIV infection most likely to have been acquired?

◯ Australia ◯ Overseas ◯ Not known

5 Perinatal exposure to HIV

How was pregnancy achieved for the child reported above?

- ◯ Not known
- ◯ Unprotected sexual intercourse with an HIV infected partner
- ◯ Unprotected sexual intercourse with an uninfected partner
- ◯ Assisted reproduction
  (Specify) _____

Has the mother had other exposed children born or breast-fed in Australia prior to the child reported above?

◯ Yes ◯ No ◯ Not known

If ***Yes,*** has perinatal exposure to HIV been documented for the other children?

◯ Yes ◯ No ◯ Not known

Mode of delivery of the child

- ◯ Not known
- ◯ Vaginal delivery
- ◯ Elective caesarean
- ◯ Emergency caesarean

If delivery was by ***emergency caesarean,*** specify the reasons for the emergency caesarean:

_____

_____

_____

Duration of ruptured membranes

- ◯ No rupture of membranes
- ◯ Less than 4 hours
- ◯ 4 hours or longer
- ◯ Not known

Was the child breast-fed?

◯ Yes ◯ No ◯ Not known

If ***Yes,*** for how long was the child breast-fed?_____(weeks)

Complete the remainder of Section 5 if the mother was diagnosed with HIV infection prior to delivery of the child.

Was the mother treated with any antiretroviral therapy during pregnancy?

◯ Yes ◯ No ◯ Not known

If ***Yes,*** please report the antiretroviral agent and date of commencement of treatment.

If the mother stopped any antiretroviral treatment prior to delivery, please report the stop date.

	Antiretroviral agent	Commencement date	Stop date
1	_____	/ /	/ /
2	_____	/ /	/ /
3	_____	/ /	/ /
4	_____	/ /	/ /
5	_____	/ /	/ /

Please report any adverse events associated with antiretroviral use during pregnancy:

_____

_____

Mother's CD4+ count close to delivery of the child

☐☐☐☐
(cells/µl)

Date of specimen collection for the measurement of CD4+ cell count / /
(DD/MM/YYYY)

Mother's viral load close to delivery of the child

☐☐☐☐☐☐☐
(RNA copies/ml)

Date of specimen collection for the measurement of HIV viral load

_____ / /
(DD/MM/YYYY)

Did the mother receive intra-partum antiretroviral therapy?

◯ Yes ◯ No ◯ Not known

If ***Yes,*** specify the antiretroviral therapy

_____

_____

Footnotes

1 High prevalence countries are countries in sub-Saharan Africa, the Caribbean and specified countries in South East Asia (Cambodia, Myanmar (Burma) and Thailand), where HIV is transmitted predominantly by heterosexual contact.

2 Communicable Diseases Network Australia. Interim surveillance case definitions for the Australian National Notifiable Diseases Surveillance System, Version 1, 1 January 2004. Australian Government Department of Health and Ageing, Canberra, ACT. 2004. Internet address: http://www.health.gov.au

Return completed password protected form to:

Skye McGregor
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Tel: 02 9385 0900 Fax: 02 9385 0920
Email: smcgregor@kirby.unsw.edu.au
Website: www.kirby.unsw.edu.au

Kirby Institute | UNSW AUSTRALIA

Office use only

State number | National number

Notification of death in a person with HIV infection

Confidential form revised : April 2015

1 Patient identification

Family name (First two letters only)

Given name (First two letters only)

Date of birth / /
(DD/MM/YYYY)

Sex ◯ Male ◯ Female ◯ Transgender

Hospital/Clinic Code (Optional)

Postcode of current residence

2 Source of information on death

(more than one may be ticked)

◯ Treating Doctor

Name

Address

Hospital/Clinic name (If appropriate)

◯ State/Territory Register of Death

◯ Other (Specify)

3 Information on death

Date of death / /
(DD/MM/YYYY)

Had the person been diagnosed with AIDS?

◯ Yes ◯ No ◯ Not known

Was the cause of death an illness related to AIDS?

◯ Yes ◯ No

*If the cause of death was **not due to AIDS**, indicate the other cause of death*

◯ Not reported
◯ Accidental
◯ Cancer
◯ Drug overdose
◯ Heart or vascular disease
◯ Liver disease
◯ Suicide
◯ Other cause
(Specify)

Return completed password protected form to:

Skye McGregor
The Kirby Institute, UNSW
Tel: 02 9385 0900 Fax: 02 9385 0920
Email: smcgregor@kirby.unsw.edu.au
Website: www.kirby.unsw.edu.au

State/Territory health authority use only

State/Territory | Initials of State/Territory Officer

Date notification received at State/Territory Health Authority / /
(DD/MM/YYYY)

Date forwarded to Kirby Institute / /
(DD/MM/YYYY)

Appendix G – Dataset specifications

The data dictionary for cases of newly diagnosed HIV infection entered into the National HIV Registry is described below.

National HIV Registry Dataset Specifications – Version 1

Version	Date	Revised by	Changes
1	12 February 2016	Skye McGregor	Version 1 of National HIV Registry dataset specifications

FIELD SUMMARY INDEX

18.	REGION OF DIAGNOSIS	66	Identification of region of previous HIV diagnosis
19.	DATE OF PREVIOUS DIAGNOSIS	67	Date of previous overseas HIV diagnosis
20.	HIV TYPE	67	Identification of HIV type
21.	SPECIMEN COLLECTION DATE FOR HIV	67	Date when laboratory specimen for HIV diagnosis for case was taken
22.	AGE AT HIV DIAGNOSIS	68	The age of the case at diagnosis
23.	LABORATORY NUMBER	68	The laboratory number allocated at the time of specimen processing
24.	CLINIC NUMBER	68	The clinic number allocated at the time of specimen processing
25.	VIRAL LOAD	69	The HIV viral load of the case
26.	DATE OF VIRAL LOAD	69	The date of viral load testing of the case
27.	CD4+ CELL COUNT	69	CD4+ cell count of the case
28.	CD4 DATE	70	The date of CD4+ testing for the case
29.	EXPOSURE	70	The reported exposure risk for the case
30.	COUNTRY OF BIRTH OF SEXUAL PARTNER	72	The country of birth of the sexual partner
31.	REGION OF BIRTH OF SEXUAL PARTNER	72	The region of birth of the sexual partner
32.	DATE OF LAST NEGATIVE HIV TEST	73	Date of the most recent negative HIV test
33.	DATE OF ONSET OF PRIMARY HIV INFECTION	73	Date of the onset of symptoms of primary HIV infection
34.	DATE OF INDETERMINATE WESTERN BLOT	74	Date of indeterminate Western Blot result
35.	SOURCE OF TESTING HISTORY	74	Source of testing history
36.	REASON FOR HIV TEST	74	Reason the case was tested for HIV
37.	CLINICAL STATUS AT DATE OF SPECIMEN COLLECITON FOR HIV DIAGNOSIS	75	The clinical status of the case at the time of specimen collection for HIV test

38.	PLACE OF ACQUISITION	76	Likely place of acquisition of HIV
39.	HIV SUBTYPE	76	Subtype of HIV
40.	DATE OF LAST CONTACT	77	If a previously notified case is subsequently seen in another State/Territory, the date of contact is recorded
41.	STATE/TERRITORY OF LAST CONTACT	77	If a previously notified case is subsequently seen in another State/Territory, the State/Territory of contact is recorded
42.	STATE/TERRITORY NUMBER OF LAST CONTACT	78	If a previously notified case is subsequently seen in another State/Territory, the State/Territory number of the case is recorded
43.	DATE OF DEATH	78	Date of death of previously notified case
44.	STATE/TERRITORY OF DEATH	78	State/Territory of death of previously notified case
45.	STATE/TERRITORY DEATH NUMBER	79	Unique State/Territory identifier for death of previously notified case
46.	CAUSE OF DEATH	79	Case of death of previously notified case

FIELD DETAILED INDEX

1. FAMILY NAME

NHR field:	FAMILY_NAME
Aliases:	
Details:	The first two letters of the surname of the case
Data type:	ALPHANUMERIC TEXT (maximum 2 characters)
Data domain:	Any sequence of alphanumeric characters
Further information:	The FAMILY NAME is used to create a 2x2 namecode for the person being notified Where unknown, the field is left blank

2. GIVEN NAME

NHR field:	GIVEN_NAME
Aliases:	
Details:	The first two letters of the given (first) name of the case
Data type:	ALPHANUMERIC TEXT (maximum 2 characters)
Data domain:	Any sequence of alphanumeric characters
Further information:	The GIVEN NAME is used to create a 2x2 namecode for the person being notified Where unknown, the field is left blank

3. ALSO KNOWN AS FAMILY NAME

NHR field:	ALSO_KNOWN_AS_FAMILY_NAME
Aliases:	
Details:	The first two letters of the alternative family (surname) name of the case
Data type:	ALPHANUMERIC TEXT (maximum 4 characters)
Data domain:	Any sequence of alphanumeric characters

Further information:	

4. ALSO KNOWN AS GIVEN NAME

NHR field:	**ALSO_KNOWN_AS_GIVEN_NAME**
Aliases:	
Details:	The first two letters of the alternative given (first) name of the case
Data type:	ALPHANUMERIC TEXT (maximum 4 characters)
Data domain:	Any sequence of alphanumeric characters
Further information:	Where unknown, the field is left blank

5. SEX

NHR field:	**SEX**
Aliases:	
Details:	A single character field indicating the current sex of the individual
Data type:	NUMERIC, INTEGER
Data domain:	1 = Male 2 = Female 3 = Transgender 0 = Not reported
Further information:	The default value for the sex of the case is 0 = not reported Where unknown, the field is left blank

6. DATE OF BIRTH

NHR field:	**DATE_OF_BIRTH**
Aliases:	DOB
Details:	The date of birth of the case
Data type:	DATE (DD/MM/YYYY)
Data domain:	A valid full century date

	Where unknown, field is blank
Further information:	**Mandatory field** If the case was diagnosed at death and the exact date of birth is unknown, the date of birth is entered as 1 January of the estimated year of birth, as reported by the coroner

7. COUNTRY OF BIRTH

NHR field:	**COUNTRY_OF_BIRTH**
Aliases:	COB
Details:	The country of birth of the case
Data type:	NUMERIC, INTEGER
Data domain:	Country of birth is recorded using the Standard Australian Classification of Countries (SACC) code (Australian Bureau of Statistics 1998) and displayed as text
Further information:	Where unknown, the field is left blank

8. REGION OF BIRTH

NHR field:	**REGION_OF_BIRTH**
Aliases:	ROB
Details:	The region of birth of the case
Data type:	NUMERIC, INTEGER
Data domain:	Region of birth is automatically generated from the COUNTRY OF BIRTH using the Standard Australian Classification of Countries (SACC) code (Australian Bureau of Statistics 1998) and displayed as text
Further information:	Where unknown, the field is left blank

9. YEAR OF ARRIVAL IN AUSTRALIA

NHR field:	**YEAR_OF_ARRIVAL_IN_AUSTRALIA**
Aliases:	
Details:	The year of arrival for cases born outside Australia

Data type:	DATE (YYYY)
Data domain:	A valid full century date Where unknown, the field is left blank
Further information:	

10. INDIGENOUS STATUS

NHR field:	**INDIGENOUS_STATUS**
Aliases:	
Details:	A single character field indicating the Aboriginal and Torres Strait Islander status of the individual.
Data type:	NUMERIC, INTEGER
Data domain:	1 = Non-Indigenous 2 = Aboriginal 3 = Torres Strait Islander 4 = Both Aboriginal and Torres Strait Islander 0 = Not reported
Further information:	ABORIGINAL AND TORRES STRAIT ISLANDER STATUS was added to notification forms in 1985 in the NT, QLD, SA, Tas, and WA; in 1992 in NSW and the ACT; and in 1998 in Vic. Default value is 0 = Not reported

11. NATIONAL HIV NUMBER

NHR field:	**NATIONAL_HIV_NUMBER**
Aliases:	
Details:	A automatically generated unique National HIV number is assigned to each new case entered onto the National HIV Registry
Data type:	NUMERIC, INTEGER
Data domain:	
Further information:	**Mandatory field**

12. LANGUAGE SPOKEN AT HOME

NHR field:	**LANGUAGE_SPOKEN_AT_HOME**
Aliases:	
Details:	Language spoken at home of the case
Data type:	NUMERIC, INTEGER
Data domain:	Language spoken at home is recorded using the Australian Standard Classification of languages (ASCL) code (Australian Bureau of Statistics, 2nd edition, 2005) and displayed as text Where unknown, the field is left blank
Further information:	

13. STATE/TERRITORY

NHR field:	**STATE_TERRITORY**
Aliases:	
Details:	The State or Territory which notifies the case
Data type:	NUMERIC, INTEGER
Data domain:	1 = ACT 2 = NSW 3 = NT 4 = QLD 5 = SA 6 = TAS 7 = VIC 8 = WA 0 = not reported
Further information:	**Mandatory field**

14. STATE/TERRITORY NUMBER

NHR field:	STATE_TERRITORY_NUMBER
Aliases:	
Details:	A notification identifier that is unique within the specified State or Territory
Data type:	ALPHANUMERIC (12 characters)
Data domain:	Any sequence of alphanumeric characters Where unknown, the field is left blank
Further information:	

15. POSTCODE OF RESIDENCE

NHR field:	POSTCODE_OF_RESIDENCE
Aliases:	POSTCODE
Details:	The permanent residential Australian postcode of the individual
Data type:	NUMERIC, INTEGER (4 digits)
Data domain:	Standard Australian postcode (4 characters) 8888 = not applicable, Leading 0 for NT postcodes NULL/blank = no resident postcode available Where unknown, the field is left blank
Further information:	

16. PREVIOUSLY DIAGNOSED OVERSEAS

NHR field:	PREVIOUSLY_DIAGNOSED_OVERSEAS
Aliases:	
Details:	Identification of previous diagnosis outside of Australia
Data type:	NUMERIC, INTEGER
Data domain:	0 = No

	1 = Yes
Further information:	Default response is 0 = No

17. COUNTRY OF DIAGNOSIS

NHR field:	**COUNTRY_OF_DIAGNOSIS**
Aliases:	
Details:	If PREVIOUSLY DIAGNOSED OVERSEAS = 1 identification of country of previous diagnosis outside of Australia
Data type:	NUMERIC, INTEGER
Data domain:	Country of diagnosis is recorded as the Standard Australian Classification of Countries (SACC) code (Australian Bureau of Statistics 1998) and displayed as text Where unknown, the field is left blank
Further information:	

18. REGION OF DIAGNOSIS

NHR field:	**REGION_OF_DIAGNOSIS**
Aliases:	
Details:	If PREVIOUSLY DIAGNOSED OVERSEAS = identification of region of previous diagnosis outside of Australia, region is automatically calculated from COUNTRY OF PREVIOUS DIAGNOSIS
Data type:	NUMERIC, INTEGER
Data domain:	Region of diagnosis is automatically generated from COUNTRY OF DIAGNOSIS and recorded as the Standard Australian Classification of Countries (SACC) code (Australian Bureau of Statistics 1998) and displayed as text Where unknown, the field is left blank
Further information:	

19. DATE OF PREVIOUS DIAGNOSIS

NHR field:	**DATE_OF_DIAGNOSIS**
Aliases:	
Details:	If PREVIOUSLY DIAGNOSED OVERSEAS = 1 the date of previous diagnosis outside of Australia is recorded
Data type:	DATE (DD/MM/YYYY)
Data domain:	Where unknown, the field is left blank
Further information:	If only the month or year of diagnosis is available, the midpoint of that month or year is given as the date of diagnosis e.g. 15 June XXXX

20. HIV TYPE

NHR field:	**HIV_TYPE**
Aliases:	
Details:	Identification of HIV-type
Data type:	NUMERIC, INTEGER
Data domain:	1 = HIV-1 2 = HIV-2 3 = HIV-1 & HIV-2 0 = Not reported
Further information:	The default value for HIV type is 1 = HIV-1

21. SPECIMEN COLLECTION DATE FOR HIV

NHR field:	**SPECIMEN_COLLECTION_DATE**
Aliases:	
Details:	Date when the laboratory specimen was taken
Data type:	DATE (DD/MM/YYYY)
Data domain:	A valid full century date
Further information:	**Mandatory field**

	The specimen collection date must be after the date of birth

22. AGE AT HIV DIAGNOSIS

NHR field:	**AGE_AT_HIV_DIAGNOSIS**
Aliases:	
Details:	The age of the case at diagnosis as automatically calculated from date of specimen collection and date of birth
Data type:	NUMERIC, INTEGER (≥0≤130)
Data domain:	A valid age in years
Further information:	**Mandatory field**

23. LABORATORY NUMBER

NHR field:	**LABORATORY_NUMBER**
Aliases:	
Details:	The laboratory number allocated at time of HIV specimen processing
Data type:	ALPHANUMERIC
Data domain:	
Further information:	Currently only used for NSW diagnoses, to allow linking to BED results

24. CLINIC NUMBER

NHR field:	**CLINIC_NUMBER**
Aliases:	
Details:	The clinic number allocated at time of HIV specimen processing
Data type:	ALPHANUMERIC
Data domain:	
Further information:	Currently only used for NSW diagnoses, to allow linking to BED results

25. VIRAL LOAD

NHR field:	VIRAL_LOAD
Aliases:	
Details:	The HIV viral load for the case
Data type:	NUMERIC, INTEGER
Data domain:	Where unknown, field is left blank
Further information:	

26. DATE OF VIRAL LOAD

NHR field:	DATE_OF_VIRAL_LOAD
Aliases:	
Details:	The date of viral load testing for the case
Data type:	DATE (DD/MM/YYYY)
Data domain:	A valid full century date Where unknown, field is left blank
Further information:	

27. CD4+ CELL COUNT

NHR field:	CD4+_CELL_COUNT
Aliases:	
Details:	CD4+ cell count of the case
Data type:	NUMERIC, INTEGER
Data domain:	Where unknown, field is left blank
Further information:	Prior to 2014 this was CD4+ cell count only if ≤3 months of diagnosis. Where available, CD4+ cell counts outside of this time period (with a date of test, as per below) is being included as it provides improved information on linkage to care.

28. CD4 DATE

NHR field:	CD4_DATE
Aliases:	
Details:	The date of CD4 testing for the case
Data type:	DATE (DD/MM/YYYY)
Data domain:	A valid full century date Where unknown, field is left blank
Further information:	

29. EXPOSURE

NHR field:	EXPOSURE
Aliases:	
Details:	The reported exposure risk of the case
Data type:	ALPHANUMERIC
Data domain:	1A = Male-male sexual contact 1A3A = Male-male sexual contact and injecting drug use 1A3B = Male-male sexual contact and receipt of blood/tissue 1A3C = Male-male sexual contact and haemophilia/coagulation disorder 1B = Bisexual contact 1B3A = Bisexual contact and injecting drug use 1B3B = Bisexual contact and receipt of blood/tissue 1C2A = Heterosexual contact with bisexual male 1C2A2B = Heterosexual contact with a bisexual injecting drug user 1C2B = Heterosexual contact with an injecting drug user 1C2C = Heterosexual contact with a person who received blood/tissue 1C2D = Heterosexual contact with a person with haemophilia/clotting disorder

	1C2E = Heterosexual contact with person from a high prevalence country 1C2F = Heterosexual contact with person with HIV infection whose exposure is other than the specified exposures 1C2G = Heterosexual contact with person with HIV infection whose exposure could not be established 1C2H = Heterosexual contact, not further specified 1C3A = Heterosexual contact and injecting drug use 1C3A2B = Injecting drug use and heterosexual contact with an injecting drug user 1C3A2E = Injecting drug use, and heterosexual contact with a person from a high prevalence country 1C3B = Heterosexual contact and receipt of blood/tissue 1C3C = Heterosexual contact and haemophilia/clotting disorder 1D = From a high prevalence country 1E = No sexual contact 1E3A = No sexual contact, injecting drug use 1E3B = No sexual contact, receipt of blood/tissue 1E3C = No sexual contact, haemophilia/clotting disorder 1F = Sexual exposure not known 1F3A = Sexual exposure not known, injecting drug use 1F3B = Sexual exposure not known, receipt of blood/tissue 1F3C = Sexual exposure not known, haemophilia/clotting disorder 4A = Mother is an injecting drug user 4B = Mother is a recipient of blood/tissue 4C = Mother is from a high prevalence country 4D = Mother has HIV infection, exposure not specified 4E = Mother had sexual contact with a bisexual male 4F = Mother had sexual contact with an injecting drug user 4G = Mother had sexual contact with a recipient of blood/tissue

	4H = Mother had sexual contact with a person with haemophilia/clotting disorder 4J = Mother had sexual contact with a person from a high prevalence country 4K = Mother had sexual contact with a person with HIV infection whose exposure could not be established 5A = An exposure other than those above applies 5A0 = Other source of exposure, not reported 5A1 = Occupational exposure in a health care setting 5A2 = Occupational exposure in a setting other than a health care setting 5A3 = Other exposure in a health care setting 5A4 = Other exposure in a setting other than a health care setting 5B = Exposure to HIV remained undetermined
Further information:	Exposure risk is decided on a hierarchy of risk

30. COUNTRY OF BIRTH OF SEXUAL PARTNER

NHR field:	**COUNTRY_OF_BIRTH_OF_SEXUAL_PARTNER**
Aliases:	
Details:	Where 1C2E is identified as exposure risk, the country of birth of the sexual partner is also entered
Data type:	DATE (DD/MM/YYYY)
Data domain:	A valid full century date Where unknown, field is left blank
Further information:	

31. REGION OF BIRTH OF SEXUAL PARTNER

NHR field:	**REGION_OF_BIRTH_OF_SEXUAL_PARTNER**
Aliases:	
Details:	Where 1C2E is identified as exposure risk, the region of birth of the sexual partner is automatically generated from the country of

	birth of the sexual partner
Data type:	NUMERIC, INTEGER
Data domain:	A valid full century date Where unknown, field is left blank
Further information:	

32. DATE OF LAST NEGATIVE HIV TEST

NHR field:	**DATE_OF_LAST_NEGATIVE_HIV_TEST**
Aliases:	
Details:	Date of the most recent negative HIV test
Data type:	DATE (DD/MM/YYYY)
Data domain:	A valid full century date Where unknown, field is left blank
Further information:	

33. DATE OF ONSET OF PRIMARY HIV INFECTION

NHR field:	**DATE_OF_ONSET_OF_PRIMARY_HIV_INFECTION**
Aliases:	
Details:	Date of the onset of primary HIV infection
Data type:	DATE (DD/MM/YYYY)
Data domain:	A valid full century date Where unknown, field is left blank
Further information:	Date of onset of primary infection is only recorded when <12 months from date of first diagnosis of HIV

34. DATE OF INDETERMINATE WESTERN BLOT

NHR field:	DATE_OF_INDETERMINATE_WESTERN_BLOT
Aliases:	
Details:	Date of the indeterminate Western Blot
Data type:	DATE (DD/MM/YYYY)
Data domain:	A valid full century date Where unknown, field is left blank
Further information:	

35. SOURCE OF TESTING HISTORY

NHR field:	SOURCE_OF_TESTING_HISTORY
Aliases:	
Details:	Source of previous negative or indeterminate testing result
Data type:	NUMERIC, INTEGER
Data domain:	1 = Patient 2 = Doctor 3 = Laboratory result Where unknown, field is left blank
Further information:	

36. REASON FOR HIV TEST

NHR field:	REASON_FOR_HIV_TEST
Aliases:	
Details:	Reason person was tested for HIV
Data type:	SELECT ONE OR MORE OF THE FOLLOWING, ALPHANUMERIC
Data domain:	1 = Reported risk behaviour for HIV infection 2 = Investigation of clinical symptoms suggestive of HIV infection

	3 = Confirmation of a previous HIV infection 4 = Partner with diagnosed HIV infection 5 = Screening for sexually transmissible infections 6 = Screening – immigration 7 = Screening – pregnancy 8 = Other If 8, specify other reason in free text field Where unknown, field is left blank
Further information:	

37. CLINICAL STATUS AT DATE OF SPECIMEN COLLECTION FOR HIV DIAGNOSIS

NHR field:	**CLINICAL_STATUS**
Aliases:	
Details:	The clinical status of the person at the date of specimen collection for HIV diagnosis
Data type:	SELECT ONE OR MORE OF THE FOLLOWING, ALPHANUMERIC
Data domain:	1 = Symptoms consistent with primary HIV infection 2 = Asymptomatic 3 = AIDS 4 = Other symptoms If 4, specify other symptoms in free text field Where unknown, field is left blank
Further information:	

38. PLACE OF ACQUISITION

NHR field:	PLACE_OF_ACQUISITION
Aliases:	
Details:	The likely place of acquisition of HIV infection
Data type:	NUMERIC, INTEGER
Data domain:	1 = Australia 2 = Overseas 0 = Not known
Further information:	Default is 0 = Not known

39. HIV SUBTYPE

NHR field:	HIV_SUBTYPE
Aliases:	
Details:	Subtype of HIV
Data type:	NUMERIC, INTEGER
Data domain:	1 = Subtype A 2 = Subtype B 3 = Subtype C 4 = Subtype D 5 = Subtype F 6 = Subtype G 7 = Subtype H 8 = Subtype J 9 = Subtype K 10 = CRF01 AE 11 = CRF02 AG 12 = CRF03 AB 13 = Other CRF

	14 = Other recombinations 0 = Not reported
Further information:	Default is 0 = Not reported

40. DATE OF LAST CONTACT

NHR field:	**DATE_OF_LAST_CONTACT**
Aliases:	
Details:	If a previously notified case is subsequently seen in another State/Territory, the date of contact is recorded
Data type:	DATE (DD/MM/YYYY)
Data domain:	A valid full century date Where unknown, field is left blank
Further information:	

41. STATE/TERRITORY LAST CONTACT

NHR field:	**STATE_TERRITORY_LAST_CONTACT**
Aliases:	
Details:	If a previously notified case is subsequently seen in another State/Territory, the State/Territory of last contact is recorded
Data type:	NUMERIC, INTEGER
Data domain:	1 = ACT 2 = NSW 3 = NT 4 = QLD 5 = SA 6 = TAS 7 = VIC 8 = WA

	0 = not reported
Further information:	

42. STATE/TERRITORY NUMBER LAST CONTACT

NHR field:	**STATE/TERRITORY_NUMBER_LAST_CONTACT**
Aliases:	
Details:	If a previously notified case is subsequently seen in another State/Territory, the unique State/Territory number of the case is recorded
Data type:	ALPHANUMERIC
Data domain:	Any sequence of alphanumeric characters
Further information:	

43. DATE OF DEATH

NHR field:	**DATE_OF_DEATH**
Aliases:	
Details:	Date of death of previously notified case
Data type:	DATE (DD/MM/YYYY)
Data domain:	A valid full century date Where unknown, field is left blank
Further information:	

44. STATE/TERRITORY OF DEATH

NHR field:	**STATE_TERRITORY_OF_DEATH**
Aliases:	
Details:	State/Territory of death of previously notified case
Data type:	NUMERIC, INTEGER
Data domain:	1 = ACT

	2 = NSW 3 = NT 4 = QLD 5 = SA 6 = TAS 7 = VIC 8 = WA 0 = not reported Where unknown, field is left blank
Further information:	

45. STATE/TERRITORY DEATH NUMBER

NHR field:	**STATE_TERRITORY_DEATH_NUMBER**
Aliases:	
Details:	Unique state/territory identifier for death of previously notified case
Data type:	ALPHANUMERIC
Data domain:	Where unknown, field is left blank
Further information:	

46. CAUSE OF DEATH

NHR field:	**CAUSE_OF_DEATH**
Aliases:	
Details:	Cause of death of previously notified case
Data type:	NUMERIC, INTEGER
Data domain:	1 = AIDS 2 = Accidental 3 = Cancer 4 = Drug overdose

	5 = Cardiovascular disease 6 = Liver disease 7 = Suicide 8 = Other cause 0 = Not reported
Further information:	Default is 0 = Not reported

Appendix H – Example national HIV surveillance reporting tabulations

See next page

Table 1.1.1: Characteristics of cases of newly diagnosed HIV infection by year[1]. Number of cases, median age, language spoken at home, proportion with late HIV diagnosis, State/Territory and percent of total cases by sex and HIV exposure category

	Year of HIV diagnosis										
Characteristic	**≤04**	**05**	**06**	**07**	**08**	**09**	**10**	**11**	**12**	**13**	**Total[1]**
Total cases											
Males (%)											
Median age (years)											
Male											
Female											
Language spoken at home[2]											
English											
Other language											
Not reported											
Late and advanced HIV infection status at HIV diagnosis[3]											
Late HIV diagnosis (%)[4]											
Advanced HIV diagnosis (%)[4]											
Median CD4+ cell count (cells/μ)											
State/Territory											
ACT											
NSW											
NT											
QLD											
SA											
TAS											
VIC											
WA											
HIV exposure category (%)[5]											
Men who have sex with men											
Men who have sex with men and injecting drug use											
Injecting drug use[6]											
Heterosexual contact											
Person from a high prevalence country											
Partner with/at risk of HIV infection											
Not further specified											
Haemophilia/coagulation disorder											
Receipt of blood/tissue											
Mother with/at risk of HIV infection											
Health care setting											
Other/undetermined											

[1]Late diagnosis and advanced infection for HIV diagnoses in 2002 only. Total percentage with late HIV diagnosis in 2002-2011 only.
[2]Not adjusted for multiple reporting.
[3]Language spoken at home was sought for cases of HIV infection newly diagnosed from 1 January 2004.

[4]Late HIV diagnosis was defined as newly diagnosed HIV infection with a CD4+ cell count of 200 or more, to less than 350 cells/μl and advanced HIV infection as newly diagnosed infection with a CD4+ cell count of less than 200 cells/μl.
[5]The 'Other/undetermined' category was excluded from the calculation of the percentage of cases attributed to each HIV exposure category.
[6]Excludes men who have sex with men

Source: State/Territory health authorities

Table 1.1.2: Number of new diagnoses of HIV infection[1], cumulative to 31 December 2013, by age group, sex and year

		Year of HIV diagnosis										
Age group (years)	**Sex**	**≤2004**	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**	**2011**	**2012**	**2013**	**Total**
0-4	M											
	F											
5-14	M											
	F											
15-19	M											
	F											
20-24	M											
	F											
25-29	M											
	F											
30-39	M											
	F											
40-49	M											
	F											
50-59	M											
	F											
60+	M											
	F											
Not reported	M											
	F											
Sub-total	M											
	F											
Total[2]												

[1]Not adjusted for multiple reporting.
[2]Totals include xx people whose sex was reported as transgender and xx people whose sex was not reported.

Source: State/Territory health authorities

Table 1.1.3: Number of new diagnoses of HIV infection in Australia in 2013, by State/Territory and whether or not HIV infection was newly diagnosed in Australia

	Place of first diagnosis of HIV infection		
State/Territory	**Newly diagnosed in Australia**	**Newly diagnosed overseas**	**Total diagnosis**
Australian Capital Territory			
New South Wales			
Northern Territory			
Queensland			
South Australia			
Tasmania			
Victoria			
Western Australia			
Total			

Source: State/Territory health authorities

Table 1.1.4: Number (percent) of new HIV diagnoses in Australia, 2009 -- 2013, and age standardised rate per 100 000 population[1] by year of HIV diagnosis and region of birth

	Year of HIV diagnosis														
	2009			2010			2011			2012			2013		
Region/Country of birth	**Number**	**%**	**Age standardised rate**	**Number**	**%**	**Age standardised rate**	**Number**	**%**	**Age standardised rate**	**Number**	**%**	**Age standardised rate**	**Number**	**%**	**Age standardised rate**
Australia															
Overseas born															
Other Oceania															
United Kingdom and Ireland															
Other Europe															
Middle East/ North Africa															
Sub-Saharan Africa															
Asia															
North America															
South/Central America and the Caribbean															
Total with a reported country of birth															
Not reported															
Total															

[1]Population estimates by country of birth and age group from the Australian Bureau of Statistics.

Source: State/Territory health authorities

Table 1.1.5 Median CD4+ cell count at diagnosis of HIV infection (number of HIV diagnoses with CD4+ cell count), 2009 - 2013, by State/Territory, HIV exposure category, newly acquired infection status, sex and year

		Year of diagnosis				
Characteristic	**Sex**	**2009**	**2010**	**2011**	**2012**	**2013**
State/Territory						
Australian Capital	M					
Territory	F					
New South Wales	M					
	F					
Northern Territory	M					
	F					
Queensland	M					
	F					
South Australia	M					
	F					
Tasmania	M					
	F					
Victoria	M					
	F					
Western Australia	M					
	F					
HIV exposure category						
Men who have sex	M					
with men[1]	F					
Injecting drug use[2]	M					
	F					
Heterosexual	M					
contact	F					
Other/undetermined	M					
	F					
Newly acquired HIV infection status						
Diagnoses of newly	M					
acquired infection[3]	F					
Other HIV	M					
diagnoses[4]	F					
Total						

[1]Includes males who also reported a history of injecting drug use
[2]Excludes men who have sex with men
[3]Newly acquired HIV infection was defined as newly diagnosed HIV infection with a negative or indeterminate HIV antibody test result, or a diagnosis of primary HIV infection within one year of HIV diagnosis.
[4]Total includes X people whose sex was reported as transgender.

Source: State/Territory health authorities

Table 1.1.6 Number of new diagnoses of HIV infection for which exposure to HIV was attributed to heterosexual contact, by exposure category of the heterosexual partner, year and sex

	Year of HIV diagnosis												
	2009		2010		2011		2012		2013		2009-2013		
HIV exposure category	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Male**	**Female**	**Total**
Person from a high prevalence country													
Sub-Saharan Africa													
South East Asia													
North Africa/Middle East													
Partner from a high prevalence country													
Sub-Saharan Africa													
South East Asia													
North Africa/Middle East													
Homosexual contact with partner at risk													
Injecting drug use													
Bisexual man													
Partner with medically acquired HIV													
Partner with HIV infection whose exposure was other than those above													
Not further specified													
Total													

Source: State/Territory health authorities

Table 1.1.7 Number of specimens tested for HIV antibody in public health laboratories, 2004 – 2012, by State/Territory and year of test

	Year of HIV antibody test								
State/Territory	**2004**	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**	**2011**	**2012**
ACT[1]									
NSW									
NT									
QLD									
SA									
TAS									
VIC									
WA									
Total									

[1]Estimated number of specimens tested for HIV antibody, adjusted for incomplete reporting.

Source: National Serology Reference Laboratory, Australia

Table 1.2.1 Characteristics of diagnoses of newly acquired HIV infection1, –2004 - 2011, by year. Total number of cases, median age, and number of cases by State/Territory, HIV exposure category, evidence of newly acquired HIV infection, sex and year

		Year of HIV diagnosis								
Characteristic	**Sex**	**2004**	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**	**2011**	**Total[1,2]**
Total cases										
Males (%)	M									
Median age (years)	M									
	F									
State/Territory										
ACT	M									
	F									
NSW	M									
	F									
NT	M									
	F									
QLD	M									
	F									
SA	M									
	F									
TAS	M									
	F									
VIC	M									
	F									
WA	M									
	F									
HIV exposure category										
Men who have sex with men	M									
	F									
Men who have sex with men and injecting drug use	M									
	F									
Injecting drug use[3]	M									
	F									
Heterosexual contact	M									
	F									
Health care setting	M									
	F									
Other/undetermined	M									
	F									
Evidence of newly acquired infection										
Testing history only	M									
	F									
Primary HIV infection only	M									
	F									
Testing history and primary HIV infection	M									
	F									

[1]Newly acquired HIV infection was defined as newly diagnosed HIV infection with a negative or indeterminate HIV antibody test result, or a diagnosis of HIV seroconversion illness, within one year of HIV diagnosis.
[2]Totals include X people whose sex was reported as transgender and 1 person whose sex was not reported.
[3]Excludes males who also reported a history of homosexual contact.

[4]'Health care setting' includes X case of occupationally acquired HIV infection.

Source: State/Territory health authorities

Table 1.2.2 Number and percentage of isolates with resistance at one or more loci, by drug class against which resistance was detected and year

			Drug class against which resistance was detected		
Year of diagnosis	**Total**	**% non-B types**	**PI[1] Number (%)**	**NRTI[1] Number (%)**	**NNRTI[1] Number (%)**
2009					
2010					
2011					
2012					
2013					

[1] **PI**: protease inhibitor; **NRTI**: Nuceloside reverse transcripterase inhibitor; **NNRTI**: Non-nucleoside reverse transcripterase inhibitor

Source: NSW State Reference Laboratory for HIV/AIDS; Victorian Infectious Diseases Reference Laboratory

Table 1.3.1 Characteristics of cases of newly diagnosed HIV infection in Aboriginal and Torres Strait Islander peoples[1], 2004 - 2012, by year. Number of cases, median age and percent (number) of total cases by sex, newly acquired infection, late HIV diagnosis, State/Territory and HIV exposure category

	Year of HIV diagnosis									
Characteristic	**2004**	**2005**	**2006**	**2007**	**2008**	**2009**	**2010**	**2011**	**2012**	**Total[1,2]**
Total cases										
Males (%)										
Median age (years)										
Newly acquired HIV infection (%)[1]										
Late and advanced HIV infection status at HIV diagnosis (%)[2]										
Late HIV diagnosis										
Advanced HIV diagnosis										
State/Territory (%)										
ACT										
NSW										
NT										
QLD										
SA										
TAS										
VIC										
WA										
HIV exposure category (%)[3]										
Men who have sex with men										
Men who have sex with men and injecting drug use										
Injecting drug use[5]										
Heterosexual contact										
Haemophilia/coagulation disorder										
Receipt of blood/tissue										
Mother with/at risk of HIV infection										
Health care setting										
Other/undetermined exposure										

[1]Information on Indigenous status was available in VIC from 1 June 1998.
[2]Late HIV diagnosis was defined as newly diagnosed HIV infection with a CD4+ cell count of 200-349 cells/µl and advanced HIV infection was defined as newly diagnosed HIV infection with a CD4+ cell count of less than 200 CD4+ cells/µl. Excludes newly acquired notifications.

[3]The ‘Other/undetermined’ HIV exposure category was excluded from the calculation of the percentage of cases attributed to each exposure category.
Source: State/Territory health authorities

Table 1.3.2 Rate[1] of diagnosis of HIV infection, –2009 - 2013, by year, Aboriginal and Torres Strait Islander status and area of residence

		Year of diagnosis				
Area of residence	**Aboriginal and Torres Strait Islander status**	**2009**	**2010**	**2011**	**2012**	**2013**
Major cities	Aboriginal and Torres Strait Islander					
	Non-Indigenous[2]					
Inner regional	Aboriginal and Torres Strait Islander					
	Non-Indigenous[2]					
Outer regional	Aboriginal and Torres Strait Islander					
	Non-Indigenous[2]					
Remote	Aboriginal and Torres Strait Islander					
	Non-Indigenous[2]					
Very remote	Aboriginal and Torres Strait Islander					
	Non-Indigenous[2]					
Total	**Aboriginal and Torres Strait Islander**					
	Non-Indigenous[2]					

[1]Rate per 100 000 population. Population estimates from 2001 Census of Population and Housing (Australian Bureau of Statistics).

[2]Includes diagnoses in people whose Aboriginal and Torres Strait Islander status was not reported.

Source: State/Territory health authorities

Appendix I – Flow charts for determining exposure category

Figure A: Primary exposure assessment pathway

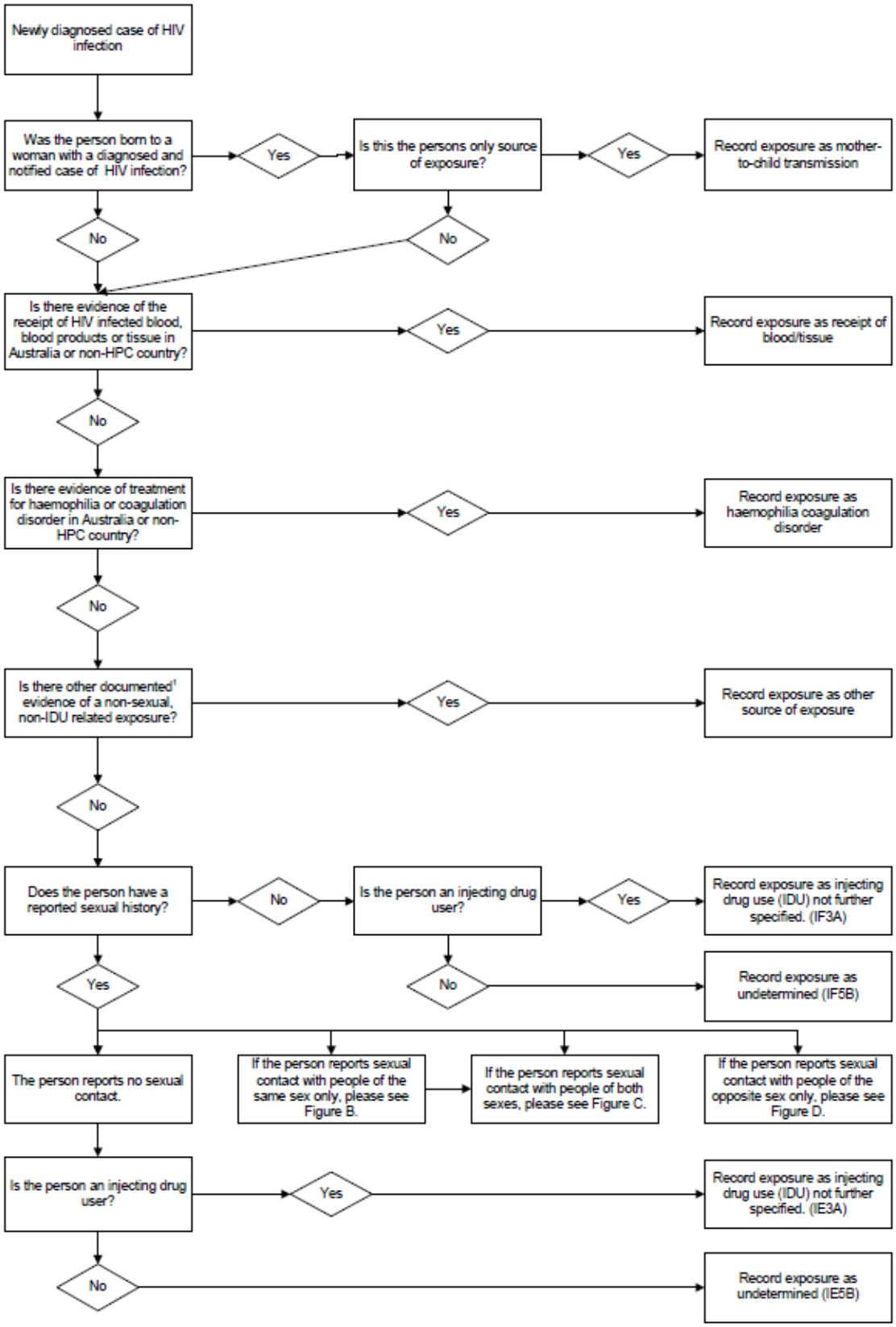


Figure B: Same sex exposure pathway

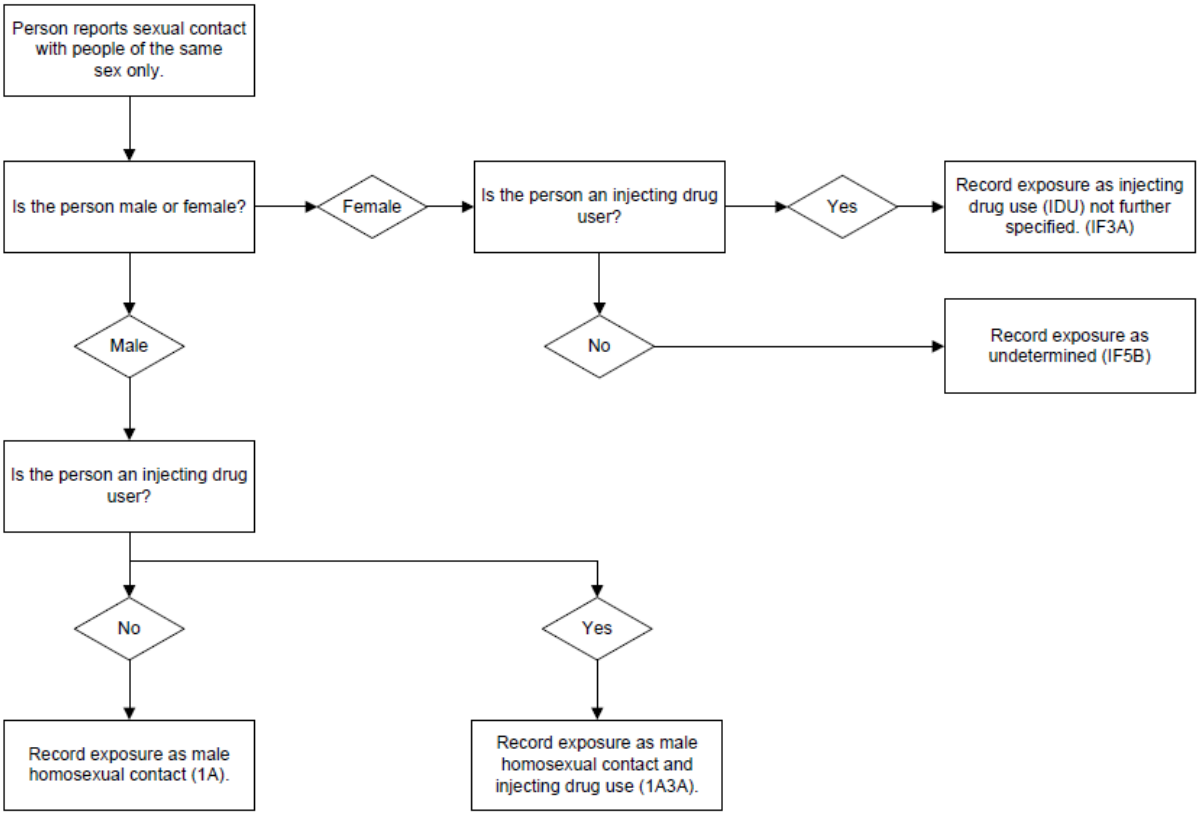


Figure C: Both sexes partners exposure pathway

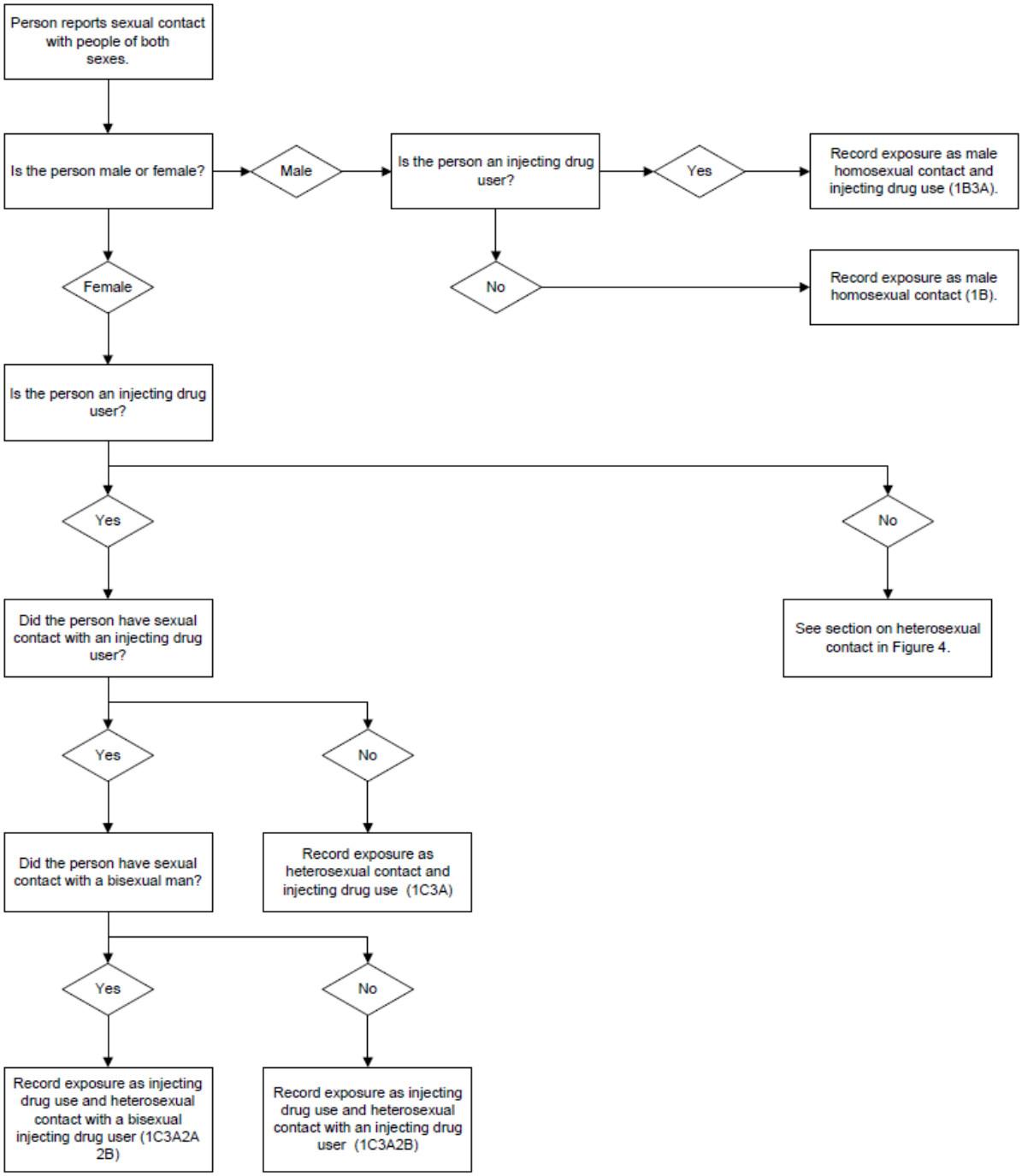
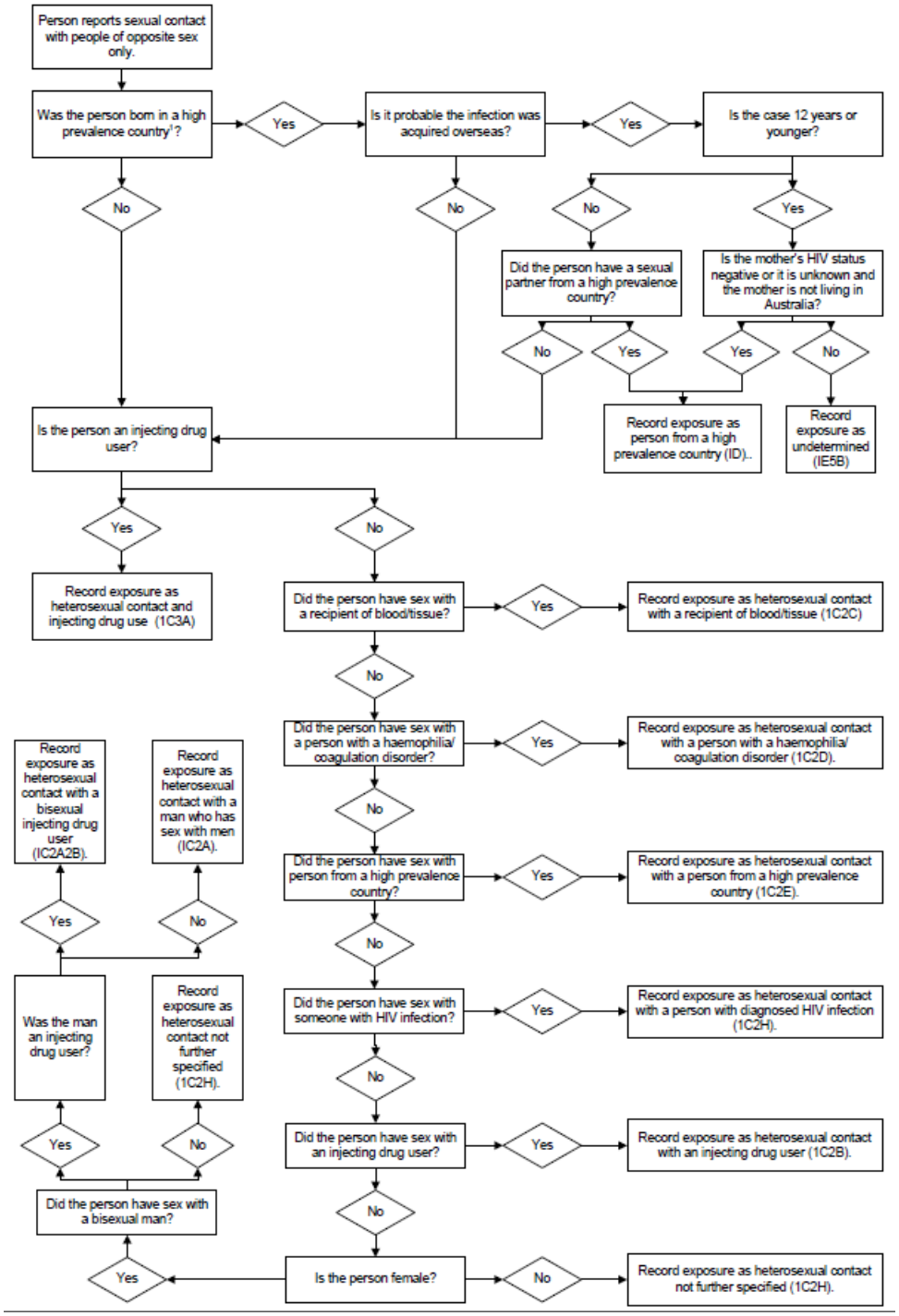


Figure D: Opposite sex partner exposure pathway



Appendix J – Data release policy for communicable disease-related data held by the Department of Health

1. Introduction

The *National Health Security ACT 2007*, provides a legislative basis for and authorises the exchange of health information, including personal information, between states and territories, and the Australian Government. The National Health Security Agreement establishes the operational arrangements to formalise and enhance existing surveillance and reporting systems. Under this agreement, states and territories forward de-identified notification data on communicable diseases to the Department of Health for the purposes of national communicable disease surveillance.

The States and Territories require the Department of Health (Health) to make data only available in accordance with the Clause 11 of the *National Health Security Agreement 2008*:

> 11. Information from communicable disease surveillance arrangements described in this Part will be disseminated through agreed dissemination agreements, including:
>
> (a) meetings of the Communicable Diseases Network Australia (CDNA);
>
> (b) the Health website;
>
> (c) *Communicable Disease Intelligence* (CDI) journal; and
>
> (d) in response to requests, with the agreement of the CDNA.

This policy is an 'agreed dissemination arrangement' and as such, release of any communicable disease data must comply with it. If a proposed release is not permitted under, or otherwise outside of scope of this policy, further agreement from CDNA will be sought under clause 11(d) for the proposed release to be permitted.

2. Purpose and scope

This policy covers the release of National Notifiable Diseases Surveillance System (NNDSS) data, and NNDSS-related enhanced datasets, and the roles and responsibilities of Health employees and the Jurisdictional Executive Group (JEG) of CDNA in this process.

It also articulates the general principles (agreed to by Health and CDNA) that should be used to guide the decision making process for releasing publicly unavailable data to third parties.

2.1. Inclusions

- Data requests for data from the NNDSS.
- NNDSS-related enhanced datasets (such as National Enhanced Listeriosis Surveillance System data, pandemic datasets including pandemic (H1N1) 2009 data, classical and variant form Creutzfeldt-Jakob disease data, influenza outbreak data).
- Other data relating to the prevention and control of communicable diseases health by the Commonwealth (including use of immunoglobulins).
- The release of HIV and AIDS data held by the Kirby Institute for infection and immunity in society (Kirby Institute). Please note that requests for HIV and AIDS data are processed separately by the Kirby Institute.

2.2. Exclusions

- Requests for data that are already publicly available such as NNDSS data published on the Health's departmental website (see 6.1 *Data that are publicly available*), published on the Kirby Institute's website or NNDSS data published in CDI.
- Requests for data relating to fewer than 4 states or territories.
- Release of other data held by OHP (e.g. the Laboratory Serology and Virology Reporting Scheme), the release of enhanced data held by the National Centre for Immunisation Research and Surveillance (NCIRS), or the release of OzFoodNet outbreak register data.

3. Roles and responsibilities

3.1. Office of Health Protection

The Office of Health Protection (OHP) acts as a custodian and data steward of the communicable disease data and OHP employees share the responsibility for maintaining and securing data and information as per Section 15[9], *Privacy Act 1988*.

OHP staff and Master of Philosophy (Applied Epidemiology) [MAE] scholars on field placements within Health, may access communicable disease data in order to fulfil the communicable disease surveillance responsibilities of the Commonwealth, as described in Part 2 of the *National Health Security Agreement 2008*. These responsibilities include detecting outbreaks, national coordination of outbreak responses, identifying national trends, guiding policy development and resource allocation at a national level. Should this work lead to the development of material for publication, these will be provided to CDNA JEG, for noting or comment prior to publication. In the case of annual reports produced by Health, these will be provided to the relevant CDNA subcommittees or working groups for noting or comment, such as the National Surveillance Committee (NSC) or the National Arbovirus and Malaria Advisory Committee (NAMAC).

All requests for communicable disease data received by OHP staff will be managed by the Data Request Coordinator. This person has responsibilities for managing the Epi Inbox, liaising with requestors and informing CDNA JEG of any requests for communicable disease data. The coordinator will keep a record of all requests for communicable disease data and will provide an annual report on these and the outcomes to the NSC and CDNA JEG. Included in this record keeping is the monitoring of applicants to ensure that they abide by the conditions under which the data were released to them, (e.g. that CDNA JEG has the right to comment on the use and interpretation of the data prior to publication, secure storage of the data, and destruction of the data after the data retention period by the applicant).

[9] *Privacy Act 1988,* Section 15 APP entities must comply with the Australian Privacy Principles: An APP entity must not do an act, or engage in a practice, that breaches an Australian Privacy Principle, where an APP entity is defined in the Act as an "agency", which itself is defined as "(b) a Department." The specific Australian Privacy Principle this relates to is Australian Privacy Principle 11 – security of personal information.

As part of the data release process, OHP staff will ensure the suitability of data for the intended use and that all request are 'fit for purpose'[10]. Poor fit means that the data are unlikely to meet the needs of those requesting it.

CDNA JEG will be informed of all requests for communicable disease data at the next CDNA meeting (teleconference or face-to-face meeting) following receipt of the request. The specified data release levels for requests can be found under Section 6.

As per Health's own internal policies[11], OHP does not charge requestors for making a request. As there is no cost recovery mechanism for data request, OHP staff will undertake data release activities within the context of other priorities within OHP and jurisdictional governments. The specific role of OHP staff with respect to data requests are:

- coordinating the data request process, assisting applicants through the process and ensure requests are fit for purpose;
- applying this data release policy, which includes deciding whether or not a request requires CDNA JEG approval; advice on this may be sought from CDNA JEG directly;
- preparing the data to be released and ensuring the data are as accurate as possible. This may include working with jurisdictions to clean data;
- preparing caveats on the interpretation, limitations and appropriate use of the requested data;
- coordinating the approval for release of the data;
- ensuring that all linelisted or higher risk data pertaining to requests are sent to applicants by secure means, such as emailed electronically as a password protected file. The password will be provided to the applicant separately;
- being available to requestors for questions on the interpretation and use of the requested data; and
- reviewing any potential publications using requested data to ensure accuracy, quality, and compliance with data release caveats prior to it going to CDNA JEG for noting and comment where required.

3.2.States and territories (CDNA JEG)

States and territories are legally authorised to collect personal information on specified communicable diseases data under their relevant public health legislation. At all times, the state and territory health departments and CDNA JEG members retain control over their data.

In the event that a request received by Health is for an individual jurisdiction's data, the request will be forwarded on to that jurisdiction, and the state or territory will follow their respective state or territory data release policy(ies) and/or legislation in agreeing to release the data to a third party.

On receipt of a request for data via the Epi Inbox, jurisdictions must provide the Data Request Coordinator with a response via the Epi inbox, in which they may agree to the supply of data as requested (with or without conditions), reject the request or seek

[10] National Statistics Service, NSS Handbook, Glossary, accessed online: http://www.nss.gov.au/nss/home.nsf/NSS/D0948DEA17A97367CA25763F000BF5C3?opendocument

[11] Australian Government Department of Health, Data Management policies v1.06.

additional information about the request. Should a jurisdiction wish to reject the request, detailed reasons must be given to enable the applicant to reconsider their request, to allow for resubmission of their application for reconsideration by the jurisdiction(s). Where there is a divergence of views amongst jurisdictions the Data Request Coordinator will inform CDNA JEG and seek a resolution.

3.3.Applicants ('third parties')

Applicants, including the person taking responsibility for the data and those who will have the authority to access and use the data, must complete an appropriately filled-out and signed "Communicable disease data request form" (data request form). However, Health may decide not to require one where the request is of a clearly non-complex and routine nature, or is covered under Section 6.3 Data provided regularly to designated institutions). The data provided to the applicant(s) must be used for the intended purpose as stated in the completed form. If the applicant(s) wishes to vary the use or reporting of the data they must complete another data request form and this will be treated as a new request.

3.3.1. Person taking responsibility for use of the data (Principal Investigator)

The person taking responsibility for the data must be specified on the data request form.

This person has responsibility for the secure storage, appropriate use of the data, annual/final reporting on use of data, and destroying the data when the data retention period elapses. It is the responsibility of the Principal Investigator to ensure that they protect the security and integrity of data released into their care. Data supplied to the applicant must meet the requirements for data storage and disposal as set out in the *National Statement on Ethical Conduct in Human Research (2007)* (the National Statement), released by the National Health and Medical Research Council (NHMRC).

This person must ensure that only those listed on the data request form as having the authority to access and use the data, do so. Data must not be provided to, accessed, or used by another party. If the Principal Investigator is leaving the project, or intends to become only peripherally involved in it, or if others not previously listed wish to access the data, the Data Request Coordinator must be contacted to seek permission for any variation to the information on the original data request form. This may require CDNA JEG to be informed, and if they deem necessary, a new data request form to be completed.

If at any point the applicants wish to publish the data[12], a draft copy of the intended publication materials/manuscript must be provided to the Data Request Coordinator for review. Applicants are obliged to take all steps to ensure that no individual, organisation or community can be re-identified from provided data. More detail can be found in section 7 Review of potential publications.

3.3.2. Annual and final reporting on use of requested data

Each year, the Data Request Coordinator will contact the Principal Investigator to seek an update on the use of requested data and any intended publications. This information will be

[12] Publishable data that require review refers to communicable disease data that are not already available in the public domain from Health and CDNA websites or from CDI or other published sources. This may include data being published in a report, a peer-reviewed journal, or presented at a conference as a presentation, abstract or poster, by the media or to public groups.

provided to CDNA JEG. At the completion of the project, the Principal Investigator should provide a final report which will confirm conclusion of the project, dates for submission of draft documents for review prior to publication and destruction of the data as stipulated in the conditions attached to the original data release.

3.4. Expert CDNA subcommittees/working groups or other parties

Expert CDNA subcommittees/working groups or other parties (such as the National Surveillance Committee and the Public Health Laboratory Network) may be asked to review requests for enhanced or laboratory data to ensure the data being released are appropriate and to provide accurate data caveats, prior to the request being sent to CDNA JEG for approval.

3.5. Ethics approval

All research that is the basis of a data request must comply with the NHMRC *National Statement on Ethical Conduct in Human Research* (2007) (the National Statement), (http://www.nhmrc.gov.au/guidelines/publications/e72). Most requests for data covered by this policy will fall under the 'low' or 'negligible risk' categories[13] as defined in the National Statement, and as such do not require review by a full meeting or a Human Research Ethics Committee (HREC) that reports annually to the NHMRC.

It is expected that, at a minimum, all proposed research will have met local ethics committee requirements for low or negligible risk research. Applicants will need to document in their request these requirements and how they have been met. This includes non-HREC levels of ethical review for research involving no more than low risk[14], where a local ethics committee has determined that a full HREC review is not required.

Where identified in the National Statement that a full HREC review is required, applicants will need to provide copies of their HREC request and approval when they submit their data request form.

CDNA JEG can provide in-principle approval for work to commence on data requests prior to HREC approval being provided to the Data Request Coordinator, however, data will not be released until this approval is provided.

Note that the Australian Capital Territory requires the applicant(s) also obtains ethics approval from the ACT Research Ethics and Governance Office in addition to HREC approval obtained elsewhere.

4. Legislation and guidelines

Health has legal obligations in regards to the collection, storage, disclosure and release of data and it must abide by the following:

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[13] NHMRC National Statement on Ethical Conduct in Human Research (2007) – paragraph 2.1.6 "Research is 'low risk' where the only foreseeable risk is one of discomfort. Where the risk, even if unlikely, is more serious than discomfort, the research is not low risk." Paragraph 2.1.7 "Research is 'negligible risk' where there is no foreseeable risk of harm or discomfort; and any foreseeable risk is no more than inconvenience. Where the risk, even if unlikely, is more than inconvenience, the research is not negligible risk." Research with more than a low or negligible level of risk must be reviewed by a HREC.

[14] NHMRC National Statement on Ethical Conduct in Human Research (2007) – paragraphs 5.1.18-23.

- *National Health Security Act 2007;*
- *National Health Security Agreement 2008;*
- *Privacy Act 1988;* and
- *National Statement on Ethical Conduct in Human Research (2007).*

5. Principles governing the release of communicable disease data

The following principles have been agreed by CDNA JEG and Health and were informed by the NHMRC principles for accessing and using publicly funded data for health research[15].

These guide Health in the decision making process in the release, to third parties, of data not available in the public domain. CDNA JEG and Health will:

- Support and encourage requests for communicable disease data as provision of data to third parties is an important public health responsibility.
- Where possible, make data publicly available in an appropriately de-identified and confidentialised form unless there are compelling reasons to the contrary.
- Ensure that any release of data takes into account privacy and legal considerations.
- Minimise the risk of individual being re-identified through "data mining" and other techniques by:
    - replacing state and territory unique identification numbers with 'dummy' identifications numbers;
    - limiting the disclosure of date of birth and residential postcode;
    - aggregating data or grouping categories (e.g. age into 5 year age-groups) where possible; and
    - only releasing data fields essential to the applicant's purpose ('fit for purpose').
- If the level of risk is greater than low[13], communicable disease data will only be released if HREC approval is obtained.
- There may be multiple requests for communicable disease data from a variety of organisations and researchers that are similar in nature. Each request should be handled individually, and without reference to previous or outstanding requests for data that are similar or the same, except that the level of clearance may differ as per Section 6.8 Requests for similar data by third parties. As a general rule, data should be provided to any applicant whose application for data meets the technical and other requirements for data release.
- Ensure appropriate caveats, recommended interpretations and links to relevant published data are provided with all data released.
- Ensure any potential publications[16] are sent to OHP for review prior to publication.
- Where a request requires CDNA JEG approval, ensure data are released under the condition that CDNA JEG has the right to view, and comment on the use and interpretation of the data, where specifically requested by a jurisdiction, prior to publication.

6. Specified data release levels

The agreement for third parties to have access to communicable disease data will remain secondary to legislative requirements and protecting individual information and privacy. The

[15] NHMRC Principles for accessing and using publicly funded data for health research, https://www.nhmrc.gov.au/principles-accessing-and-using-publicly-funded-data-health-research.
[16] Publication includes public presentations, intended publications, research, media articles and other documents for public dissemination.

process for approval of release of communicable disease data varies according to the degree of detail that is being requested, see below for more information.

6.1. Data that are publicly available

These data are available to third parties and do not require any approval:

6.1.1. Data Aggregate data available from http://www9.health.gov.au/cda/source/cda-index.cfm.

- Notifications (by diagnosis date) of all diseases by state and territory and Australia by selected month and year (counts and crude rates).
- Notifications (by diagnosis date) of all diseases by state and territory and Australia and year (counts and crude rates).
- Notifications (by diagnosis date) of selected diseases by month and year, state and territory and year, and age group and sex for Australia (counts and crude rates).

6.1.2. Aggregate data available from http://www9.health.gov.au/cda/source/cda-index.cfm.

6.1.3. CDNA fortnightly reports available from http://www.health.gov.au/internet/main/publishing.nsf/Content/cdnareport.htm.

- Notifications (by diagnosis date) of counts of 65 nationally notifiable diseases by state and territory and Australia by fortnight.

6.1.4. Public datasets available from http://www9.health.gov.au/cda/source/cda-index.cfm and http://kirby.unsw.edu.au/surveillance/Australian-HIV-Public-Access-Dataset.

6.1.5. Information stating that no cases have been notified to NNDSS.

6.1.6. Data published in CDI - http://www.health.gov.au/internet/main/publishing.nsf/Content/cda-pubs-cdi-cdicur.htm).

6.2. Requests for data by third parties that have a low risk of re-identification of individuals

The following types of requests may be released to a third party with the approval of an Assistant Secretary (AS) within OHP:

6.2.1. Requests for combinations of aggregate data already publicly available:

- Total number of cases
- Age (which may be in five-year age groups)
- Sex
- Year of Diagnosis and/or Year of Notification, and
- State and territory

(e.g. Age group and sex broken down by state for selected disease(s).)

6.2.2. Requests for data by internal parties for the specific purpose of outbreak investigations or informing policy and practice.

- Requests for communicable disease data (national level data, national data by state and territory, linelisted data) may be released to internal parties such as Health, AHPPC, and CDNA subcommittees and working groups for specific purposes following internal clearance within OHP. Conditions may apply to the release of this data, i.e. that the data must be destroyed after the data retention period, are not published, and are not used for any other purposes.

6.2.3. Requests for aggregated data by third parties that have been deemed low-risk[17].

- Such requests may include aggregate requests for fields including:
  - Total number of cases
  - Age (which may be in five-year age groups)
  - Sex
  - Year of Diagnosis and/or Year of Notification
  - State and territory, Australian Statistical Geography Standard (ASGS)[18] Statistical Local Areas (SLA) 2, 3 or 4[19]
  - Place of acquisition[20]
  - Organism serogroup/subtype[7]
  - Indigenous status[7]
- All request for aggregated communicable disease data are delegated to Health for AS approval, unless the request contains a combination fields that Health has assessed may increase the risk of an individual being potentially re-identified (i.e. a request that includes Indigenous status, age/age-group and sex). In this circumstance, CDNA JEG will be informed of the request at the next fortnightly teleconference, at which time they can decide if it requires CDNA JEG approval or if the request can be delegated to Health for approval.

6.2.4. Requests for linelisted data by third parties that have been deemed low-risk and delegated to Health for AS approval by CDNA JEG.

- *Examples of these include requests for an update to a previously CDNA JEG approved request for linelisted salmonellosis and campylobacteriosis data by notifying jurisdiction, notification received/true onset/diagnosis dates, sex, serovar and phage type from 1991 to 2014, and linelisted hepatitis C data by postcode only from 2010-2014 for geomapping.*

6.3. Data provided regularly to designated institutions

CDNA JEG members have agreed that data can be provided to designated institutions for specified purposes without further referral to them. The designated institutions will be sent letters from the Chair of CDNA informing them that they have been deemed a designated institution by CDNA JEG, outlining what data will be provided, how regularly the data will be provided and what purposes it can be used for. Designated institutions are required to provide a list of upcoming publications with expected dates to the Data Request Coordinator. All publications will be submitted to the Data Request Coordination for sending to CDNA JEG for information prior to being made public.

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[17] A request for data will be deemed low-risk by CDNA JEG when the combination of requested fields has a low chance of re-identifying individuals. For example, when a combination of demographic data fields that distinguishes groups has an estimated resident population of greater than 1,000. The '1,000 denominator population rule' is an example of the 'data reduction' principle described in Appendix 4 of the National Statistical Service Handbook. The population group are defined using any demographic information that is relevant (in the sense that the combinations of the demographic data items may enable individuals in the community to be identified) and for which resident population estimates are available from the Australian Bureau of Statistics (ABS). Hence the populations may be defined on the basis of geography (e.g. postcode or region of residence), age, sex, country of birth, Indigenous status, or marital status.

[18] From July 2011, the Australia Bureau of Statistics replaced the Australian Standard Geographical Classification (ASGC) with the ASGS. The ASGS is broken down into Statistical Local Areas 4 through to 1. More information can be found here http://www.abs.gov.au/websitedbs/D3310114.nsf/home/Australian+Statistical+Geography+Standard+(ASGS).

[19] SLA 4 contains 106 regions with populations in the range of 100,000 to 500,000, SLA 3 contains 351 regions with populations in the range of 30,000 to 130,000 and SLA 2 contains 2,214 regions with populations in the range of 3,000 to 25,000.

[20] May only be released as aggregate data.

Should a designated institution wish to use the provided data for purposes other than those specifically stated in the letter, they will need to go through the standard data release process.

Currently, these designated institutions are:

1. The National Centre for Immunisation Research and Surveillance of Vaccine Preventable Diseases.
2. The Kirby Institute for infection and immunity in society.
3. WHO Collaborating Centre for Reference and Research on Influenza.

6.4. Requests for communicable disease data not in the public domain by third parties which require approval from CDNA JEG.

Whilst communicable disease data sent to Health by states and territories is de-identified, there still may be a risk that a person could be re-identified if the notification of the disease (particularly if the disease is rare) is provided by a small geographic area or cultural community, or if certain combinations of fields for an individual (such as date of birth, postcode, Indigenous status) are released.

Requests for data that are potentially re-identifiable, such as linelisted[21] data, will require the approval of CDNA JEG members, unless specifically delegated to Health for AS approval as per Section 6.1.6. These requests may require HREC approval before being released to the applicant. The following fields; **either alone or used in conjunction with other fields**, *may* pose a risk of re-identifying an individual:

- jurisdictional unique identification numbers (should be replaced with dummy identification numbers[22]);
- date of birth;
- age at onset (in years);
- sex;
- Indigenous status;
- resident postcode/resident location;
- country of birth (enhanced datasets);
- place of acquisition;
- true onset date;
- organism serogroup/subtype;
- vaccination status;
- enhanced data fields; and
- died[23].

6.5. Data completeness

For a trial period of 12 months following the endorsement of this policy by CDNA JEG and as long as the data request meets the requirements of the data release policy, data will be released to requestors regardless of completeness.

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[21] If CDNA JEG deem a request for linelisted NNDSS data by a third party to be low-risk, it will be delegated to Health for AS approval.

[22] Unique identification numbers assigned by states and territories will never be released by the Department because of the potential risk of being used to re-identifying individuals. However, 'dummy identification numbers' may be assigned by Health in requests for unit record data where it is important to ensure that cases are not double-counted during analysis.

[23] Death data may be unreliable and incomplete.

Requestors will be provided with a comprehensive set of caveats to guide analysis and interpretation.

6.6. Review of requests by expert groups

Requests for disease type (other than species and serogroup), such as phage type, toxin type and genotype may be subject to consultation with the laboratory(ies) responsible for the disease typing through the PHLN representative on CDNA. The laboratory(ies) may provide comment on the use and interpretation of the data. This process will coincide with the CDNA JEG approval process.

6.7. Appropriate referencing of communicable disease data

When referencing the use of communicable disease data, such as NNDSS data, in potential publications, requestors should use the following wording:

National Notifiable Diseases Surveillance System data, accessed DD MM YYYY.

An appropriate acknowledgement would be:

National Notifiable Diseases Surveillance System data on *X disease(s)* were provided by the Office of Health Protection, Department of Health, on behalf of the Communicable Diseases Network Australia.

6.8. Requests for similar data by third parties

Where a request from a third party, including a commercial entity (such as a vaccine company), for communicable disease data is very similar to one made by another party, which has already had CDNA JEG approval, and the data request is 'fit-for-purpose', the subsequent request(s) may not need to be re-approved by CDNA JEG.

In these circumstances CDNA JEG will be asked to delegate the request to Health for AS approval at the next appropriate CDNA meeting.

7. Review of potential publications

Requestors will send any potential publications to the Data Request Coordinator for review prior to publication. All potential publications will be sent to CDNA JEG for noting.

If the request is assessed by OHP as requiring CDNA JEG approval or at the request of a CDNA JEG member, the potential publication will be sent to CDNA JEG for comment.

CDNA JEG reserves the right of approval or veto of data and interpretations prior to publication.

8. Data retention period

By default, all data sent to the applicant(s) must be destroyed after twelve months from the date the data were received. If the applicant(s) wish to retain the data for a period longer than this, they must indicate and justify the retention period required on the data request form.

9. Appeals

If applicants wish to appeal the decision of a state/territory to not release data, they will be provided details for an appropriate contact person in that state/territory to correspond with.

10.Further information

IF YOU REQUIRE FURTHER ASSISTANCE, HAVE QUESTIONS ABOUT DATA AVAILABILITY, THE REQUEST PROCESS OR ON DATA INTERPRETATION, PLEASE CONTACT THE DATA REQUEST COORDINATOR BY EMAIL TO epi@health.gov.au.