Australian Government
Australian Institute of Health and Welfare

The inclusion of Indigenous status on pathology request forms

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Authoritative information and statistics to promote better health and wellbeing

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Australian Institute of Health and Welfare
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Abbreviations

AACR	Australasian Association of Cancer Registries
ABS	Australian Bureau of Statistics
ACD	Australian Cancer Database
ACT	Australian Capital Territory
AHMAC	Australian Health Ministers' Advisory Council
AIDS	acquired immunodeficiency syndrome
AIHW	Australian Institute of Health and Welfare
APHCRI	Australian Primary Health Care Research Institute
CALD	Culturally and Linguistically Diverse
CD	compact disk
CDC	Communicable Disease Centre
CDNA	Communicable Diseases Network Australia
CEO	Chief Executive Officer
COAG	Council of Australian Governments
CRCAH	Cooperative Research Centre for Aboriginal Health
DH	Department of Health
DoHA	Department of Health and Ageing
DVA	Department of Veterans' Affairs
GPNs	General Practice Networks
GP	general practitioner
HER	Electronic Health Record
HIA	Health Insurance Act 1973
HIV	human immunodeficiency virus
HMDS	Hospital Morbidity Data System
HPV	human papillomavirus
IHI	Individual Healthcare Identifier
IIICDRPSC	Improving Indigenous Identification in Communicable Disease Reporting Project Steering Committee

IT	information technology
MSIA	Medical Software Industry Association
NAGATSIDID	National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data
NATA	National Association of Testing Authorities
NCOPP	National Coalition of Public Pathology
NCSP	National Cervical Screening Program
NEHIPC	National E-Health and Information Principle Committee
NEHTA	National E-Health Transition Authority
NHDD	National Health Data Dictionary
NHISSC	National Health Information Statistics and Standards Committee
NHMRC	National Health and Medical Research Council
NIHIP	National Indigenous Health Information Plan (Australia)
NIRA	National Indigenous Reform Agreement
NIRAPIMG	National Indigenous Reform Agreement Performance Information Management Group
NMDS	National Minimum Data Set
NNDSS	National Notifiable Disease Surveillance System
NPTP	Nurse Pap Test Providers
NSW	New South Wales
NT	Northern Territory
PCEHR	Personally Controlled E-Health Record
PHC RIS	Primary Health Care Research and Information Service
PIP	Practice Incentive Program
PIT	Pathology Information Transfer
PKI	Public Key Infrastructure
QLD	Queensland
RCPA	Royal College of Pathologists of Australasia
SA	South Australia
SAHC	South Australian Health Commission

TAS	Tasmania
TSI	Torres Strait Islander
VCCR	Victorian Cervical Cytology Registry
VCS	Victorian Cytology Service
VIC	Victoria
VII	Voluntary Indigenous Identifier
WA	Western Australia
WACCPP	Western Australian Cervical Cancer Prevention Program

Symbols

–	nil or rounded to zero
. .	not applicable
n.a.	not available
n.p.	not publishable because of small numbers, confidentiality or other concerns about the quality of the data

Summary

Most pathology request forms do not include an Indigenous status identifier. This means that Indigenous data cannot flow from medical practitioners to pathology laboratories and from pathology laboratories to state and territory health registries. The inclusion of Indigenous status on pathology forms depends on information from the 'source' of pathology service requests—medical practitioners, surgeons or administrative staff who complete patient records. As pathology providers rely on the request form, the quality of Indigenous status information collected and recorded at source is imperative to improving identification in health registries.

Under the National Indigenous Reform Agreement (NIRA) in 2008, the Council of Australian Governments (COAG) agreed to various data quality improvements. Many of these, detailed in Schedule F of the NIRA, are focused on improving Indigenous identification in key health data sets (COAG 2011). This document was prepared by the AIHW with the input of state and territory cancer, communicable disease and cervical screening registries; Medicare Australia, the Department of Health and Ageing, the National Coalition of Public Pathology, the Public Health Laboratory Network, National Advisory Group Aboriginal and Torres Strait Islander Health Information and Data, the National Health Information Statistics and Standards Committee, and the National Indigenous Reform Agreement Performance Information Management Group.

Work on the business case began in November 2009. A consultation draft was completed in March 2010 and the Australian Institute of Health and Welfare consulted state and territory disease registries (within health departments) between April and May 2010. National committees were consulted extensively between June 2010 and August 2011. This report reflects the work undertaken during that period.

The business case shows that to improve Indigenous identification in the national health registries for cancer, communicable disease and cervical screening, the inclusion of Indigenous status on pathology request forms is key.

Some jurisdictions have already introduced Indigenous status on their pathology request forms. In addition, while the business case was being developed, progress has been made in e-health records development and uptake. The recommendations build on these two key developments.

Recommendation 1: There should be a focus on improving Indigenous identification in national health registries as part of broader work using electronic health records, and it should be part of any development of a National Minimum Data Set on primary health care.

Recommendation 2: Jurisdictions should progress the inclusion of Indigenous status on pathology request forms through mechanisms identified below:

- Continuation of projects/pilot studies to include Indigenous status on pathology forms and consideration of their roll out state-wide.
- Changes to state and territory public health legislation and regulations.
- Changes for disease registries to adhere to the national standard format for Indigenous status.
- Coordination between jurisdictions to achieve standardised requirements for pathology providers (and others affected by the proposed changes).

1 Introduction

Aboriginal and Torres Strait Islander people are one of the most disadvantaged groups in Australia. Indigenous people die younger, have a much higher prevalence of disease and are more likely to experience disability and reduced quality of life due to ill health, than other Australians (ABS & AIHW 2008).

Accurate identification of Aboriginal and Torres Strait Islander people is vital for understanding trends and disparities in health status. This data is important for planning and improving health services to meet the needs of Indigenous Australians.

The 1997 *Aboriginal and Torres Strait Islander Health Information Plan … This time let's make it happen* (the Plan) recommended that 'all major health and related collections include accurate Indigenous identification' and that 'a single classification standard' be applied to an Indigenous identification field in all future health collections across all jurisdictions and all health services (ATSIHWIU 1997 pp74–76). In 2003, all Health Ministers endorsed the National Strategic Framework for Aboriginal and Torres Strait Islander Health, with the first recommendation being to implement the 1997, using the Australian Bureau of Statistics standard for identifying Aboriginal and Torres Strait Islander people.

The National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID) oversees the improvement of information on the health of Indigenous Australians Improving Indigenous identification in cervical screening registries and on cancer and communicable disease notifications by including Indigenous identification on pathology forms has been a priority area for NAGATSIHID.

Among the initiatives in Schedule F is a proposal for the Australian Institute of Health and Welfare (AIHW) to develop a business case for including Indigenous status on pathology request forms, with the aim of improving Indigenous identification in cancer, communicable disease and cervical screening registries nationally.

Accordingly, this business case has been developed to present options for improving Indigenous identification in the Australian Cancer Database, National Notifiable Disease Surveillance System and National Cervical Screening Program. This will involve state and territory registries that feed into the national registries (See Appendix E, F & G for full details of the national registries).

Currently, Indigenous status data is either not collected at all or collected for only a small number of cases in cervical screening registries, and is under-reported in communicable disease and cancer registries. This is because cervical screening registries solely rely, and communicable disease and cancer registries partly rely, on pathology providers for their data, and pathology providers usually do not have access to Indigenous status information. The main, often only, source of information pathology providers have about their clients are the pathology request forms sent to them by physicians.

Most pathology request form templates do not include an Indigenous status indicator. Consequently, the forms do not generally request physicians to include Indigenous status, and as a result, pathology systems do not include Indigenous status. When a pathology provider notifies a state registry, therefore, they usually cannot provide the Indigenous status of the patient. Thus, an important source of data for monitoring health status is not available.

This document presents a case for ensuring Indigenous status information is available to pathology providers and collected by registries. It identifies the main changes that would need to occur and the stakeholders that are likely to be impacted. It also identifies costs to government, software vendors and pathology providers, and the benefits that would come from including Indigenous identification on pathology forms. The business case notes that changes to forms and electronic systems generally depends on Indigenous status information being available from the 'source' of pathology service requests, such as medical practitioners or hospital records.

Other considerations for improving Indigenous identification including the E-Health Record Individual Healthcare Identifier (IHI), the development of a Primary Health Care National Minimum Dataset, Medicare's Voluntary Indigenous Identifier (VII) and the Practice Incentive Payment Indigenous Health Incentive are also discussed.

The structure of the report is as follows:

- This chapter describes the background to the development of the business case to include an Indigenous status identifier on pathology request forms.
- Chapter 2 outlines previous and current studies which examine how Indigenous identification in health registries may be improved
- Chapter 3 provides information on the current situation including:
    - details on the national standard included in the National Health Data Dictionary
    - details of pathology request forms
    - an overview of data flow from pathology services to registries
    - communicable disease, cancer, cervical screening and other registries
    - pathology providers and laboratories and
    - software packages used by hospitals, practices, pathology laboratories and registries.
- Chapter 4 provides the recommendations of the 2011 business case
- Chapter 5 outlines what work has been undertaken since the 2011 business case including developments in E-Health
- Appendix A includes changes identified by the 2011 business case including software, process and practice, and legislative changes required
- Appendix B details a cost benefit analysis
- Appendix C provides early identified options to improve Indigenous identification that were included in the consultation draft of the business case
- Appendix E provides details of the Communicable disease registries by jurisdiction
- Appendix F provides details of the Cancer registries by jurisdiction
- Appendix G details of the Cervical screening registries by jurisdiction
- Appendix H contains an example pathology request form which includes an Indigenous identifier.

2 Previous and current studies

2.1 Previous studies

Several studies have investigated ways in which Indigenous identification in health registries may be improved. Two studies of note have looked specifically at pathology testing and notification processes, and how inclusion of Indigenous status on pathology request forms may lead to improved identification in cervical cancer and communicable disease registries.

These studies are discussed below. Also discussed is a study which looked at improving the identification of Aboriginal and Torres Strait Islander people in general practice.

Feasibility study into increasing the completeness of the Aboriginal and Torres Strait Islander identifier in ACT Government registries

In 2004, Acumen Alliance, commissioned by ACT Health, undertook a study to assess the feasibility of improving the identification of Aboriginal and Torres Strait Islander people in the ACT Communicable Disease, Pap Smear and Cancer registries, by including Indigenous status on the ACT Pathology's pathology request form (ACT Health 2007). The overall objective of the study was to assess whether it would be feasible to increase Indigenous identification in these registries through adding the ABS standard question on Indigenous status to the pathology request form. It assessed the scope, issues and cost of implementing the necessary changes and identified the implications for national implementation.

The study identified a number of additional system and process changes that would be necessary to capture Indigenous status, including:

- changes to forms and computer systems used by General Practitioners (GPs) and hospitals to collect and record the identifier
- changes to computer systems used by pathology laboratories to accommodate the identifier
- changes to procedures/training for GPs, hospitals and pathologists
- additional effort by GPs, hospitals and pathologies to record the identifier, and
- promotional campaigns targeting health professionals and the general community to educate them on the importance of identification and increase the rate of identification.

The study made two key recommendations. The first was to expand the scope of the project to take a national approach rather than a jurisdiction-based approach. Consultation with laboratories, GP and pathology software companies revealed that they would be reluctant to make changes if they applied to a single jurisdiction as many operate across multiple jurisdictions and additional effort and cost would be required to maintain different software versions.

The second recommendation was to capture Indigenous identification for more pathology results than just those in the cancer, communicable disease and cervical cancer registries, in order to collect data on a wider range of health issues such as diabetes.

Improving Indigenous identification in communicable disease reporting systems

A discussion paper entitled *Improving Indigenous identification in communicable disease reporting systems* was published in November 2004 under the guidance of the Improving Indigenous Identification in Communicable Disease Reporting Project Steering Committee (IIICDRPSC). The paper made recommendations for action in the short, medium and long-term.

The paper highlighted that systems for communicable disease reporting differ around the country and rely increasingly on pathology-based reporting. In most states and territories, the main source of information on communicable diseases is from pathology laboratories rather than medical practitioners, and medical practitioners in hospitals provide only a small proportion of notifications as most people with communicable diseases are not treated in hospital. Therefore the lack of Indigenous status on pathology forms greatly impacts the quality of Indigenous identification in communicable disease data.

The paper noted that relying primarily on pathology-based notifications results in the total ascertainment of cases to be higher as pathology tests are regarded as more reliable than clinical examination alone. However it also means that patient information, including Indigenous status, is limited. More complete data can only be obtained from the requesting medical practitioner or the patient through follow-up which can be time consuming and costly. The inability to transfer Indigenous identification data and other patient demographic information from medical practitioners to pathology laboratories, and from pathology laboratories to state and territory communicable disease units, was identified by key stakeholders as a major limitation. Electronic and automated systems were seen as possible ways to reduce the burden. The paper acknowledged that it would probably take leadership from the Australian Government for the collection and reporting of Indigenous status to become routine (IIICDRPSC 2004).

Various other limitations to improving the quality of Indigenous identification were identified. Some arose out of jurisdictional differences in legislation, notification and reporting systems. Current practices of the states/territories differ in:

- legislation enabling the collection and reporting of communicable disease information
- who collects Indigenous identification and how it is collected
- whether collection and recording accords to the ABS standard for Indigenous status
- Indigenous identification data completion rates.

Other limitations raised were due to deficiencies in systems and primary data collections, and limitations due to incomplete data. Organisational and cultural issues such as limited staff training to collect the information, reluctance of Aboriginal and Torres Strait Islander people to identify, and lack of public health awareness were also identified as limitations.

A number of key recommendations were made in relation to data collection. These included improving GP capacity to collect standard demographic data including Indigenous identification; and negotiation by the Australian Government to make changes to pathology reporting systems to include Indigenous identification data from primary collectors. The paper stated that 'after the option of improving GP capacity to collect Indigenous identification, the option of including Indigenous identification on pathology request forms and reporting would have the greatest impact on Indigenous identification rates in

communicable disease notifications' (page 63). This benefit would be greatest in states and territories that rely the most on pathology-based reporting.

Key recommendations were also made in relation to data recording and reporting. These included jurisdictions enabling sharing and matching of Indigenous identification data across health information systems; increasing and improving the capacity of electronic transfer of demographic data including Indigenous identification within and across systems (i.e. from GPs to pathology laboratories and back, from laboratories to jurisdictional health authorities and between different elements in health systems).

NSW Health investigation of barriers to including Indigenous status on pathology forms

In 2008, as part of a project to improve reporting for Sexually Transmitted Infections, NSW Health undertook to investigate barriers to including Indigenous status on pathology forms. At the time, the Public Health Laboratories Network and Medicare Australia advised that any changes to core information on pathology request forms needed to be approved by Medicare. This information was presented to the Communicable Diseases Network Australia (CDNA) which advised that due to the national implications, it would take the lead on this issue. As a result, NSW Health has not actively pursued Medicare Australia approval to amend pathology request forms.

Improving identification of Aboriginal and Torres Strait Islander people in mainstream general practice

The Cooperative Research Centre for Aboriginal Health has identified strategies to improve identification processes in mainstream general practice. Its project explored three questions:

- What strategies to improve the identification of Aboriginal and Torres Strait Islander people have been trialled before and what is worth trialling (feasible and acceptable) in the future?
- How can mainstream general practice be encouraged to improve identification processes for Aboriginal and Torres Strait Islander people?
- What are the links between improved identification and quality of care?

The study was conducted in two phases. The first phase included a review of the literature and interventions to improve identification; review of current medical software; analysis of Primary Health Care Research and Information Service (PHC RIS) and Medicare General Practice data; a workshop to review the evidence and provide advice to the next phase of the study; a call for public submissions through mainstream and Indigenous media; and interviews in Australia and New Zealand.

Phase two methods included case studies of General Practice Networks (GPNs) and their constituent practices; and focus group discussions with GPs, GP educators and Practice Nurses to discuss how best to embed identification in clinical practice.

In December 2009, CRCAH made the following recommendations:

1. Support the integration of identification into practice management.
2. Assist general practices to foster an environment in which Aboriginal and Torres Strait Islander people feel comfortable identifying.
3. Encourage community members to self-identify.

4. Assist general practices to develop systems for identification.
5. Evaluation, promotion and advocacy of best practice models (CRCAH 2009).

2.2 Current studies

The Victorian Department of Health (DH), Western Australian Department of Health and ACT Health are undertaking pilot projects to record Indigenous status in their cervical screening registries.

Victoria

The Victorian project coordinated by Papscreen Australia involves two phases. The first phase targeted 300 Nurse Pap Test Providers (NPTP) who use the Victorian Cytology Service (VCS). They were asked to collect Indigenous status information between September and December 2008. Rather than issuing a new pathology request form, a stamp with the standard ABS Indigenous status question was added. The form did not need Medicare approval.

About 40 nurses attended a training workshop where key Aboriginal women in the community spoke about the importance of collecting this information. During the period of analysis, 5753 Pap tests were conducted by 289 nurse providers. Of these, 48% had Indigenous status recorded. Approximately 33% of nurses didn't record Indigenous identification, 13% always did and 54% recorded it some of the time (Table 2.1). Of the nurses who attended the workshop and were surveyed, 93% went on to record Indigenous identification all of the time.

Table 2.1: Results of Stage 1 of Victorian DH pilot study to record Indigenous status in the PapScreen Victoria Program

Whether nurse recorded Indigenous status	Proportion
Did not record Indigenous status	33%
Always recorded Indigenous status	13%
Recorded Indigenous status some of the time	54%

A follow-up survey asked 39 nurses about difficulties and reasons why Indigenous status was not recorded. Among the reasons given were that the provider doesn't have Aboriginal and Torres Strait Islander clients; the nurse didn't receive the new request pad, and the provider is still using the old VCS pad. Among the reasons given for only recording Indigenous status some of the time were that women who are obviously from overseas aren't asked the question, nurses forgot to ask the question, and the question was only asked if the nurse knew the patient was Indigenous.

Cervical screening pathology providers in Victoria met to discuss introducing an Aboriginal and Torres Strait Islander status identifier into cervical screening data collection. Laboratories raised a number of issues regarding computer systems and data transfer, patient management and logistical issues, including:

Computer systems and data transfer

- Each registry has different computer systems, all of which need a significant resource investment to set up and maintain, and each has slightly different needs regarding the data being sent.

- A range of mechanisms is required to transfer information for different registries. Some pathology labs can't integrate the data from some systems into their own computer systems to enable them to use information in a streamlined manner. The process then is manual, time-consuming and at greater risk of human error.

Patient management

- Transient patients may have an incomplete patient history on any given registry.
- Women in border regions for whom mobility is high may have an incomplete patient history on any given registry.
- Clashes with coding used by different states and territories. This is gradually being resolved with some registries moving from ICD9 or ICD10 to ICD O3 in the next couple of years.
- Due to privacy legislation, some registries cannot share information with other registries.
- Some registries are unable to send patient histories to some labs.

Reasons for this may include privacy considerations.

Logistical issues which need complex programming

- Different mechanisms of receiving histology results (e.g. hard copy report, SNOMED coding, numeric coding) and different coding requirements.
- Different format of patient follow-up information.
- Different mechanisms for verifying all patient details are received.

The Victorian DH is about to begin phase two of the project. PapScreen Victoria has appointed a project officer to coordinate this, along with a project about the inclusion of Culturally and Linguistically Diverse (CALD) Identifiers in cervical screening. Phase two aims to increase the proportion of NPTP collecting Indigenous status information and will involve:

- Working more closely with the Aboriginal and Torres Strait Islander health sector and developing a communication strategy.
- Inviting GPs onto the working group.
- Investigating medical software usage.

As well as this project, Victorian DH is involved in the Victorian Women's Cancer Screening Data Linkage project. Its main objective is to use data linkage to provide baseline information about cervical screening uptake amongst Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities. The project plans to use data linkage to obtain information on Indigenous and ethnic status from related data sets. The data sets that the project proposes to link are:

- Victorian Cervical Cytology Register
- Victorian Admitted Episodes Dataset
- Victorian Emergency Minimum Dataset
- BreastScreen Victoria Register.

Western Australia

The Western Australian Cervical Cancer Prevention Program (WACCPP), Department of Health WA, is also working to include Indigenous status on pathology forms. Initial stages

aim to have all public hospital laboratories in the state collecting and recording Indigenous status information. Currently, of the 9 laboratories contributing data, the 4 public hospital laboratories (PathWest) have modified their system to be able to store Indigenous status.

In late 2008, PathWest introduced the Indigenous status question on some of their pathology request forms. This was as a result of the work WACCPP is undertaking but also in response to a formal request from the Communicable Disease Centre (CDC) to include aboriginality as part of the daily notification of positive results it receives by electronic download from PathWest.

The question adopted by PathWest is not the standard question and is not mandatory. It asks of Aboriginal descent with a Y/N tick box. A previously unused field within the laboratory computer system (Ultra) is used to record Indigenous status as [A] Aboriginal, [U] Unknown or [O] Other. The requesting practitioner is responsible for completing the Indigenous identifier field on the request form. Although some GPs have begun to complete these forms, the data cannot be mapped to the national standard.

Since 2009, WACCPP has been working with PathWest to modify the question format and the recording categories (that is, separate categories for Aboriginal and/or TSI) so that the standard question is used consistently on all forms, in line with the national standard. Once this has been achieved with the public hospital laboratories, it will be presented to private laboratories for incorporation.

To date, PathWest has not expanded the data collection fields on the request form or the laboratory computing system to align with the national standard. This is due to:

- The issue with non-compliance by requesting practitioners in completing the field, which limits its value.
- Space restrictions on regulated request forms.
- National agreement is needed to change the standard pathology request form format adopted by Medical Practice software providers across Australia.
- Significant IT changes are required to modify the expanded field of entries in the laboratory and possibly the hospital computing system.
- Issue of duplicate data collection. Anecdotally it is believed by some pathologists that Indigenous status is recorded by Medicare Australia upon registration of a patient, however it is not made available to other health agencies.

Australian Capital Territory

ACT Health is involved in a pilot project to include Indigenous status on the pathology request forms used by ACT Pathology, and to modify ACT Pathology's computer system to be able to record and receive this information. Rather than Pathology reception staff asking the question, patients having their blood taken will be given a card containing information on what patient information is needed (including Indigenous status) and why (accreditation and to support government reporting). They will then be given the opportunity to state whether they are of Aboriginal and Torres Strait Islander origin. Posters and brochures on the importance of Indigenous identification will also be introduced in collection centres.

This will be trialed for one month in April 2010 in one of the seven collection centres. Any issues will be discussed and addressed, and if considered feasible the trial will be rolled out to all seven collection agencies.

South Australia

SA Pathology (trading as IMVS Pathology) is the sole provider of pathology in the Public Hospital sector and a major provider to the private GP and Specialist market. Its pathology request form does not provide a field for Indigenous status. The SA Department of Health and SA Pathology are working together to address this. The project scope under development includes a review of impacts on affected registries such as Cancer and modifications to SA Pathology's information and technology system to be able to record and receive this information. Importantly, SA Pathology will take legislative approach to enable its pathology forms to be amended to include a field for Indigenous status. 'Aboriginal Identifier' training for relevant staff in SA Pathology will follow.

3 The situation in 2011

3.1 National standards

The National Health Data Dictionary (NHDD) is the authoritative source of health data definitions where national consistency is required under the National Health Information Agreement. The NHDD includes the national standard for Indigenous status which was developed by the Australian Bureau of Statistics (ABS) to improve the quality, availability and comparability of Indigenous statistics across data collections; it includes a standard Indigenous status question module.

By Commonwealth definition, the term 'Indigenous status' refers to whether a person is of Aboriginal or Torres Strait Islander origin, identifies as such and is considered as such by the community with which he or she is associated. It is recognised that the third element cannot be measured by the standard question module (HDSC 2006 pp820–824). The national standard question is as follows:

Box 3.1: Standard NHDD Indigenous status question

[Are you] [Is the person] [Is (name)] of Aboriginal or Torres Strait Islander origin?

(For persons of both Aboriginal and Torres Strait Islander origin, mark both 'Yes' boxes.)

□ No

□ Yes, Aboriginal

□ Yes, Torres Strait Islander

Source: HDSC 2006.

Note that the standard question does not include a category for 'Not known'. However, in NSW where the response has been been refused or not recorded, the code 'Not stated/inadequately described' may be used in data collections.

The NHDD recommends the following detailed output classification structure for Indigenous status, which is consistent with the ABS:

1=Aboriginal but not Torres Strait Islander origin

2=Torres Strait Islander but not Aboriginal origin

3=Both Aboriginal and Torres Strait Islander origin

4=Neither Aboriginal nor Torres Strait Islander origin

9=Not stated/inadequately described.

Data can then be presented according to these detailed categories or in broader groupings such as Indigenous, non-Indigenous and not stated (HDSC 2006 pp820–824).

National best practice guidelines for collecting Indigenous status in health data sets

The AIHW has produced National Best Practice Guidelines that document the recommended national approach for collecting and recording accurate information on the Indigenous status

of people attending health services. They set out best practices in collecting and recording this item, and strategies that can be implemented by data collectors, data managers and data custodians.

The Guidelines address the need for a more systematic national approach to ensure the standard Indigenous status question is asked correctly and consistently of all clients of health services, and that this information is recorded properly.

The Guidelines were informed by a review of previous research into Indigenous under-identification in administrative data collections, consultation with key stakeholders and a series of research projects commissioned by the National Health and Medical Research Council (NHMRC) and carried out by the AIHW.

The Council of Australian Governments (COAG) National Indigenous Reform Agreement (NIRA) sets out a timeline for all jurisdictions to complete implementation of the guidelines by December 2012.

The Guidelines were published by the AIHW in April 2010.

3.2 Pathology request forms

Pathology request forms are generally prepared by Approved Pathology Authorities or Approved Pathology Practitioners (pathology services accredited by Medicare Australia allowing them to bulk bill for tests as specified within the Medicare Benefits Schedule). They are distributed to requesting practitioners and previously needed to be approved by Medicare. Since 2010, approval from the Department of Health and Ageing has been required. In order for a Medicare benefit to be paid for a pathology test, amongst other things, the request form must be approved by Medicare Australia. Medicare Australia also has the right to require inclusions on the request form. Pathology request forms which are the subject of a Medicare benefit can therefore have the Indigenous identifier mandated (more than half of pathology tests are the subject of a Medicare rebate). The National Association of Testing Authorities, through which all pathology laboratories are required to be accredited, may also need to be informed of changes or additions to pathology request forms.

The minimum data requirements for written requests for pathology services includes the name of the person to whom the request is directed, practice address and provider number of the requesting practitioner, the requesting practitioner's signature and date of request, patient's name, address, date of birth, sex and Medicare number and details of the hospital status of the patient (if applicable). Indigenous status is not required.

In most states and territories, pathology request forms do not include Indigenous status. Request forms for some public pathology services include an Indigenous status item but this field is rarely completed by the requesting clinician (communication with National Coalition of Public Pathology, July 2010). In Queensland, Western Australia, the Northern Territory, Victoria and New South Wales, a small proportion of pathology request forms include Indigenous status.

- Queensland Pathology (public hospital laboratories—Auslab) includes a field for Indigenous status on its request form.
- In New South Wales, one laboratory includes a field for Indigenous status.

- The Northern Territory Government Pathology Service, which is used by public hospitals, includes a question on Indigenous status on its request form. There is a very poor compliance in this being completed, however, with a high error rate in obtaining second patient identifiers. The computer system used by Pathology "Labtrack" includes Indigenous status as a compulsory field and when uploaded from the Department's "Caresys" will automatically be filled, but this does not appear on the lab result. As Indigenous status is not a mandatory criteria for accreditation, it is not focused on nor reported on.
- In Western Australia, PathWest includes a field for Indigenous status on some of its pathology request forms but it does not accord with the national standard (see Appendix H for an example).
- The Victorian Cytology Service is collecting Indigenous status as part of pilot projects (see section 1.2 for more detail).
- Since May 2010, ACT Pathology has been trialling the collection of Indigenous status in one of its collection centres. If considered feasible, it will be rolled out to all seven collection agencies.
- In South Australia, Indigenous status is not included on pathology request forms. The SA Department of Health and SA Pathology are working together to address this issue which will include reviewing modifications to SA Pathology's information and technology system to be able to record and receive this information.

There is no national standard for the structuring of pathology reports, but there may soon be some uniformity as a result of the Structured Pathology Reporting of Cancer Project. This project aims to standardise reporting of cancer cases in Australia, including standardising the format of pathology reports and developing HL7 messaging standards and archetypes in conjunction with the National E-Health Transition Authority (NEHTA). The project is being overseen by the Royal College of Pathologists Australasia with clinical consultation from the Cancer Institute, in conjunction with Cancer Australia.

3.3 Overview of data flow

Although there is some variability between registries, data is transmitted through broadly the same process. Figure 3.2 outlines the data flow from the patient first contacting the service provider through to the pathologist providing data to the registry.

Most patients complete a patient registration form when first attending a service provider. This information, which may or may not include Indigenous status, is either entered into some form of practice software, into a paper-based patient file or both. Not all practice software which has the ability to record Indigenous status conforms to the national coding standard.

When requesting pathology services, the service provider either electronically generates a pathology request form from the software or manually completes the form. In some cases, electronic forms are directly transmitted or emailed to the pathology service. These forms are not required to include Indigenous status.

On receiving the form, pathologists who employ patient management software ensure the relevant data is in their system and conduct the required pathology services. On receiving test results that require submission to a registry, they either:

- telephone the registry hotline

- complete a paper form and fax or post it to the registry or send it direct to the registry's printer
- mail or fax the result to the registry
- enter the required information using an online data submission process or
- submit the data electronically directly to the registry.

In some states and territories (e.g. WA and QLD), information is most commonly transmitted electronically from the pathology laboratories to the registries, while in other states and territories (e.g. NSW, ACT and NT) it is more commonly transmitted as paper reports. All registries except the NSW Cervical Cytology Registry can record Indigenous status data. Not all registries use the national standard so data may differ between registries and jurisdictions.

Once information is stored by the registries within each jurisdiction, the data are reported within the jurisdiction and forwarded to the national data collection (AIHW for cancer and cervical screening; DoHA for communicable diseases) to be collated and reported nationally. These national collections (Australian Cancer Database, National Notifiable Disease Surveillance System and National Cervical Screening Program) include a data item for Indigenous status which is in accordance with the national standard, although not all jurisdictional registries may record the data in that format. Note that the National Cervical Screening Program is not a national database for cervical screening as such, but rather the AIHW receives aggregated data from the states and territories to collate nationally.

The inability to transfer Indigenous identification data from medical practitioners to pathology laboratories, and from pathology laboratories to state and territory registries, is a major limitation to improving Indigenous identification in communicable disease and cervical screening data, which largely rely on pathology to obtain patient information. It is also a notable (but less major) limitation to improving Indigenous identification in cancer data.

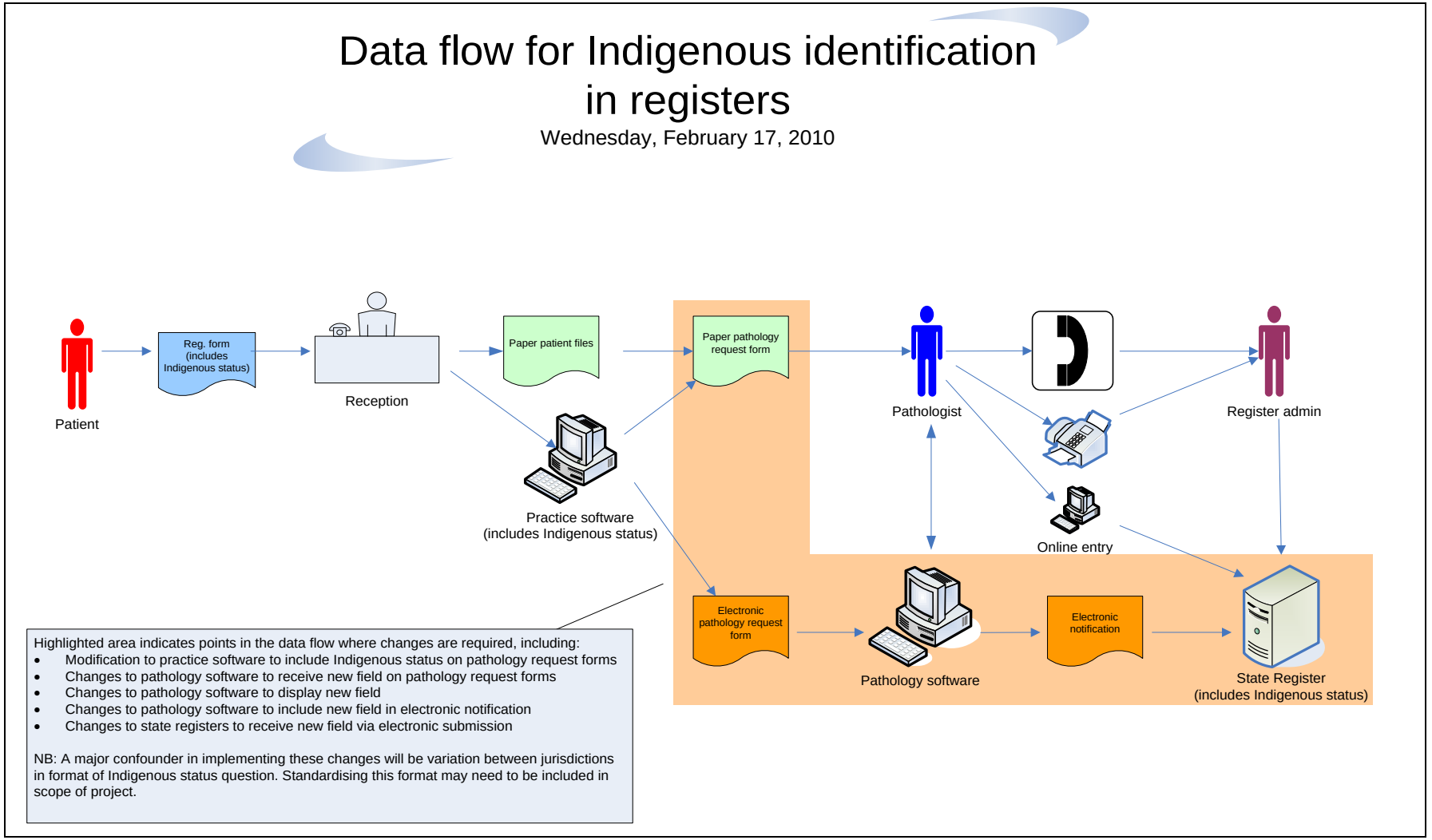
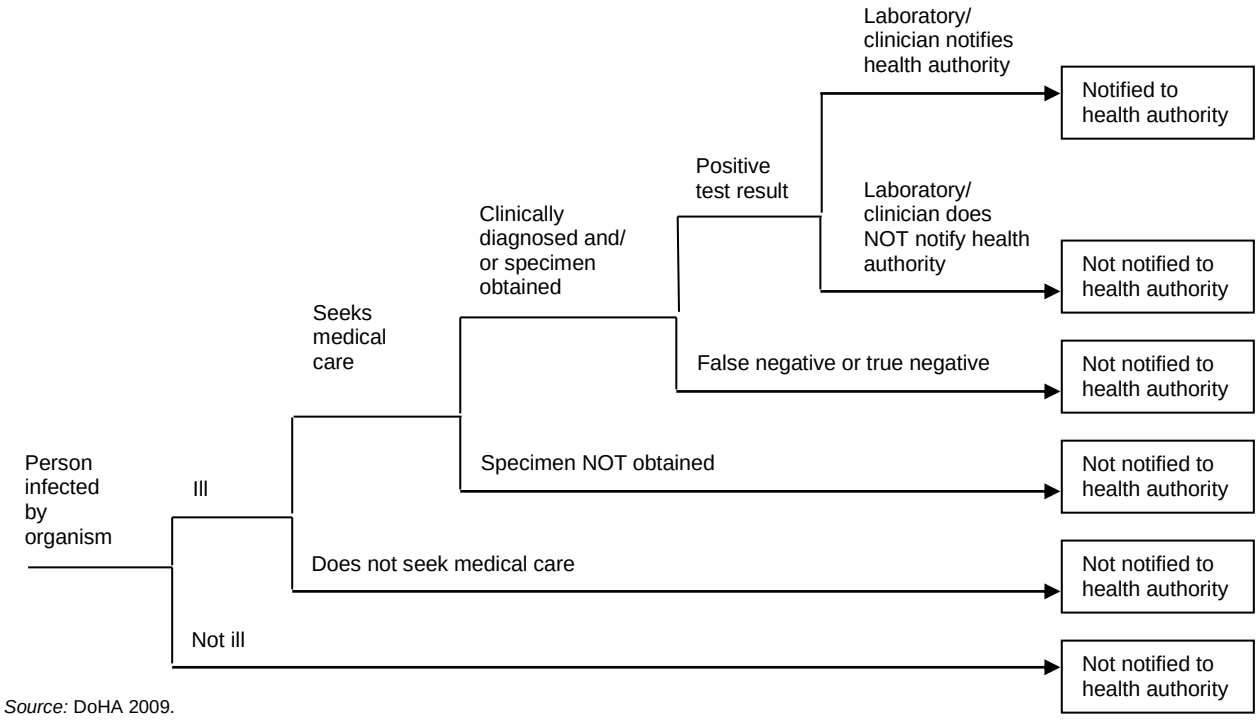


Figure 3.2: Data flow for Indigenous identification in registries

3.4 Communicable disease registries

Background

Notifiable communicable diseases must be reported in Australia. Medical practitioners and/or pathology laboratories are required under public health legislation to report communicable diseases to the relevant state or territory registry. Notified cases only represent a proportion ('notified fraction') of the total incidence of the disease as not all infected people seek medical care, and not everyone seeking medical care is clinically diagnosed with the disease (Figure 3.3).



Source: DoHA 2009.

Figure 3.3: Points at which Indigenous status may be collected or transferred

Information on communicable diseases is obtained from pathologists and medical practitioners. Information from hospitals may also be used; however, most cases of a communicable disease do not result in hospitalisation.

In some states and territories, medical practitioners use online notification forms for reporting communicable diseases, while in other jurisdictions paper notification forms are used. Some conditions require immediate telephone or fax notification. Pathology laboratories generally do not use the same notification forms as medical practitioners, but rather are required to notify diseases through a different process, mostly involving electronic transfer of data.

National situation

State and territory health departments collect notifications of communicable diseases under their public health legislation and are required under the National Health Security Act 2007 to forward this information to the National Notifiable Disease Surveillance System (NNDSS) for national collation. In most states and territories, it is not a legislative requirement to collect and report Indigenous identification in communicable disease notifications (IIICDRP 2004).

Until recently, the states and territories voluntarily provided de-identified information on notifiable diseases to the Australian Government Department of Health and Ageing to be collated in the NNDSS. Under the National Health Security Agreement 2008, it is now mandatory for states and territories to provide de-identified information on notifiable diseases.

In 2007, 69 diseases were nationally notifiable. Not all of these were notifiable in each jurisdiction. The NNDSS is complemented by other surveillance systems which provide information on various diseases, including four that are not reported to the NNDSS (AIDS, HIV, and the classical and variant forms of Creutzfeldt-Jakob disease). The collation of national data began in 1990 through the collaboration of the Australian Government and the states and territories through the Communicable Disease Network of Australia (CDNA). Data are sent electronically from the states and territories daily or several times a week.

While the NNDSS includes Indigenous status that uses the national standard, it is not mandatory for the states and territories to supply it. Not all states and territories use the national standard for Indigenous status on their notification forms and in their communicable disease reporting systems. All jurisdictions supply Indigenous status information to the NNDSS in the ABS standard question format. Depending on the format of data from pathology labs, medical practitioners and hospitals, some states and territories may need to align data to the standard format before sending to the NNDSS.

The quality and completeness of data compiled in the NNDSS are influenced by various factors. Notifications may be required from treating clinicians and/or diagnostic laboratories and/or hospitals. The mechanism of notification varies between states and territories and some diseases are notifiable by different mechanisms. The proportion of cases seen by health care providers that are the subject of notification to health authorities is not known with certainty for any disease, and may vary among diseases, between jurisdictions and over time.

The completeness rate (proportion of records that have Indigenous status information) in communicable disease notifications, is assessed annually for each state and territory. Completeness gives an indication of missing data but not the accuracy of available data. Completeness varies greatly by state and territory and by disease, depending on the processes that individual states and territories have in place to obtain the information. In 2008, Indigenous status was complete in 50% of NNDSS notifications.

Diseases that are followed up in enhanced surveillance to seek additional information related to risk (e.g. some sexually transmissible diseases and vaccine preventable diseases), generally have higher Indigenous identification completion rates as this information can be sought if not already held. The Communicable Disease Network Australia has a list of diseases where there has been agreement to a target of 90% completion of Indigenous status. In 2008, there were seven diseases for which notifications were 100% complete (donovanosis, measles, leprosy, tetanus, Murray Valley encephalitis, Japanese encephalitis and Kunjin virus

infection) and a further five diseases which exceeded 90% completeness for Indigenous status (typhoid, tuberculosis, meningococcal infections, *Haemophilus influenzae* type b infection and syphilis).

State and territory situation

See Appendix E for detailed information on the individual state and territory communicable disease registries in relation to legislation, sources of information for communicable disease notifications, notification mechanisms, Indigenous status format on notification forms and in data reporting systems, transmission of data from local registries to the Commonwealth for national collation, and Indigenous status completion rates. A summary can be found in Table 3.1.

Table 3.1: Indigenous status in communicable disease notifications to state and territory health departments

State/Territory	Proportion of notifications which source information from pathology only[(a)]	Completion rate[(b)] (2008)	Indigenous status recorded in national standard format?	Legislative changes required to mandate the collection of Indigenous status by pathology?	Legislative changes required to mandate the collection of Indigenous status by GPs, hospitals
NSW	95%	25%	√	X	X
VIC	50%	53%	√	√	X
QLD	99%	42%	√	√	√
WA	27%	78%	X	X	X
SA	15%	85%	√	√	√
TAS	95%	56%	√	X	X
ACT	98%	12%	X	√	√
NT	98%	94%	√	X	X

(a) 2005 for Qld, WA, Tas & ACT; 2008 for NSW, SA & NT; 2007 to 2008 for Vic.

(b) Completion rate is the proportion of notified cases that have Indigenous status information recorded.

In most states and territories, the main source of information on communicable diseases is from pathology laboratories rather than from medical practitioners. In New South Wales, Queensland, Tasmania, the Australian Capital Territory and the Northern Territory, 95% or more of notifications were reported by the laboratory only. In Victoria and Western Australia, around half of notifications were reported by the medical practitioner and laboratory. In South Australia, around three-quarters of notifications were reported by the medical practitioner and laboratory. Only Western Australia reported greater than 15% of notifications were reported by doctors only.

In most states and territories, it is not a legislative requirement to collect and report Indigenous identification in communicable disease notifications (IIICDRP 2004). Legislative changes are needed in Queensland, South Australia and the Australian Capital Territory to mandate the collection of Indigenous status by GPs and hospitals, and in Victoria, Queensland, South Australia and the Australian Capital Territory for collection by pathology laboratories.

Although it may not be required, Indigenous identification data for notifiable communicable diseases is collected by GPs and other medical practitioners in all states and territories. It is not, however, collected by pathology laboratories in most states and territories (see section

2.2 for details of which labs and jurisdictions include Indigenous status on pathology forms). Western Australia and the Northern Territory have the potential to data match/share with their hospital information systems to provide additional Indigenous status information. In Queensland, hospital admission data and vaccination data may be used to obtain missing Indigenous status information.

In most states and territories, communicable diseases are most commonly notified by fax, mail or phone. Some states and territories such as Victoria have online notification forms, while other jurisdictions use paper forms. These are generally required to be completed by medical practitioners, while pathology laboratories generally notify diseases through a different process, such as by faxing or posting the result to the registry. In Victoria, pathology laboratories are required to notify diseases in writing within five days, and in addition, immediately by telephone for Group A diseases. In Queensland and Western Australia, the vast majority of notifications from pathology laboratories are electronic. Indigenous status information is not required from laboratories.

Not all states and territories use the national standard for Indigenous status on their notification forms and in their communicable disease reporting systems. New South Wales, Victoria, Queensland, South Australia, Tasmania and the Northern Territory use the national standard, while the other jurisdictions can provide data for the categories 'Indigenous', 'non-Indigenous' and 'not stated' but do not identify Torres Strait Islanders separately.

The completeness rate (proportion of cases that have Indigenous status information) in communicable disease notifications, is assessed annually for each state and territory. Completeness gives an indication of missing data but not the accuracy of available data. Completeness varies greatly by state and territory and by disease. In 2008, Indigenous status was complete for 93% of notifications in the Northern Territory, 85% in South Australia, 78% in Western Australia, 56% in Tasmania and 53% in Victoria. In the remaining jurisdictions, less than 50% of notifications were complete.

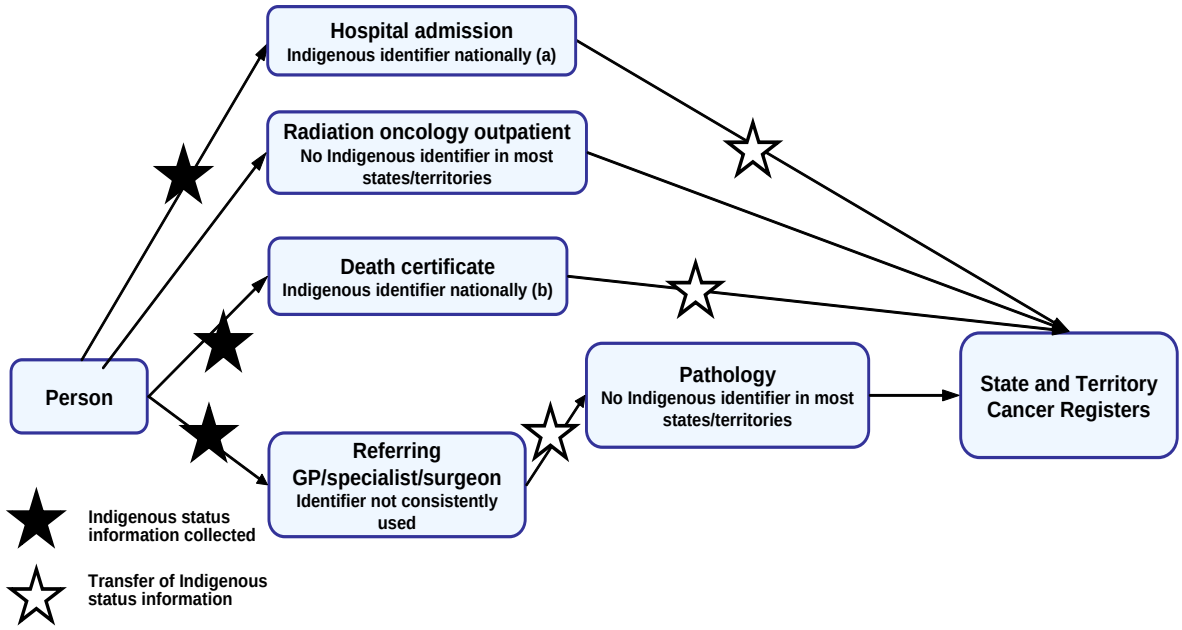
3.5 Cancer registries

Background

Notification of all diagnoses of, and deaths due to, cancer (with the exception of basal cell and squamous cell carcinoma of the skin) is required by law in all Australian states and territories. Each state and territory operates its own cancer registry to record all cases of cancer in residents.

The registries obtain their information from a variety of sources. Although these vary from state to state, notifications are generally received from pathology laboratories, radiation oncology units, hospitals, and Registrars of Births, Deaths and Marriages. Some states and territories also receive information from nursing homes.

Figure 3 outlines the four potential flows of information to the cancer registry: pathology, hospital admission, radiation oncology and death certificate. Some allow for Indigenous status to be recorded/reported and others do not.



(a) Hospital data by Indigenous status are published for NSW, Vic, Qld, WA, SA and NT only.

(b) Deaths data by Indigenous status are published for NSW, Qld, WA, SA and NT only.

Figure 3.4: Points at which Indigenous status may be collected or transferred

For most cancer notifications, the standard flow of information would involve the GP referring a patient (usually via a letter) to a surgeon or specialist for a biopsy. Results would be reported on a histopathology report by the hospital or specialist. Some patients may also be referred to an oncologist for scans. Around 90% of tumours are confirmed by histopathological examination (the microscopic examination of tissue by a pathologist) and haematology (deals with aspects of diseases that affect blood such as leukaemia and lymphoma). A smaller proportion of cases are not histopathologically verified, but instead are clinically diagnosed and tumour specific. These are usually diagnosed in hospital or through radiology/imaging (imaging data is not collected by cancer registries). Lastly there are tumours that are treated in an ambulatory care setting and Indigenous status is not recorded unless the patient dies and it is recorded on their death certificate. These cancers include melanoma and CLLs (leukaemia). CLLs, melanoma and clinically diagnosed cancer are the only cancers that are not notified by hospital or death certificate.

Sources of information

Hospitals

Hospital admissions staff ask the patient for their Indigenous status and it is recorded in the hospital database and forwarded to the relevant state or territory cancer registry where required. The person in charge of the hospital, or someone on their behalf, is legally required to notify the relevant registry of a cancer diagnosis, in between 30 days and 3 months of diagnosis.

In practice, the staff member entering the cancer diagnosis into the hospital's electronic administration system is reminded (e.g. by a 'pop-up screen') to notify the state and territory cancer registry. This may be done electronically or sometimes by paper forms.

Death certificates

For medical cause of death certificates completed by doctor and death registration forms completed by the funeral director, relatives or friends are asked for the Indigenous status of the deceased person. Where the cause of death is cancer, these data are sent to the cancer registries.

Radiation oncology

In most states and territories, radiation oncology services do not ask patients about their Indigenous status and therefore it cannot be transferred to the registries. In New South Wales and Queensland, however, Indigenous status is requested from radiotherapy and medical oncology departments. In the Northern Territory radiation oncology services use the same patient identifiers as the public hospital system. As this contains an Indigenous identifier, Indigenous status can be obtained from the hospital database.

Pathology

Pathology services do not deal directly with the patient and thus are unable to ask for demographic information such as Indigenous status. The referring doctor may ask for the patient's Indigenous status but this is rarely recorded on the pathology request form due to an absence of Indigenous status on the form. In rare instances where the GP may note a patient's Indigenous status on the form, the information is 'lost' at the pathology service and not transferred to the pathology report or to the registries. In most states and territories, legislation holds the person in charge of a pathology service responsible for forwarding a copy of the pathology report to the cancer registry, usually between seven days and three months.

Pathology reports are the principal source of notifications of cancer diagnoses in all jurisdictions and, indeed, diagnosis through a pathological examination is considered to be the gold standard. This is therefore a critical point in the flow of information about the patient to the cancer registry.

Data matching of numerous sources

Although there is no Indigenous status information on the pathology report, data matching with subsequent reports, such as hospital admissions or death registrations, is undertaken to establish the Indigenous status of a person with cancer. Data matching is undertaken for most patients, as only a small number of cancer cases (e.g. melanoma) rely on the pathology report alone for patient demographic information. In some cases where Indigenous status is missing on other sources, the information may be obtained through direct follow-up with the hospital or treating doctor.

When a report, usually a pathology report, is received with no Indigenous status, the field is entered either as 'missing, not stated/inadequately described' or 'non-Indigenous'. When a second record is received, usually from a hospital, radiation oncology department or from Births, Deaths and Marriages, the indicated Indigenous status is used to overwrite the missing information. Indigenous status information may sometimes be missing from the secondary source, resulting in missing Indigenous status information for some records.

National situation

The individual state and territory cancer registries through the Australasian Association of Cancer Registries (AACR) work in partnership with the Australian Institute of Health and

Welfare (AIHW) to compile the Australian Cancer Database (ACD). The database is maintained in National Cancer Statistics Clearing House at AIHW and contains data on all invasive cancers diagnosed in Australian residents. Data are transmitted electronically from the state and territory registries to the AIHW as identified unit record files, usually as compressed files on CD in zipped and encrypted form.

The data items enable national analysis of cancer data by site. The ACD also undertakes data linkage with the National Death Index which enhances the accuracy and completeness of national cancer information.

The ACD includes a field for Indigenous status according to the national standard. Data from the states and territories that is not in the correct format is mapped to the NHDD standard categories. Because questions and response options used to identify Indigenous status may vary by source of information, adherence to national standards is not guaranteed.

Ascertainment of cancer cases is considered close to complete for all state and territory cancer registries, but Indigenous identification is not complete for any cancer registry. In some cases, cancers in Indigenous people are not notified because of lower rates of autopsy. In other cases, the cancer is registered without Indigenous status. In 2006, the national completion rate (proportion of cancer notifications for which Indigenous status was recorded) was 80% (AIHW unpublished data).

State and territory situation

See Appendix F for detailed information on the individual state and territory cancer registries relating to legislation, sources of information for cancer notifications, notification mechanisms, Indigenous status format on notification forms and in data reporting systems, transmission of data from the registry to the Commonwealth for national collation, and Indigenous status completion rates. The text and table below summarises this information.

Table 3.5.1: Indigenous status in state and territory cancer registries

State/Territory	Proportion of notifications which source information from pathology (%)	Completion rate 2006[(a)]	Indigenous status in national standard format?	Are legislative changes needed to mandate the collection of Indigenous status by pathology?	Are legislative changes needed to mandate the collection of Indigenous status by hospitals?
NSW	86	n.a.	√	√	X
VIC	n.a.	76.6	X	√	X
QLD	80	83.1	√	√	X
WA	n.a.	98.4	X*	X	X
SA	n.a.	83.2	√	√	X
TAS	94	39.4	√	√	X
ACT	n.a.	n.a.	√	√	√
NT	95	97.0	√	X	X

New WA data is in the standard format but non-standard format is retained for preservation of historical data.

(a) Completion rate is the proportion of records that have Indigenous status information recorded.

In all states and territories except the Australian Capital Territory, hospitals are legally required to collect and report Indigenous identification in cancer notifications. Western

Australia and the Northern Territory are the only jurisdictions for which no legislative change is required to mandate the collection of Indigenous status by pathology laboratories.

In all states and territories, information on cancer notifications come mainly from pathology laboratories, radiation oncology units, hospitals, and Registrars of Births, Deaths and Marriages. Some states and territories may also receive information from nursing homes. In Tasmania and the Northern Territory, over 90% of cancer notifications use pathology reports as a source of information, in New South Wales 86% do, and in Queensland an estimated 80% do. Indigenous status data is usually only recorded in hospital records or death registrations.

In New South Wales, Queensland, the Australian Capital Territory and the Northern Territory, pathology laboratories notify cancer cases by paper form. In Victoria, Western Australia and Tasmania, larger laboratories notify cases electronically, while most of the smaller laboratories use paper forms. In South Australia, paper, fax, electronic and other mechanisms are used.

Questions and response options used to identify Indigenous status may vary by source of information and by state and territory and thus adherence to national standards is not guaranteed. New South Wales and Queensland have cancer notification forms that include the standard Indigenous status question and recording categories. All jurisdictions except Victoria and Western Australia comply with the national standards for recording Indigenous status. Both states include an additional category of 'Aboriginal +/or Torres Strait Islander (unspecified)'. Although Western Australia has a high coverage rate of cancer registrations for Indigenous people overall, historical data do not separately identify Aboriginal Australians and Torres Strait Islanders. New data do provide such a distinction. Northern Territory institutions use the standard Indigenous status format. Pathology reports sent to the Northern Territory Cancer Registry do not include Indigenous status.

The AIHW estimates that in 2006, Indigenous status was complete for 98% of notifications in Western Australia, 97% in the Northern Territory, 83% in South Australia and Queensland, 77% in Victoria and 39% in Tasmania. Estimates of the level of under-reporting of Indigenous status in mortality and hospital data can also be used to give an indication of the quality of Indigenous cancer notifications. It has been estimated that under-reporting in the Northern Territory is 15–20%, in Western Australia 25–30% and in South Australia 30–35% (Cunningham & Paradies 2000). More recent hospital admission data suggests that under-reporting is less than 10% in Western Australia and the Northern Territory. However, hospital admission data are only one of a number of sources of information for cancer registries.

3.6 Cervical screening registries

Background

Cervical screening is provided as part of mainstream health services across Australia, usually by general practitioners. Cervical screening registries are referred to as cervical cytology or Pap test registries in some states and territories.

Each jurisdiction maintains a cervical screening registry that generally reports cases of cancer to state and territory registries. The registries promote regular participation, facilitate the follow-up of abnormal Pap tests, assist with accurate reporting of Pap tests by pathology laboratories and facilitate the monitoring and evaluation of the effectiveness of initiatives aimed at improving participation in screening services.

Cervical screening data generally only come from pathology laboratories. In most states and territories, demographic data from laboratories are limited to the information on the pathology request form, which usually does not include Indigenous status. Indigenous status therefore cannot be recorded even though most registries have a field for Indigenous status in their recording systems.

In some jurisdictions, public health legislation does not allow Indigenous status information to be collected in cervical cytology registries. Legislation may therefore need to be amended.

National situation

Each of the eight states and territory cervical cytology registries provide data to the AIHW on participation in cervical screening, early re-screening, and low- and high-grade abnormality detection. Data are then compiled for national monitoring as part of the National Cervical Screening Program (NCSP). Data are submitted electronically, mostly by encrypted email as excel spreadsheets, and generally under a strict protocol agreed to by the registries. Data includes all women screened in each jurisdiction, not just women resident in each jurisdiction. The two exceptions to this are Victoria and the Australian Capital Territory, which only supply data on residents.

NCSP data includes an Indigenous status item according to the national standard but it is not completed due to the absence of this field on pathology forms.

It should also be noted that a National HPV Vaccination Registry is being established. Housed in Victoria, it will be an additional source of information on cervical cancer among Australian women. It may soon be possible for information to be exchanged between the cervical screening registries and the HPV registry.

State and territory situation

See Appendix G for detailed information on the state and territory cervical screening registries relating to legislation, sources of information for tests, notification mechanisms, Indigenous status format on notification forms and in data reporting systems, and transmission of data for national collation. The text and table below summarises this information.

Table 3.6.1: Indigenous status in state and territory cervical screening registries

State/Territory	Proportion of records that rely on pathology only	Does State/Territory registries have capacity to record Indigenous status?	Do State/Territory registries have capacity to record Indigenous status in the national standard format?	Are legislative changes required to enable collection of Indigenous status?	Are legislative changes required to mandate collection of Indigenous status?
NSW	100%	X***	X***	X***	√
VIC	100%	√	√	X	√
QLD	100%	√	√	√**	√
WA	100%	√	√	X	X*****
SA	100%	X*	X*	X	√
TAS	100%	√	√****	X	√
ACT	100%	√	√	X	√
NT	100%	√	√	X	X

* The South Australian Cervix Screening Program does not collect Indigenous status, however from 2010, a new system was implemented with the capacity to receive and store this information according to national standards.

** Legislative changes are needed, and currently being sought, to enable collection of Indigenous status by the Qld Pap Smear Register.

*** A recent amendment to the NSW Public Health Act 1991 will permit the collection and storage of Aboriginality on the New South Wales Pap Test Register from 1 January 2012.The NSW Pap Test Registry is building the capability to record Indigenous status information.

**** Tasmania does not collect Indigenous status in the national standard format, but has the capacity to record it this way.

***** Although WA legislation requires a patient's Indigenous status to be provided, the field to indicate it is optional and cannot be made mandatory until the information is available from laboratories.

Cervical screening data come solely from pathology laboratories. In most jurisdictions, records are sent electronically to the registry although some smaller labs send hard-copy reports for which data must be entered manually. In Victoria and the Northern Territory, results are sent in varying forms such as paper, fax or electronically. Data sent electronically is often via encrypted email attachments for security.

All cervical screening registries except South Australia and New South Wales have a field for recording Indigenous status according to the national standard. Although South Australia and New South Wales do not have the capacity to store Indigenous status information, a new system is being implemented that does have the capacity to receive and store this information in the standard format.

As demographic data from laboratories are limited to the information on the pathology form (which usually does not include Indigenous status), Indigenous status in cervical screening data cannot be recorded in most states and territories. In Victoria, a small proportion of records have Indigenous status recorded as part of a pilot study (see section 1.2). In Queensland, about 5% of records have Indigenous status recorded as some pathology request forms include Indigenous status, but it is not mandatory and is often overlooked. In all other jurisdictions, Indigenous status is not recorded.

Queensland legislation may need to be amended as it does not allow Indigenous status information to be collected in its cervical screening register. An amendment to the New South Wales Public Health Act 1991 permits the collection and storage of Aboriginality on the New South Wales Pap Test Register from 1 January 2012. In the Australian Capital Territory, a regulatory change was made to enable the collection of Indigenous status by the Australian Capital Territory Cervical Screening Register. In all states and territories except the Northern Territory, it is not mandatory for cervical screening registries to collect Indigenous status information.

3.7 Other health registries

Other national health registries such as the National Diabetes Register, the Breast Screen Australia Program and the National Bowel Cancer Screening Program rely on registration forms or questionnaires completed by the client/participant to obtain demographic information, including Indigenous status. These forms include the standard Indigenous status question. Although screening for diabetes, breast cancer and bowel cancer involve pathology testing, no client information is sourced from pathology laboratories. Including Indigenous status on pathology request forms will therefore have little impact on improving Indigenous identification in these registries. These health registries will therefore not be discussed further in this business case.

3.8 Pathology providers and laboratories

Pathology activities may be performed in centralised laboratories, specialised units or in clinical near-patient situations. Pathology operations usually consist of a number of collection centres serviced or supported by a smaller number of central laboratories. All pathology testing must be undertaken in laboratories accredited by the National Association of Testing Authorities (NATA). Along with NATA, the Royal College of Pathologists of Australasia (RCPA) conducts regular audits to ensure accreditation standards are maintained.

Public pathology laboratories account for about 40% of the pathology market and private laboratories for 60%. Australia has around 20 state-wide pathology services run by state and territory health departments including ACT Pathology; Pathology Queensland; Northern Territory Government Pathology Service; SA Pathology; PathWest (WA), Royal Hobart Hospital Service and Launceston General Hospital Pathology Department (Tasmania); in New South Wales—Sydney South West Pathology Service, South Eastern Area Laboratory Service, Western Pathology Cluster, Northern Pathology Cluster; and in Victoria — Melbourne Health, Eastern Health Pathology, Austin Health, The Alfred Hospital, Monash Medical Centre (Southern Health), Royal Women's and Children's Parkville, Victorian Cytology Service, Victorian Infectious Disease Reference Laboratory, Goulburn Valley Health Pathology Service and Swan Hill Hospital.

There are about 350 private pathology businesses in Australia, but IBISWorld estimates that the top four account for around 90 per cent of industry revenue (NEHTA 2009). Sonic HealthCare Limited holds the largest share of the market (38%), with more than 60 laboratories servicing 700 collection centres across 13 pathology companies nationally (NEHTA 2009). Its companies include Sullivan Nicholaides Pathology, Douglas Hanley Moir Pathology, Barratt & Smith Pathology, Southern. IML Pathology, Capital Pathology,

Melbourne Pathology, Launceston Pathology, Hobart Pathology, North West Pathology, Clinpath Laboratories, Bunbury Pathology and Clinpath Pathology.

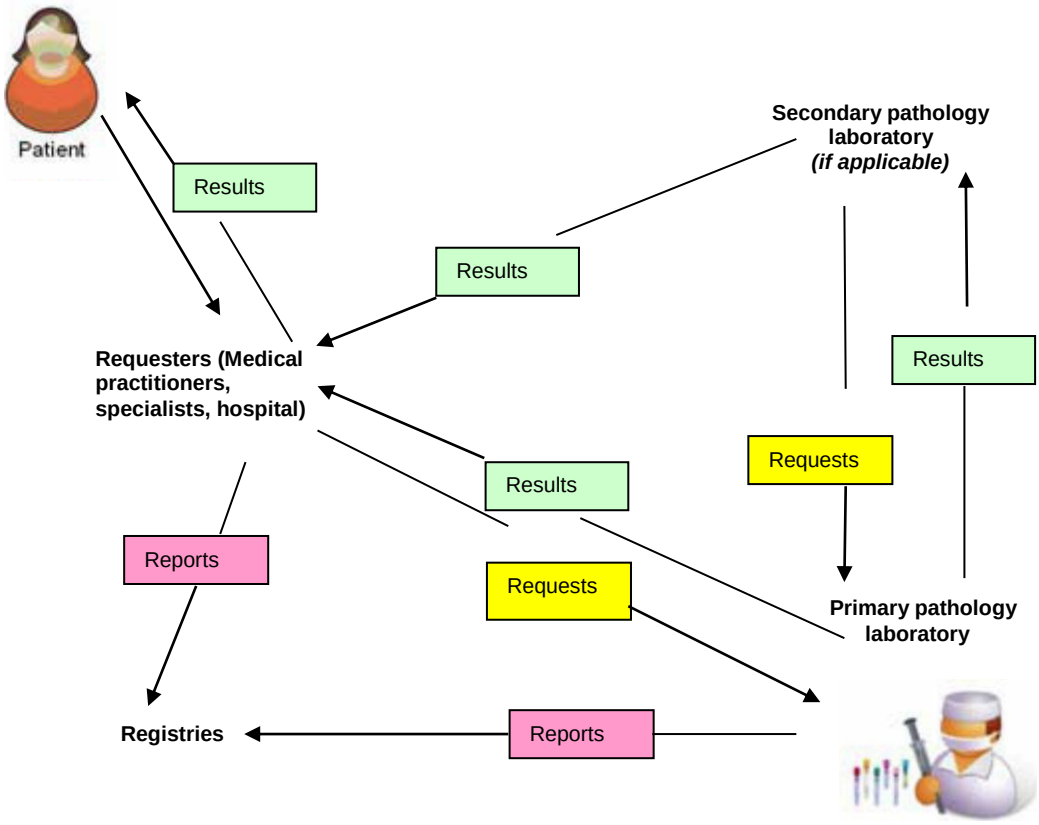
Primary Health Care Limited holds 37% of the market. It merged with Symbion Health in 2008 and operates 95 laboratories and 795 collection centres nationally. Its companies include SDS Pathology, Dorevitch Pathology, Gippsland Pathology Service, Symbion Laverty Pathology, QML Pathology and Western Diagnostic Pathology.

Healthscope Limited (11% of the market) includes Gribbles Pathology Group and Davies Campbell de Lambert. It operates about 30 laboratories and more than 175 collection centres in all states except Tasmania.

St John of God Health Care Inc (5% of the market) is a not-for-profit Catholic health care provider with 24 laboratories and 93 collection centres in regional Victoria and Western Australia.

A trend in the private pathology industry is a shift from a large number of small partnership-based firms to a few larger corporate firms (Sethuraman & Tirupati 2005). The industry is expected to become further concentrated (NEHTA 2009).

Figure 4 shows typical information flows involving pathology laboratories. The major referral base is medical practices which account for an estimated 70 per cent of revenue (NEHTA 2009). Pathology results are generally reported to both the relevant state and territory registry and to the requester of the test (usually the medical practitioner or hospital).



Source: National E-Health Transition Authority (NEHTA) 2009; NEHTA 2008.

Figure 3.8.1: Pathology test-report cycle flows

Pathology requests are usually initiated by medical practitioners (GPs), specialists or other clinicians (e.g. for community-based patients, in hospital settings for admitted and non-admitted patients, and for patients attending outpatient clinics and other health services) but could also be initiated by nursing staff in hospitals, nurse practitioners out of hospitals, dentists, infection control practitioners, officers in insurance companies and occupational health and environmental specialists—NEHTA 2009). Specimens are collected in various ways including:

- in a surgery or a health service by the patient's treating clinician or their staff
- at a collection centre by the staff of the pathology service
- at a hospital in an emergency department or at the bedside by hospital staff or in a collection centre run by the pathology service
- at a person's home via a domiciliary collection service run by the pathology provider
- at an aged care facility or other institution by staff of the facility.

The laboratory constructs a report containing the results and information from the request form. The laboratory then transfers the report (in most cases electronically) to the pathology requester, other authorised recipients and the relevant state and territory disease registry.

Request sources and pathways vary across pathology services. Patient information available through pathology request forms relies largely on the information provided by the requesting clinician. The ability of a pathology service to collect information directly from patients is limited to particular request and specimen collection scenarios.

Although most pathology requesters use an approved form, some use their own stationery (Communication with National Coalition of Public Pathology (NCOPP), July 2010).

Many of the major pathology providers use propriety software and may operate call centres that GPs and others can contact to follow up results. Some also maintain websites via which additional tests can be requested and results can be obtained (National E-Health Transition Authority 2008).

While less than 10% of pathology requests are received electronically, the reporting of results back to requesters is becoming increasingly electronic (industry sources suggest it is around 70%). Non-electronic reporting mainly includes reporting to specialists who have relatively low IT usage and GPs who prefer paper-based reporting (National E-Health Transition Authority 2008).

The electronic mechanisms used to transfer pathology results to clinicians and registries vary (e.g. email, web services, direct transfer into system etc.). There is no national standard for the structuring of the pathology report for the clinician or registry and there is often variability in the way information is reported from a laboratory to a clinician or registry, both electronically and on-paper. In most cases, the pathologist defines the structure of the report and this may vary from recipient to recipient based on agreements between the laboratory and clinician. Pathologists have considerable control over most paper reports but this is not always the case with electronic reports. There is no generic mechanism for sending requests or receiving results electronically.

The format of pathology reports and the exchange of information between pathology providers and health service providers is likely to soon be more uniform as a result of the Structured Pathology Reporting of Cancer project and the National-E-Health Transition Authority's (NEHTA) work on electronic information exchange. The Structured Pathology Reporting of Cancer project is being overseen by the Royal College of Pathologists

Australasia and aims to standardise reporting of cancer cases in Australia, including standardising the format of pathology reports. The NEHTA has developed a Pathology Result Reporting Package that has specifications for structured reporting, clinical terminology, identifiers, interoperability and secure messaging. Eventual benefits are structured reporting via improved specifications (detailing the content and structure of information in a standardised pathology result report), and improvements in the flow of information between pathology laboratories and clinicians through electronic transfer based on established practices and emerging trends.

3.9 Software vendors

Multiple elements of the data flow rely heavily on certain software packages.

Hospital and practice software

Hospital and practice software packages record and store patient information, and generate pathology request forms. They are the first point in which Indigenous status information is recorded. It is crucial that they collect the right information in the right format for each of the following steps to be effective. The capability of recording Indigenous status information appears to be in place in the large majority of hospital and practice software, most of which have the capacity to store this information in the ABS standard format. Some packages are able to electronically generate pathology request forms. In other cases, the information has to be transferred to the pathology request form by other means such as by hand or by attaching a sticky label with the patient's details.

A number of software vendors provide products to medical practices with varying market share and distribution across Australia. The Medical Software Industry Association (MSIA) is the main peak body representing these groups. The most common electronic patient information management system used by GPs in Australia is Medical Director, used in around 70% of practices. Version 3, the latest version, can import pathology results directly into the patient record. It includes an item for Indigenous status but not in the ABS standard format. Instead, it has a yes/no field for Indigenous origin.

Both Medical Director and Best Practice (the second main medical software provider) can enter Indigenous status at either reception or within consultation, and both are easy to change at any time (Kelaher et al 2009).

Other major clinical information systems include CommuniCare, Genie, BestPractice, Locum, MedTech, PractiC, Profile, TotalCare and ZedMed (NEHTA 2009). Smaller less popular software programs often have the ability to registry Indigenous status but it is often not on the 'front page', easily accessible or obvious (Kelaher et al 2009).

Aboriginal Medical Services have different systems, many of which do not include Indigenous status (particularly remote Northern Territory health clinics).

Pathology software

Pathology software packages receive pathology requests from treating service providers, including patient information, and supply relevant registries with information recorded by the pathologist. The software must be able to receive Indigenous status information, display it to the user and, where relevant, submit it directly to registries. The software has not

included this capability as Indigenous status information was not included on the current pathology request forms.

Most pathology companies have different software and systems. AUSLAB Pathology Management System is common, operating in both small regional laboratories and in laboratories in large referral centres across Australia. It is the only system used by pathology laboratories in Queensland. Other major information systems include Cerner, GE Healthcare, IBA/iSoft, MacCauley Software, Intersystems, PJACC and Kestral, the latter commonly used by major pathology providers such as Sonic Healthcare (NEHTA 2009).

Most electronic messages are sent by pathology providers using their own propriety systems. Many of the major pathology providers have proprietary software loaded onto GP desktops which are installed and maintained by pathology staff (National E-Health Transition Authority 2008). Two standards are used for the electronic ordering and reporting of pathology in Australia: Pathology Information Transfer (PIT) and Health Level 7 (HL7) (National E-Health Transition Authority 2008). Some public pathology providers use a field in the HL6 v2.4 message for capturing Indigenous status (e.g. Pathology Queensland and South Eastern Area Laboratory Services (NSW)).

The National E-Health Transition Authority has developed a Pathology Result Reporting Package that aims to standardise reports sent electronically to requesting clinicians. Other than those included in a standard report transmission, notifications to public health bodies or registries are out of the scope of the current version of this package (1.0). (The package's specification will be ready to be implemented after testing by the pathology reporting community (National E-Health Transition Authority 2008). Subsequent versions will be expanded to include additions such as secure messaging. Notification to registries is not listed to be included in future versions at this stage (National E-Health Transition Authority 2008).

The Royal College of Pathologists of Australasia (RCPA) has also developed protocols for the structured pathology reporting of cancer. These include guides and forms which are optional but can be used in the absence of existing local structured reporting forms and guides, or to provide guidance on what should be included in local structured pathology reporting forms for cancers. Of the 6 out of 16 protocols published so far, the forms do not include Indigenous status; at this stage they are focused on including only data needed for patient identification that are directly related to the patient's cancer or are needed by the pathologist to complete the report.

In order to include Indigenous status on the forms, this data item would need to be included in the protocol guide and forms for each of the 16 protocols, be added to any electronic forms and added to the archetypes for messaging standards by NEHTA.

Registry software

The registries are all based on different software platforms. All registries except the NSW Pap Test Register and the SA Cervix Screening Program can receive, store and report Indigenous status information, but the format varies slightly from registry to registry. The South Australian program was able to record Indigenous status information from 2010.

The capability to electronically receive this information direct into their systems from the medical practitioner, pathologist or hospital is not yet available for all registries. Some (e.g. Tasmanian Cancer Registry) routinely receive electronic notifications from several sources, but the database is not automatically populated without clerical processing. The New South

Wales Pap Test Register receives information electronically directly from pathology into the register's database but it would need to be modified to receive, store and report Indigenous status information. The NT Cervical Cytology Registry receives test results from laboratories electronically but cannot receive information from other sources electronically. Modifications to allow this are estimated to be expensive.

Registries that do not receive notifications from laboratories electronically may need to develop messaging capability. Labs would need to provide the reports in a standard format and via a common messaging system such as HL7. Registries would need to make changes to their information systems to accept the message and load the information into their databases.

4 Recommendations of the 2011 business case

Recommendation 1: Long-term: National implementation to improve Indigenous identification in national health registries as part of broader work to improve primary care data collection.

This involves a coordinated approach to national implementation of a National Minimum Data Set (NMDS) on primary health care, and the announcement of the new E-Health record and reforms to the funding arrangements for primary care, which include the introduction of new reporting mechanisms.

The aim is to standardise collection and recording of primary health care data across a number of sectors, including pathology.

Implementation of a primary health care NMDS will involve consultations with primary health care providers, pathology providers and software companies to make the necessary changes. It would need to ensure that changes enabling the collection and recording of Indigenous status information would be made through this broader work on improving primary health care data.

This strategy for national implementation is considered more cost-effective than including Indigenous status on pathology request forms as an isolated project. It avoids the potential for a lack of coordination across government causing duplication of effort.

Recommendation 2: Short-term: Jurisdictions should progress improvements in Indigenous identification in the national health registries through mechanisms identified below

Recommendation 1 will involve longer time frames than if Indigenous status was included on pathology forms as an isolated project. The business case therefore makes a second recommendation that jurisdictions could progress improvements in Indigenous identification in their registries through the following mechanisms:

- *Continuation of projects/pilot studies to include Indigenous status on pathology forms and consideration of their roll out state-wide.*

Some states and territories are undertaking projects which involve the introduction of Indigenous status on pathology request forms to enable this information to be recorded in their cervical screening registries. Continuation of these projects and their roll out state-wide to cover all pathology providers and collection centres and not just those currently involved in the pilot studies, should be considered. This would not only enable Indigenous status information to be collected by cervical screening registries more widely, but would also improve Indigenous identification in state and territory cancer and notifiable disease registries.

- *Progressing changes to state and territory public health legislation and regulations.*

Jurisdictions should seek amendment to their public health legislation to enable the collection of Indigenous status by registries and to facilitate the collection of Indigenous status by GPs, hospitals and pathologists.

The Northern Territory, for example, has amended its Cancer Registration Act to make it mandatory for medical practitioners, pathology laboratories, hospitals and the Registrar of Births, Deaths and Marriages to collect and report Indigenous status. This has facilitated the inclusion of Indigenous status on pathology request forms, and reporting of this information by pathology laboratories.

- *Progressing changes for disease registries to adhere to the national standard format for Indigenous status.*

Jurisdictions should negotiate with disease registries that do not use the standard format for Indigenous status on their notification forms and systems, to make the necessary changes to adhere to the standard.

- *Coordination between jurisdictions to achieve standardised requirements for pathology providers (and others affected by the proposed changes).*

Jurisdictions should aim to standardise requirements for pathology providers, registries and clinicians in the collection, recording and transmission of Indigenous status information (for example, the mechanisms used for transfer of pathology results to the registry, and the structure of the laboratory's report to the registry).

Most consultations for this project have indicated general support for Recommendation 2 (improving Indigenous identification in the national health registries as part of broader work on primary health care data), while taking on elements of Recommendation 1 (those that can be progressed by jurisdictions in the short-term).

The business case therefore makes two recommendations to improve Indigenous identification in cancer, communicable disease and cervical screening registries.

5 Work following the development of the business case

The AIHW has worked with National E-Health Transition Authority (NEHTA), as well as the Department of Health and Ageing (DoHA), on the longer-term option of investigating and promoting the capture of Indigenous status in e-health systems.

Two separate programs are being undertaken by NEHTA in relation to pathology and both may impact on the recording of Indigenous status on pathology reports and therefore on the data provided to collections such as cancer registries.

The programs are:

- E-pathology: deals with the transmission of pathology information between requester, the pathology laboratory and third parties.
- Personally Controlled E-Health Record (PCEHR): pathology reports can be uploaded by laboratories with permission from the patient (through the requester, after reviewing the report and deciding with the patient).

E-pathology

One of the issues of particular concern to AIHW is that of data generated by pathology processes, which have a direct impact on national cancer, communicable disease and cervical screening registries. Accurate data capture is essential to monitor Closing the Gap measures.

In order to transmit Indigenous status data from the patient to these data collections, the chain of steps throughout the pathology process must all operate correctly.

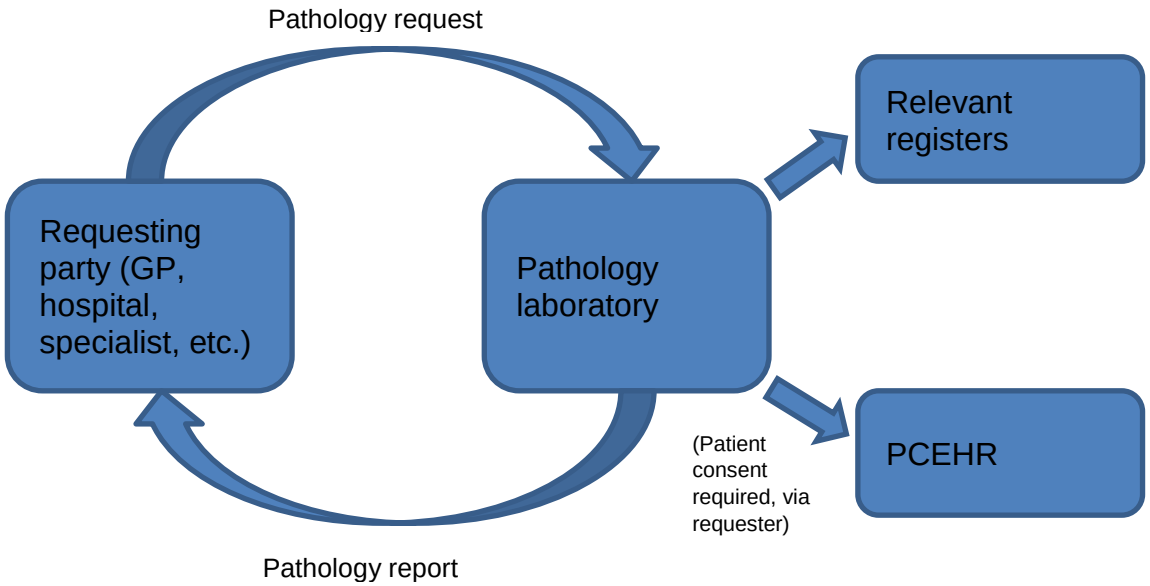


Figure 5: E-pathology request cycle

In relation to the recording and transmitting of Indigenous status information, important points to note are:

- Notifications to data collections are made by the pathology laboratory and use data included in the pathology request form.
- It is critical that Indigenous status be included in pathology e-request forms, as this provides the basis for the Indigenous status information sent to data collections.
- The pathology e-request and the e-report (which are based on HL7 messaging standard—AS 4700.2 in Australia) have the capacity to record Indigenous status, but it depends on business processes as to whether this field is completed.

Australian Standard in e-pathology

All electronic pathology messaging is governed by the Australian Standard 4700.2, which has the capacity to record Indigenous status but is an optional field. Whether this is recorded depends on business processes.

Table 5.1: AS 4700.2 Patient Identification Section

Sequence	Field Length	Optionality	Item Number	Element name
10	250 characters	Optional	00113	Race

Source: AS 4700.2.

AS 4700.2 has been revised and Indigenous status is still optional. This revised standard was put out for public comment in May 2012. On 10 July 2012, National Advisory Group for Aboriginal and Torres Strait Islander Health Information and Data (NAGATSIHID) wrote a letter to NEHTA stating that Indigenous status should be made mandatory in the Standard. Public consultation closed on 23 July 2012.

Personally Controlled E-Health Record

A central element of e-health is the PCEHR, which enables individuals to gather electronic health information in one place, accessible to healthcare providers authorised by the individual. Since July 2012, all Australians have been able to sign up and it will be implemented incrementally across the health sector.

Preliminary work by the AIHW indicates that Indigenous status is not being captured systematically in the PCEHR. Indigenous identification could be improved by either adding it as a core element so that it can be collected at a single point (e.g. registration) and linked to all elements of the PCEHR; or by ensuring that Indigenous status is included in each individual component of the PCEHR. It is currently included in only three of the seven PCEHR clinical documents.

Table 5.2: Proposed clinical documents in the PCEHR

Clinical document name	Who provides to PCEHR	NEHTA data specification template available	Indigenous status required
Shared health summaries	Author of the information only	Yes Embedded in the PCEHR, not a document to be uploaded	√
Event summaries	Author of the information only	Yes Embedded in the PCEHR, not a document to be uploaded	√
Referrals	Author of the information only	Yes	√
Discharge summaries	Author of the information only	Yes	X
Specialist letters	Author of the information only	Yes	X
Pathology Result Reports	Author of the information only	No Only included as a pdf, not as a PCEHR-specific form.	Using AS 4700.2, it has an 'optional' rather than a 'mandatory' field
Prescribing and Dispensing Information	Author of the information only	No Not finalised	n/a

Source: NEHTA

On 6 June 2012, AIHW wrote to NEHTA and DoHA to highlight deficiencies in the e-health system.

Primary Health Care National Minimum Data Set

Recommendation 1 specified the development of a National Minimum Data Set for primary health care:

- National implementation to improve Indigenous identification in national health registries as part of broader work to improve primary care data collection.

In October 2010, Australian Health Ministers' Advisory Council (AHMAC) was briefed on the project, and the AIHW understands that responsibility for implementing the NMDS was handed over to the Commonwealth (DoHA) at that time. Since then, progression of a NMDS has been slower than expected.

As directed by the National E-Health and Information Principle Committee (NEHIPC), the AIHW reviewed costing on the inclusion of Indigenous status on paper-based pathology forms. This recommendation has been overtaken by events in e-health over the past 18 months as more and more pathology requests and reports are done electronically.

Appendix A Changes identified by the 2011 business case

The business case recognises that significant changes to the broad process through which the registries receive their data have occurred and that future focus should be upon the content of the data that is transmitted between the treating service provider and the pathologist and then to the registry.

In this context, the points in the data flow that have been identified as requiring change are described below, beginning with the software changes and ending with process impacts.

A.1 Software changes

Negotiation with software companies will be needed to ensure that medical practitioner, hospital and pathology information systems make changes to standardise data fields nationally for the recording of Indigenous identification. Exploring options to increase the automated or electronic transfer of data between GPs, pathology providers and registries should also be considered.

Medical practice software

Practice software in this context refers to all patient management systems employed by medical practitioners who request pathology services.

The key change needed is to ensure that the pathology request forms generated include Indigenous status information in the recommended format <http://www.aihw.gov.au/indigenous/iiatsiphd.pdf>. A move to electronically generated pathology request forms will allow for implementation of mandatory fields such as Indigenous status to be completed and be less prone for error.

This means that the software must first record data in this format. It is believed that this format is not currently employed consistently across all software packages. If this is the case, data standards would need to be harmonised between software vendors and a re-coding of previously entered data might be needed.

Hospital software

Hospital software refers to patient management systems used by hospitals across Australia.

Similar to practice software, the key change needed is to ensure that pathology request forms generated by the software include Indigenous status information.

All hospitals are required to have a field for Indigenous status in their patient management systems. It is believed that most hospitals record Indigenous status information in the recommended format. For hospitals that don't, software changes would be needed to ensure the Indigenous status field is in accordance with the national standard.

Pathology software

Pathology software must be capable of manually and electronically receiving pathology request data that includes Indigenous status. It must also be capable of displaying this information in the recommended format and transmitting it to the registries. This is likely to require additional data items in software databases as well as new display items and changes to outputs. Laboratory reports will need to be updated to include Indigenous status.

The increasing corporatisation of private pathology laboratories into larger companies that are likely to share information technology systems presents a good opportunity to introduce standardised Indigenous status into pathology software.

Registry systems

Practice and pathology software vendors operate nationally. If each jurisdiction continues to request data in different formats, software will need to vary depending on the state or territory. This would create significant technical challenges to software vendors. For this reason, request forms and databases should be brought into line with national standards.

To make this happen, all paper- and web-based forms used by cancer, communicable disease and cervical screening registries would need to be standardised, as would the data entry components and the databases themselves. For a number of registries that do not record Indigenous status in accordance with the national standard (this includes the NSW Pap Test Register, SA Cervical Screening Program, Victoria Cancer Council, WA Cancer Registry, WA Notifiable Disease Database and the Australian Capital Territory Communicable Disease Control database), system changes would be needed. This may require expensive re-coding of previously entered data.

Some registries may have to change their format for data transmission with pathology laboratories to include Indigenous status. The inclusion of Indigenous status information in any electronically submitted data would require changes to the uploading system. This would be significant for some jurisdictions, and less so for others, depending on the software used.

Initial consultations between AIHW and state and territory cancer, communicable disease and cervical screening registries, indicated few impediments to the receipt of Indigenous status information from pathology service providers, and the recording of this information in the required format in their systems.

From a communicable disease perspective, the rapid inclusion of an Indigenous identifier is considered feasible as it is collected in the National Notifiable Diseases Surveillance System (NNDSS) and jurisdictional databases. Minor changes would be needed by some jurisdictions to meet national standard identifier usage. These changes would provide immediate benefits to the completeness of existing Indigenous identifiers and subsequent analysis and recommendations.

A.2 Process and practice changes

Changes to pathology request forms

A major change required in order for pathology laboratories to store Indigenous status information is the addition of Indigenous status to the list of minimum data requirements for pathology request forms. Forms currently in use would need to be modified and any new forms developed would need to include this data item. Most pathology testing for Indigenous clients is performed by public pathology laboratories, with some already capable of collecting Indigenous status on their request forms. Hence, collecting Indigenous status should be easier to implement in the public sector than the private pathology sector.

Education of service providers

Service providers need considerable education about the importance of collecting Indigenous status. This major task is the focus of several other COAG funded projects aimed at improving Indigenous health, such as implementation of the AIHW National Best Practice Guidelines for collecting Indigenous status in health data sets (see Section 2.1 for more information).

Minimal changes to processes within the practices of treating physicians and service providers are required with the exception of the question format for Indigenous status, which will need to be changed to match the national standard if it doesn't already. This would require some education of practice managers and software users.

Pathology laboratories would experience some change to the data they are provided with and are capable of providing to the registries. This would require some education and information to ensure the data is managed correctly.

The state and territory registries would begin receiving Indigenous status information from pathology forms. Staff would need to be informed that they need to refer to this additional source (as well as other sources) when recording Indigenous status. Existing business rules may need to be modified to reflect this change.

Registries would need to be informed of any changes required to the Indigenous status question format on their forms and in their databases. If changes are made, users of registry data would need to be informed.

A.3 Legislative/regulatory changes

In most states and territories, the collection of Indigenous status by medical practitioners, hospitals and pathologists in cancer, communicable disease and cervical screening data is not mandatory but is allowed under public health legislation. In some states and territories, legislative amendments will be needed for pathologists and health registries to collect Indigenous status information. In some cases this may be relatively simple to achieve, such as in reporting Indigenous status for notifiable disease notifications which requires changes to regulation only.

In Queensland, a regulatory change is needed, and being sought, to enable the Pap Smear register to collect Indigenous status information.

If the collection of Indigenous status in notifications of cancer, communicable disease and cervical screening by pathologists, medical practitioners and hospitals is made mandatory, guidelines and regulations under state and territory Public Health Acts will need to be amended. The only jurisdictions for which legislative changes are not required to make the collection of Indigenous status mandatory are Western Australia and the Northern Territory.

To mandate the collection of Indigenous status data on pathology request forms, amendments to the *Health Insurance Act 1973* (HIA) and its subordinate legislation would be needed. There are a number of issues with this.

Currently, subordinate regulations under the HIA mandate that certain fields must be completed on a pathology request form for a Medicare benefit to be payable. Although the Commonwealth theoretically has the power to amend these instruments to include an Indigenous identifier, legal advice to DoHA indicates that an attempt to mandate the collection of patient data that is not specifically linked to eligibility for health insurance would be beyond the powers of the Act.

Even if the HIA allowed for the imposition of mandatory data collection via the request form inclusions, it is the responsibility of the requesting doctor to collect patient Indigenous status information, not the pathologist (or their staff at collection centres/laboratories). It would not be reasonable to compel pathologists to collect, record and transmit Indigenous status information which is outside of their control to obtain. The consequence of making Indigenous status a mandatory field on the request form is that if the information is absent, the services could be ineligible for a Medicare benefit.

Given that no other Medicare funding arrangements impose a mandatory requirement in relation to Indigenous status, any move to broaden the scope of the HIA to allow a mandatory requirement would be out of step with current policy on promoting voluntary self-identification and would be considered to be beyond the power of the primary legislation.

Appendix B Cost benefit analysis

B.1 Benefits

Implementing the changes described above would ensure that all registries that rely on pathology data have access to Indigenous status information collected in a standard format. This would not address issues relating to lack of willingness of service providers to ask patients the question on Aboriginal and Torres Strait Islander identity, or reluctance of patients to identify as Aboriginal or Torres Strait Islander. These issues would need to be addressed elsewhere.

It would, however, ensure that where this information is requested and received, it is appropriately stored and transmitted to pathology providers and then to registries as required. This would fill a significant gap in the data collection system for registries that rely on pathology data. It is expected that this would immediately improve Indigenous identification in data that largely rely on pathology forms for patient information — communicable diseases (in most jurisdictions, more than 85% of notifications rely on pathology) and cervical screening (100%). This may bring the collection of Indigenous status data in registries up to the same level that exists in data sources that rely on information from general practitioners such as the Medicare Benefits Schedule which has around 50% coverage. Although this is not perfect, it far exceeds the quality of Indigenous status data collected in registries currently.

Cancer data would also benefit from the inclusion of Indigenous status on pathology forms. Although most cancer registries rely largely on other sources (e.g. hospital records and death certificates) for Indigenous status information, in cases where Indigenous status is missing on these sources (80% nationally and ranging from 39% to 98% across the states and territories), Indigenous status on the pathology form could be useful. A small number of cancers such as melanoma are only notified via a pathology report, and information on the incidence of these cancers among the Indigenous population is a further benefit.

Significant benefits can be achieved from improved identification. The immediate benefit is better quality information on the prevalence of cancer and communicable diseases for Indigenous people. As well as providing a clearer picture of Indigenous health, better information enables health outcomes to be measured and monitored and can be used for the planning and delivery of health services.

Better quality data will improve reporting against performance measures and targets such as those in COAG's Intergovernmental Agreements on Federal Financial Relations (e.g. National Indigenous Reform Agreement; National Healthcare Agreement), the Aboriginal and Torres Strait Islander Health Performance Framework and the Overcoming Indigenous Disadvantage Report. These are used by governments and policy makers to inform the development of policy in Aboriginal and Torres Strait Islander health, and to measure achievement against government commitments.

Improved Indigenous identification can therefore lead to more effective planning and provision of health services, resources, policies and interventions, and would enable assessment of the impact of services and interventions. This in turn would lead to better health outcomes for Aboriginal and Torres Strait Islander people.

As pathology reports are the main source of information used by communicable disease registries and the only source of information used by cervical screening registries, including Indigenous status on pathology forms will have more impact than improving Indigenous status information in hospitalisation data and other sources.

By including Indigenous identification on pathology forms, improved identification in registries may lead to improved identification in other data sources, such as hospitalisation data in the case of cancer and communicable disease notifications, and deaths data in the case of cancer notifications. These data in turn could potentially be used, for example in data linkage studies, to assess levels of Indigenous under-identification in these data sets.

National implementation of including Indigenous status on pathology forms will alleviate issues that would arise if only some jurisdictions implemented the changes. For example, pathology labs working across state and territory borders will not need to maintain two different versions of pathology forms or patient and pathology software. There will be consistency across jurisdictions in respect to what information is collected, recorded and reported for Indigenous Australians in cancer, communicable disease and cervical screening data.

As pathology request forms rely largely on patient information provided by the requesting doctor, and some doctors are better at completing request forms than others, efforts to capture Indigenous status at the time of consultation and the initiation of the pathology request have benefits and cost advantages. Many GP requesters use practice management software to populate their pathology request forms and some pathology services receive electronic requests directly into their laboratory information system. A move to increase automated or electronic transfer of data between GPs, pathology providers and registries will be of long-term benefit as it will reduce error, saving time for those responsible for entering the data, and reduce the need to fill in forms.

To ensure Indigenous status information captured via pathology request forms is reliable and useful, data quality issues would need to be addressed. Various initiatives are focused on improving the quality of Indigenous status information in GP data, which may lead to improvement in the recording of Indigenous status information by GPs in their patient information systems and on pathology request forms. For example:

- The Cooperative Research Centre for Aboriginal Health (CRCAH) has identified strategies to improve identification processes in mainstream general practice. Its recommendations were published in August 2010 by the Australian Primary Health Care Research Institute (APHCRI) and the Lowitja Institute entitled *Improving the identification of Aboriginal and Torres Strait Islander People in Mainstream General Practice.* This report can be found at the following link: <http://www.anu.edu.au/aphcri/Spokes_Research_Program/Kelaher_Indigenous_identification_report.pdf>.
- The AIHW *National best practice guidelines for collecting Indigenous status in health data sets* covers general practice data. Jurisdictions received COAG funding to implement the guidelines by December 2012, which is expected to improve the quality of Indigenous status information collected and recorded by GPs. The guidelines can be found at the following link: <http://www.aihw.gov.au/publications/ihw/29/11052.pdf>.

Evidence from projects trialling the inclusion of Indigenous status on pathology request forms indicate that if GPs, nurses and staff are trained on the importance of accurately collecting and recording Indigenous status, they generally record this information often and accurately. For example, the Victorian Department of Health pilot study to record

Indigenous status on the Victorian Cervical Cytology Service's pathology request forms indicates that after attending training on the importance of collecting Indigenous status information, 93% of nurses went on to record it all of the time.

B.2 Costs

Public sector

It is estimated that public sector jurisdictional based costs will include:

- Costs to the state and territory registries to make system changes to either add an item on Indigenous status (New South Wales Pap Test Register) or to ensure Indigenous status is recorded according to the national standard (Victorian and Western Australian cancer registries; and Western Australian, Australian Capital Territory and Northern Territory communicable disease registries).
- Costs associated with establishing the registries' ability to receive, store and report on any new information transmitted from and to the laboratories (i.e. Indigenous status).
- Costs to enable information from pathology labs to be received electronically and automatically loaded. Steps required include scoping changes by IT consultants, testing and implementing changes to the registry databases, and then implementing the changes with the laboratory systems.
- Costs involved to make legislation changes needed for collection of Indigenous status information by the registries (e.g. Queensland Pap Smear Register).
- If considered feasible, costs involved to make legislative changes to make it mandatory for Indigenous status to be collected by GPs, hospitals and laboratories.
- If considered feasible, costs to recode previously entered Indigenous status data to the national standard.
- In some jurisdictions (e.g. New South Wales) some pathology laboratories may need to request funds to make required changes to information systems.

It is estimated that public sector national based costs will involve:

- Costs for DoHA to change documentation and legislation to include Indigenous status as a mandatory data field on pathology request forms.

Private sector

The cost of influencing private pathology providers to include Indigenous status needs to be considered as they appear to have a slightly larger market share than public pathology providers. It is recommended that any compensation for private sector costs be negotiated with the Medical Software Industry Association and any other identified peak bodies in the first stages of the project, when more detailed requirements analysis has been completed and technical specifications are available.

It is estimated that private sector costs will include:

- Costs to change GP and clinician's software to enable recording of Indigenous status in the national format, and to transfer this data to pathology laboratories.
- Costs for laboratories to implement change to their systems to cater for storing and transmitting any new information (i.e. Indigenous status).

- Costs for laboratories to change pathology request forms to include Indigenous status.

As discussed under section 3.9, many GPs and clinicians use the same software (i.e. Medical Director), and thus the costs for system changes will not be as significant as for pathology laboratories which use a vast array of systems and software (i.e. there are about 180 pathology software companies in Australia, some of which have a number of providers attached to them, each of which will have personalised data upgrade requirements). Many pathology information systems are maintained by software companies under contract while others are maintained in house. The amount of work and time required to make a change and to test it varies across systems with some being more flexible than others. There are also associated resource consequences to be considered.

Implementing a change to pathology request forms involves design, printing and distribution costs. Sufficient lead time needs to be given to pathology services to make changes, to deplete old stock and to advise requesters of change. Some requesters take a long time to move to new request forms despite reminders (Communication with NCOPP, July 2010). Some public pathology laboratories can already collect Indigenous status on their pathology request forms.

Space is at a premium on the pathology request form as it is already heavily populated with information and legislated requirements for Medicare benefits payment and other purposes. For Indigenous status to be included, a balance would need to be achieved between the amount of detail in the request form, the space available, data quality and expected outputs.

There would be high costs if a move from paper to electronic transmission of data from GPs and hospitals to pathology and the registries was recommended. This would involve including Indigenous status on the electronic request and transmission forms and making changes to software so that data can be transmitted directly into pathology and registry systems.

Estimated costs for implementation

It is anticipated that there would be little or no costs to the disease registries as most can already record Indigenous status information. There would also be little cost to GPs and pathology laboratories as most have the capacity to store Indigenous status (Medical Director, for example, already does). The biggest costs would be for modifications to GP software to transfer Indigenous status to the pathology forms, and for an Indigenous status item to be included on the pathology forms. Software companies will most likely require funding to do this.

Some jurisdictions already collect Indigenous status on pathology forms; their costs are likely to be minimal. For example:

- Indigenous status is already incorporated into public laboratories in Queensland.
- In the Northern Territory, a small proportion of pathology request forms include Indigenous status (e.g. the NT Government Public Pathology Service used in public hospitals).
- PathWest (Western Australia) and the Victorian Cytology Service are collecting Indigenous status as part of pilot projects (see Section 2.2).
- From May 2010, ACT Pathology is trialling the collection of Indigenous status in one of its collection centres with the possibility of this being rolled out to all seven collection agencies.

A 2007 feasibility study into increasing the completeness of Indigenous status in ACT Government registries provided some estimated costs for implementation in the ACT. These included:

- Costs to GP systems and processes, involving a 'one-off' cost of $2,000 to $3,000 per GP to upgrade patient recording systems if Indigenous status is not already captured; and an annual cost of $3,000 to $5,000 in the initial 'back-capture' period (expected to be in the first two years of implementation).
- Costs to pathology systems and processes, involving a "one-off" cost of $3,000 to $4,000 per pathologist for system changes; and an annual cost of $60,000 per pathologist to cater for the increased number of data-entry staff. Less funding will be required if GPs transmit requests electronically to pathologists who have the facility to automatically upload into their systems, reducing the need for data entry.
- Costs to registries' systems and processes, which would be minimal since most registries already record Indigenous status in the correct format.

The Victorian Cytology Service (VCS) has provided estimated costs based on its pilot study to include Indigenous status on pathology request forms. The cost to change their information system is:

- IT development costs = $9,401.60
- Specification development and user acceptance testing = $3,037.84
- Total cost=$12,439.44.

These costs do not include any interface functionality between the Victorian Cervical Cytology Registry and private laboratories (out of scope of the study).

PathWest (WA) has provided costings based on its pilot study with the WA Cervical Screening Prevention Program. It has provided partial costing for the changes needed to implement Indigenous status on its pathology forms. It estimates it would cost around $6,000 for internal coding changes to receive, store and transmit Indigenous status information. The costs of changing PathWest's paper forms used by internal requestors (i.e. hospitals and outpatient clinics) are estimated to be $100. PathWest was unable to provide estimates for changes to the software form used by external clients (e.g. GPs, medical specialists) for pathology requests across Australia as a change to this document has nationwide implications. PathWest was also unable to provide costs within Health Information Network applications to enable broadcast of Indigenous status.

Medicare's e-Health Practice Incentives Payments (PIP) may cover some of the identified costs described above, such as those associated with GPs to upgrade their systems, capped to $12,500 per practice per quarter, and up to a maximum of $50,000. The PIP eHealth Incentive encourages practices to keep up-to-date with the latest developments in eHealth. As technology develops, practices will be able to securely exchange information such as discharge summaries, pathology and specialist reports, send electronic referrals and pathology orders and prescribe electronically. Patient information sent and received electronically will be added directly into a patient's electronic health record. Practices can receive these payments if they have secure messaging capability (provided by an eligible supplier), a Public Key Infrastructure (PKI) certificate for the practice and each practice branch, individual practitioner PKI certificates, and access to a range of key electronic clinical resources.

Incentives

The use of incentives for health service providers and pathologists to collect and improve Indigenous identification could be explored. Making the collection of Indigenous status part of GP accreditation is one such way. Currently GP accreditation criteria states that practices must be 'working towards' improving identification. However unless this is strengthened and enforced (such as linked to funding), significant changes may not occur.

Incentives to software providers to make changes to bring GP and pathology software in line with the national standard for Indigenous status could also be considered.

B.3 Conclusion

The full task of standardising and improving Indigenous status data in the cancer, communicable disease and cervical screening registries nationally must be considered a long-term project, potentially requiring significant investment. Improving Indigenous identification in the health registries by including Indigenous status on pathology request forms is feasible based on cost-benefit analysis presented in this report. It is also feasible for Indigenous status information to be recorded in pathology systems via programming/software changes, and transferred to the health registries, albeit with some yet to be determined costs to pathology service providers and/or software vendors.

Appendix C Options to improve Indigenous identification

Three options for improving Indigenous identification in the health registries were included in the consultation draft of this business case. These are described below.

The first involves including Indigenous status on pathology forms and can be implemented in the short-term with appropriate funding. The second involves a national coordinated approach to improving Indigenous identification in health registries in the context of development of a National Minimum Data Set on primary health care, and the announcement of the new E-Health record. The third option involves data linkage and data sharing.

Option 1: Improving Indigenous identification in the national health registries through inclusion of Indigenous status on pathology request forms

This option could involve a national approach or states and territories could implement it on their own.

If a national approach was adopted, the inclusion of Indigenous status on pathology forms would need to address the regulatory and infrastructure changes required at the Commonwealth and state and territory levels.

If a jurisdiction based approach was adopted, leading states and territories could be modelled for best practice. The Northern Territory, for example, has amended the Cancer Registration Act making it mandatory for medical practitioners, pathology laboratories, hospitals and the Registrar of Births, Deaths and Marriages to collect and report Indigenous status. This has facilitated the inclusion of Indigenous status on pathology request forms, and reporting of the information by pathology laboratories.

A national approach would be more effective and practical than a jurisdiction based approach. The large-scale infrastructure changes required would be more cost-effective and better received by affected stakeholders if it was implemented nationally. Many pathologists and suppliers of medical and pathology software operate across jurisdictions with standardised forms and computer systems. If implemented in some jurisdictions only, different sets of forms and software would need to be maintained. This would most likely be logistically complex, expensive and strongly resisted by pathologists and software companies that operate nationally.

Option 1 would involve the following steps in implementation for both a national and jurisdiction based approach (not in any specific order):

1. Funding

Determine funding required to manage this work and to implement changes required, including the ongoing collection of data from pathology forms. Determine source of funding for this work.

2. Negotiate governance and regulatory changes

Establish legislation changes and governance arrangements, where necessary, to support the flow of Indigenous status information from first contact with the health provider to pathology services and then through to the state and territory and national registries.

This may involve the following:

- Seek amendment to regulations regarding minimum data required for an eligible pathology request form to include the standard Indigenous identification question.
- Seek amendment to public health legislation to enable the collection of Indigenous status by cervical screening registries in states and territories where legislation does not permit this information to be collected (New South Wales and Queensland).
- Review and seek amendment to public health legislation to facilitate the collection of Indigenous status by GPs, hospitals, pathologists and the registries.

This could involve legislative changes making it mandatory for medical practitioners, pathology laboratories and hospitals to collect and report Indigenous status, and to allow the Registrar General to seek additional information from doctors when not otherwise supplied (such a change to legislation was made in the Northern Territory Cancer Act 2009). If collection of Indigenous status was to be made mandatory by laboratories, a provision may need to be considered in the legislation that pathology services do not need to provide data that is not reasonably available to them. In some cases it will not be possible for pathology services to provide this information if it has not been supplied to them by the medical practitioner or hospital. Including such a provision would potentially overcome any issues or penalties associated with non-compliance.

3. Standardise disease registries to national standard for Indigenous status

Negotiate with registries which do not use the standard format for Indigenous status on their notification forms and systems, to make the necessary changes to adhere to the standard.

This may include the following:

- Changes to patient forms used by the registries, including online forms, to standard question format if not already in place.
- Changes to databases used by registries to data element formats if not already in place.
- Re-coding of old data to standard Indigenous status reporting categories if considered feasible.
- Changes to registry software to allow electronic submission of Indigenous status data if not already in place.
- Changes to data element format in reporting functions if not already in place.
- Education of registry staff in data element format and database changes if required.

4. Modify medical practice (patient), pathology and hospital software to include Indigenous status

Negotiate the software changes to medical practice (patient), pathology and hospital software to include Indigenous status, ensuring there is consistency between the practice, pathology and registry systems before rolling them out nationally.

This may include the following:

- Modification of software used by medical practices, pathology laboratories and hospitals to include the standard Indigenous status data item if not already included.
- Modification of medical practice and hospital software to produce modified pathology request forms.
- Modifications to pathology software to include Indigenous status in extracts for submission to registries.
- Changes to registry systems to accept modified pathology forms which include Indigenous status.
- Explore options to increase the automated or electronic transfer of data between medical practitioners, pathology and the registries.

5. Modify pathology request forms to include Indigenous status

Negotiate the required modifications to pathology request forms so that Indigenous status information is captured using the national standard.

This would involve modification of pathology request forms by pathology providers to include the standard Indigenous status question.

6. Implement software and process changes

Roll out the software and process changes and communication packages with users and affected people and groups.

Option 2: Improving Indigenous identification in the national health registries as part of broader projects aimed at improving primary health care data collection

This option would involve improving Indigenous identification in the cancer, communicable disease and cervical screening registries as part of broader projects aimed at improving primary care data collection. For example, the AIHW has been asked by the National Health Information Statistics and Standards Committee (NHISSC) to develop a National Minimum Data Set (NMDS) for primary health care. Simultaneously the government has endorsed the development of an Electronic Health Record (EHR) as well as announced significant reforms to the funding arrangements for primary care, which include the introduction of new reporting mechanisms.

The primary health care NMDS aims to standardise collection and recording of primary health care data across a number of sectors, including pathology. As part of the work on the primary health care NMDS, the AIHW has committed to providing the National E-Health Transition Authority, who are currently progressing the EHR project, with a list of data requirements for the EHR. The NMDS and this list will include Indigenous status. There will likely be a greater commitment by GPs and pathology laboratories to collect, record and report Indigenous status information if it is part of a NMDS.

If included on the EHR, Indigenous status information would be automatically transferred across the health system and would mean that upon consent, Indigenous status information will always be available rather than each individual health agency being required to collect Indigenous status. This has the advantage of providing a coordinated system for recording Indigenous status.

A limitation of this option is that it will take longer to implement than Option 1 as work on an NMDS for the pathology sector has not begun and it may take some years before data is available for use from the EHR. It is likely, however, that Option 2 would require many of the same system changes as Option 1. If this option was chosen, it would be far more cost-efficient than Option 1 and would avoid the potential for a lack of coordination across government causing duplication of effort and confusion.

Option 3: Improving Indigenous identification in the national health registries through data sharing across systems

There is potential for data linkage to enable health systems that collect Indigenous identification data to share the data so that improvements in any one system can flow through to other systems such as the health registries. This already occurs in a number of jurisdictions. For example, in the Northern Territory and Queensland, data matching is used to augment Indigenous identification in communicable disease notifications from other sources such as hospitals. In Queensland there is also an initiative to link pathology systems to patient registration details in public hospitals (IIICDRP 2005).

If this option was chosen, jurisdictions would need to establish processes to enable sharing of data (including Indigenous status) across health systems. This option may be of limited benefit to jurisdictions which do not have patient/client master indexes.

The main benefit of this option is that once collected in the health system, Indigenous status information can be shared, which eliminates its repeated collection and limits follow-ups by health service providers to obtain missing information. Given that data linkage requires data from multiple collections, an issue to consider would be how to determine Indigenous status for individuals who have not been asked their Indigenous status and their Indigenous status assumed or guessed, or those who have inconsistently identified themselves as being of Aboriginal and Torres Strait Islander origin.

Concerns about risks to privacy and confidentiality may also need to be addressed. This option would therefore require high-level negotiation to progress. It may be feasible in the long term.

Appendix D Other sources of Indigenous status information

While the focus of the business case is on the inclusion of Indigenous status fields within the pathology system, other options that could feed into the system or be used in data matching to improve Indigenous identification should be considered. Following are some possibilities, notwithstanding that various impediments exist to their use for the above purposes.

D.1 Medicare Voluntary Indigenous Identifier (VII)

The Voluntary Indigenous Identifier has been included on Medicare registration forms since November 2002. This was introduced (as an' opt in' option for people) to enable access to mainstream Medicare services and the Pharmaceutical Benefits Scheme by Indigenous Australians to be assessed more accurately. The VII covers about 50% of the Indigenous population, and it is likely to take several years before coverage becomes sufficiently extensive to overcome data deficits in other areas.

Another major limitation of VII data from Medicare records is that it can only be used for the purpose it was originally collected (i.e. it will be used to determine eligibility for Medicare benefits and to maintain a record of entitled persons for government programs administered by Medicare). This limitation may apply to any proposal to transfer the Indigenous status information from Medicare records to a pathology service request when issued by medical practitioners, or any proposal to link Medicare data with registry data to obtain Indigenous status information.

D.2 E-Health Record—Individual Healthcare Identifier (IHI)

The National E-Health Strategy aims to address the way information is accessed and shared across the health system to support population health surveillance, guide policy, service planning, innovation and clinical and operational decision making. This includes the development of healthcare identifiers, in particular the introduction of an Individual Healthcare Identifier (IHI), and the establishment of Electronic Health Records (E-Health Records).

In December 2009, COAG committed to introducing an IHI. In June 2010, Federal Parliament passed legislation to set up a Healthcare Identifiers Service operated by Medicare which will allocate IHI's to all patients under the Healthcare Identifiers Act. Healthcare professionals will be able to retrieve a patient's IHI using their current Medicare care or Department of Veterans' Affairs (DVA) treatment card, or via a demographic search.

The IHI will allow the government to introduce personally controlled electronic health records. The IHI will be separate to the electronic health record, as it will hold only enough information to clearly identify a person. The decision to establish a personally-controlled electronic health record is personal and requires individual consent. If consented to, it enables access by the individual and their health professionals to the individual's health records across the health system.

Cultural identity including Indigenous status is not planned as a data item for inclusion in the IHI. Inclusion of Indigenous status would open the way for automatic transfer of Indigenous status information across the health system, such as is currently being trialled in the Northern Territory with the introduction of the E-Health Record.

Regulations to support the operation of the Healthcare Identifiers Service will be considered by the Federal Executive Council. These will help healthcare providers and software vendors better understand how the IHIs will affect their business practices.

Like the Medicare VII, it may take some years to populate data items in the IHI and for data to be available from E-Health Records, as individuals choose to 'opt in' to the E-health record and/or nominate their Indigenous status. Pursuing the inclusion of Indigenous status as a routine item within the IHI, and E-Health Records more broadly, should be considered.

E-Health pilot tests/trials have just been announced in which three GP Divisions will be the first to trial the implementation and use of personally controlled health records which will be evaluated after one year. The AIHW could consider discussing with NEHTA whether Indigenous status could be one of the data items that are evaluated in order to assess whether Indigenous status would be captured well in GP systems and then effectively transmitted to pathology forms.

D.3 Practice Incentive Program (PIP) Indigenous Health Incentive (IHI)

Administered by Medicare Australia on behalf of the Department of Health and Ageing, the Practice Incentive Program (PIP) was developed to provide incentives that encourage general practices to improve the quality of patient care. Under the PIP, the Indigenous Health Incentive began in May 2010 and aims to support GPs and Indigenous health services to provide better health care for Indigenous Australians, including best practice management of chronic disease. The incentive is part of the Australian Government Indigenous Chronic Disease Package.

A sign-on payment ($1,000) is made to participating PIP practices that join the incentive, and in addition, patient registration payments of $250 are paid to the practice for each Indigenous patient aged 15 and over and registered with the practice for chronic disease management in a calendar year.

The IHI will not capture all Indigenous persons — it only include practices that are fully accredited and registered with PIP and which have signed up to the IHI; and patients of those practices who are 15 years or over with an established chronic disease. This is a major limitation of the usefulness of this data for improving Indigenous identification.

A second major limitation is privacy as the IHI restricts the data from being used for purposes other than what it is originally collected for (i.e. DoHA/Medicare reporting on the program).

D.4 Primary health care National Minimum Dataset

The AIHW, on request by the National Health Information Standards and Statistics Committee, is undertaking a project to develop a National Minimum Data Set (NMDS) for primary health care. The NMDS will provide a mechanism to record and report data in a uniform standard across all primary care service areas, including pathology. It will provide

the ability to improve evidence-based decision-making, health planning and an avenue to compare data and health outcomes across multiple primary health care sectors.

The project is being progressed through a staged process. A concept paper for the creation of an NMDS has been completed by the AIHW and was provided to NEHIPC through NHISSC in August 2010, and later forwarded to AHMAC for consideration.

Although sectors and data items to include within the initiative have not yet been finalised, it is anticipated that Indigenous status will be one of the data items collected as part of the primary care NMDS. It is expected that work related to the pathology sector will begin in 9 to 12 months.

Implementation of the NMDS will most likely involve consultations with primary health care providers, pathology providers and software companies regarding the changes needed for the NMDS to be established and maintained. An alternative to implementing the inclusion of Indigenous status on pathology forms is to ensure that the changes are made as part of the broader work the AIHW is doing on the primary health care NMDS, noting that this will involve longer time frames for implementation than if done in isolation.

D.5 Data sharing across systems

A number of jurisdictions use data linkage to enable health systems to share Indigenous identification data so that improvements in any one system can flow through to other systems such as the health registries. For example, in the Northern Territory and Queensland, data matching is used to augment Indigenous identification in communicable disease notifications from other sources such as hospitals. In Queensland there is also an initiative to link pathology systems to patient registration details in public hospitals (IIICDRP 2005).

Data linkage and sharing across systems would enable Indigenous status information to be shared, eliminating its repeated collection and limiting follow-ups by health service providers to obtain missing information. There may be concerns about risks to privacy and confidentiality which would need to be addressed.

Appendix E Communicable disease registries

New South Wales

Legislation

The New South Wales Public Health Act 1991 and Regulations enables the collection and reporting of communicable disease information. The Act specifies that the notifier (if the information is available to them) needs to provide the information specified on the 'Approved form'. In 2008, the ministerially approved form was amended to require reporting of Indigenous status on the Medical practitioner/Hospital Notification form and the Laboratory Notification form. Thus no legislative changes are required to collect Indigenous status for communicable disease notifications.

Sources of information

Around 95% of notifications in 2008 were reported by pathology laboratories with only 1.5% provided by medical practitioners.

Table E1: Sources of notifications

	Pathology laboratory only	Medical practitioner only	Both
	Per cent	Per cent	Per cent
2005	70–80	20–30	<1
2008	95	1.5	1

Source: Oxenford 2005; cited in 2007 Annual report of the National Notifiable Diseases Surveillance System; and NSW Department of Health, unpublished data.

Notification mechanisms

Notifications are sent by fax, mail or phone from GPs and/or labs. Work is being done to progress electronic laboratory notifications with a private laboratory due to begin electronic notification this year.

Notification of Indigenous cases

Communicable disease notification forms use the standard Indigenous status question.

The Communicable Diseases Branch undertakes work to improve the quality of Indigenous status information such as manual follow-up of missing information and data linkage. The branch is working on a data linkage project involving its notifiable diseases database and other datasets (namely hospital admissions, Registry of Births, Deaths and Marriages and Midwives Data Collection). Depending on the usefulness of the resulting data, this may be set up to be done on a regular basis (i.e. annually).

Recording of Indigenous data in registry information system

The Notifiable Diseases Database System uses the standard Indigenous status format.

Transmission of data for national collation

Notifications data are transferred to the NNDSS via electronic uploads at least weekly.

Completion Rate

The completion rate for Indigenous status for notifiable communicable diseases in 2008 was 25% (DoHA 2010 forthcoming).

Victoria

Legislation

In 2010, legislation regarding communicable disease notifications in Victoria changed from the Health (Infectious Diseases) Regulations 2001 to the Public Health and Wellbeing Regulations 2009. Under Schedule 6 of the Regulations, medical practitioners are required to report on Indigenous status for all Group A, B, C and D diseases. It is not a legislative requirement for pathology laboratories to report on Indigenous status.

Sources of information

In Victoria, 50% of notifications in 2007 to 2008 were reported by pathology laboratories only with 7% provided by medical practitioners only.

Table E2: Sources of notifications

	Pathology laboratory only	Medical practitioner only	Both
	Per cent	Per cent	Per cent
2005	50	7	43
2007 to 2008	50	5	45

Source: Oxenford 2005; cited in 2007 Annual report of the National Notifiable Diseases Surveillance System; & Victoria Department of Health, unpublished data.

A high volume of diseases are processed by the primary laboratories. Less common diseases that require specialised typing go to the reference laboratories.

It is possible to link registry data with hospital data and other sources to obtain patient demographic information, but this is not routinely done.

Notification mechanisms

Notifications can be received from GPs via telephone (where an officer will complete the Notifiable Conditions Form with the GP over the phone); online via a secure e-form; or faxing or posting the Notifiable Conditions Form or enhanced data collection forms.

Pathology laboratories are required to notify diseases in writing within five days, and in addition, immediately by telephone for Group A diseases.

Pathology laboratories post or fax the laboratory result to the department. This is done on paper forms and does not uniformly include Indigenous status. Different request forms are used by different laboratories, and for different diseases in some cases.

The Notifiable Disease Database is being updated to a web-based interface to enable electronic transfer of data.

Notification of Indigenous cases

Notification forms use the standard Indigenous status question.

Recording of Indigenous data in registry information system

The Notifiable Infectious Disease Surveillance does not use the standard Indigenous status format. The categories used are:

1. Aboriginal but not Torres Strait Islander origin
2. Torres Strait Islander but not Aboriginal origin
3. Aboriginal and Torres Strait Islander origin
4. Not Aboriginal or Torres Strait Islander origin
5. Declined to a resident of New South Wales
6. Question not able to be asked
9. Missing/Not stated

Indigenous status is a mandatory data item in the information system.

Transmission of data for national collation

Information is sent to the NNDSS Data Acquisition System for national collation via email.

Completion rate

The completion rate for Indigenous status for notifiable communicable diseases in 2008 was 53% (DoHA 2010 forthcoming).

Queensland

Legislation

The Public Health Act (2005) and Health Regulations enable the collection and reporting of communicable disease information. There is no legislative requirement in Queensland to collect/report Indigenous status information in communicable diseases.

The Act specifies that notifications should be made in the 'required format'. Indigenous status is not included as a data item under the required format. Queensland Health has advised that regulation changes soon to take place may change this.

Sources of information

In Queensland, 99% of notifications in 2005 were reported by pathology laboratories with less than 1% provided by medical practitioners.

Table E3: Sources of notifications

	Pathology laboratory only	Medical practitioner only	Both
	Per cent	Per cent	Per cent
Queensland	99	<1	<1

Source: Oxenford 2005; cited in 2007 Annual report of the National Notifiable Diseases Surveillance System.

Hospital admissions data and data from the vaccination registry may also be used to obtain missing information on the pathology request form (IIICDRP 2004).

Notification mechanisms

More than 90% of notifications enter the registry by electronic transfer from pathology laboratories. This includes the public laboratories and the two major private pathology services, which together account for the majority of notifications in Queensland (QML, Sullivan Nicilades and Queensland Pathology). The other 10% of notifications are received on paper, mostly from interstate, cross-border and small laboratories.

There is no electronic receipt of notifications from GPs or hospitals, only the three major private laboratories.

Notification of Indigenous cases

The standard Indigenous status question is used on disease notification forms. Indigenous status information is obtained either from periodic upload of information from the hospital system, from information recorded if the person has been notified previously, or if the person is recorded on the vaccination registry. Indigenous status for a small proportion of all notifications is obtained through direct follow-up (enhanced surveillance) with clinicians.

Recording of Indigenous data in registry information system

The Notifiable Conditions Registry uses the standard Indigenous status format.

Indigenous status is a mandatory data item.

Transmission of data for national collation

Data is transmitted from the registry to the Commonwealth for national collation electronically by encrypted e-mail. Information is sent automatically every 12 hours.

Completion rate

The completion rate for Indigenous status for notifiable communicable diseases in 2008 was 42% (DoHA 2010 forthcoming).

Western Australia

Legislation

Diagnosing doctors, nurse practitioners and laboratories are required by legislation to provide name, address, phone number, gender, date of birth, and 'any other relevant information required by the approved form'. The WA Health Act as amended in 2006 states that doctors and laboratories must provide the required information "to the extent [that they have] that information."

This places a mandatory requirement on provision of information on Indigenous status, to the extent that this information is known, given that there is a field for Indigenous status on the WA notification forms for communicable diseases and HIV/AIDS.

Sources of information

In Western Australia, 27% of notifications in 2005 were reported by pathology laboratories with 15% provided by medical practitioners.

Table E4: Sources of notifications

	Pathology laboratory only	Medical practitioner only	Both
	Per cent	Per cent	Per cent
Western Australia	27	15	58

Source: Oxenford 2005; cited in 2007 Annual report of the National Notifiable Diseases Surveillance System.

Data received by the registry is matched with information from GPs, specialists and pathologists. Western Australia can data match/share with its hospital information systems to derive additional information on notifiable disease cases, including Indigenous status information, but this is not done routinely.

Notification mechanisms

GPs and hospital doctors notify diseases by paper forms (post), fax or by telephone. Pathology labs notify the registry electronically by encrypted email, or in a small number of cases, by phone, fax, or paper reports.

The WA Department of Health is creating a new notification form and adjusting its system capability.

Notification of Indigenous cases

Western Australia does not use the standard Indigenous status question on its standard disease notification form. Its question/options are:

Ethnicity = Aboriginal or Torres Strait Islander,

= Other

The specific HIV/AIDS notification form does include the standard Indigenous status question format.

Recording of Indigenous data in registry information system

The Notifiable Infectious Diseases Database does not use the standard Indigenous status format. Data are recorded according to the categories 'Indigenous', 'non-Indigenous' and 'not stated', and does not define whether the individual identifies themselves as Aboriginal, Torres Strait Islander, or both.

Indigenous status is not a mandatory field.

Transmission of data for national collation

De-identified data are sent by encrypted email to the NNDSS for national collation.

Completion rate

The completion rate for Indigenous status for notifiable communicable diseases in 2008 was 78% (DoHA 2010 forthcoming).

South Australia

Legislation

The *SA Public & Environmental Health Act 1987* facilitates the collection of notifiable disease information by placing a duty upon doctors and laboratories to forward any relevant data r as designated in Schedules 1 and 2 of the Act to the South Australian Health Commission (SAHC) (now replaced by SA Health). Although this is the general legal framework for the collection of notifiable disease data, the format of the report and the quantity and nature of the data required can be determined by SA Health. An Indigenous status field is included on the medical notification form but its completion is not mandatory.

Source of information

In South Australia, 15% of notifications in 2008 were reported by pathology laboratories, 9% by medical practitioners and 77% by both laboratories and medical practitioners.

Table E5: Sources of notifications

	Pathology laboratory only	Medical practitioner only	Both
	Per cent	Per cent	Per cent
2005	24	17	59
2008	15	9	77

Note: 96% of the 2008 medical practitioner-only notifications pertain to clinical diagnoses of varicella.

Source: Oxenford 2005; cited in 2007 Annual report of the National Notifiable Diseases Surveillance System; & SA Department of Health, unpublished data.

Notification mechanisms

Diseases are notified via fax, paper forms or telephone. The collection and transmission of notifiable disease data is facilitated by the use of the standard notification/reporting form which is used by medical practitioners. This form seeks common core data that includes

patient identification, age, sex, residential location, date of onset, as well as details pertaining to the reporting doctor.

Notification of Indigenous cases

The standard Indigenous status question is used.

Recording of Indigenous data in registry information system

The Surveillance & Investigation Section uses the standard Indigenous status format. It does not include any mandatory fields but an alert is flagged if no response is recorded.

Transmission of data for national collation

Data are provided to the NNDSS via encrypted email.

Completion rate

The completion rate for Indigenous status for notifiable communicable diseases in 2008 was 85% (DoHA 2010 forthcoming).

Tasmania

Legislation

The Tasmanian Public Health Act 1997 legislates the collection and reporting of communicable disease information. *The Guidelines for the Notification of Notifiable Diseases, Human Pathogenic Organisms and Contaminants* under the Act state that 'any medical practitioner and person superintending or in charge of a hospital or laboratory must notify the Director of actual or suspected cases of notifiable diseases'. The guidelines state that notification must include whether the patient is Aboriginal or Torres Strait Islander. The collection and reporting of Indigenous identification by GPs, hospitals and pathology is therefore mandated (despite pathology labs currently being unable to collect this information).

Source of information

In Tasmania, 95% of notifications in 2005 were reported by pathology laboratories with 5% provided by medical practitioners.

Table E6: Sources of notifications

	Pathology laboratory only	Medical practitioner only	Both
	Per cent	Per cent	Per cent
Tasmania	95	5	<1

Source: Oxenford 2005; cited in 2007 Annual report of the National Notifiable Diseases Surveillance System.

Notification mechanisms

Pathology request forms are generally hand-written by the GP or hospital, not electronically generated. Notifications are sent by pathology to the registry by fax, or if the laboratory is connected to the registries' IT system, they can be printed directly from the registries' computer. No notifications are sent electronically.

Notification of Indigenous cases

The standard Indigenous status question is used. A follow-up (case report) form is used in addition to the standard notification form for some disease notifications, which the GP is asked to complete. Indigenous status is asked in a two-step process:

1. Is the person of Aboriginal or Torres Strait Islander origin? (Yes/no/unknown)
2. If yes, to which of the following origins does this person identify? (Aboriginal/TSI/Both Aboriginal and TSI).

Recording of Indigenous data in registry information system

The Communicable Disease Control Prevention Unit uses the standard Indigenous status format.

Specialised services such as family planning and sexual health services also have Indigenous status recorded.

Transmission of data for national collation

Data are sent from the registry to the Commonwealth for national collation via email in an Excel spreadsheet that is individually de-identified and coded.

Completion rate

The completion rate for Indigenous status for notifiable communicable diseases in 2008 was 56% (DoHA 2010 forthcoming).

The Communicable Disease Prevention Unit follows up with GPs to obtain missing Indigenous status information for priority diseases. This has resulted in good coverage for these diseases (e.g. Chlamydia which is 75% notified by GPs has around 70% completeness for Indigenous status).

Australian Capital Territory

Legislation

The *Public Health Act 1997* legislates the collection and reporting of communicable disease information in the ACT. Although the Act enables the collection of Indigenous status information in communicable disease reporting, there is no specific legislation that mandates it.

Source of information

In the ACT, 98% of notifications in 2005 were reported by pathology laboratories with 1% provided by medical practitioners.

Table E7: Sources of notifications

	Pathology laboratory only	Medical practitioner only	Both
	Per cent	Per cent	Per cent
Australian Capital Territory	98	1	1

Source: Oxenford 2005; cited in 2007 Annual report of the National Notifiable Diseases Surveillance System.

Notification mechanisms

Pathology laboratories fax through the results of people with notifiable conditions to the registry. Notifications can also be phoned through or faxed through on ACT's notification form.

Notification of Indigenous cases

Notification forms use a variation of the standard Indigenous status question format. On the official notification form, the options for Aboriginal or Torres Strait Islander identity are:

- No
- Yes, Aboriginal
- Yes, Torres Strait Islander
- Yes, Aboriginal and Torres Strait Islander
- Not stated
- Not asked.

On disease investigation forms, the options are:

- Aboriginal
- Torres Strait Islander
- Aboriginal and Torres Strait Islander
- Not Indigenous
- Not stated
- Not collected
- Unknown.

Recording of Indigenous data in registry information system

The ACT Communicable Disease Control does not use the national standard for Indigenous status. Recording categories used are:

Aboriginal or Torres Strait Islander
Non-Aboriginal or Torres Strait Islander
Unknown.

Transmission of data for national collation

ACT Communicable Disease Control uses a Microsoft Access data dispatch that automatically generates a report and sends (de-identified data) via email to the Commonwealth for national collation.

Completion rate

The ACT completion rate for Indigenous status for notifiable communicable diseases in 2008 was 12% (DoHA 2010 forthcoming).

Northern Territory

Legislation

The Notifiable Diseases Act 1981 enables the collection and reporting of communicable disease information. In 1999, a legal requirement was introduced to report 'Aboriginal/Non-Aboriginal' with disease notifications (IIICDRP 2004). This has since been changed to Indigenous status in the schedule of items collected. The requirement to report Indigenous status applies to both laboratory and doctor notifications.

Source of information

In the Northern Territory, 98% of notifications in 2008 were reported by pathology laboratories with 2% provided by medical practitioners.

Table E8: Sources of notifications

	Pathology laboratory only	Medical practitioner only	Both
	Per cent	Per cent	Per cent
2005	95	5	<1
2008	98	2	<1

Source: Oxenford 2005; cited in 2007 Annual report of the National Notifiable Diseases Surveillance System; & NT Department of Health and Community Services unpublished data.

The Northern Territory also has the potential to data match/share with hospital information systems to provide additional Indigenous status information.

Information from the vaccination registry in the Northern Territory may also be used to obtain Indigenous status of children.

Notification mechanisms

Notifications are sent to the regional offices of the Centre for Disease Control by fax (some labs, GPs) or internal mail (hospital labs non-urgent notifications).

Notification of Indigenous cases

The standard Indigenous status question is used on communicable disease notification forms. These are used only for the few notifications by doctors. The hospital information system uses the standard Indigenous status question.

Recording of Indigenous data in registry information system

The standard Indigenous status question is used.

Transmission of data for national collation

Data are sent to the National Notifiable Diseases Surveillance System nightly via the Data Acquisition System.

Completion rate

The completion rate for Indigenous status for notifiable communicable diseases in 2008 was 94.5% (DoHA 2010 forthcoming).

Appendix F Cancer registries

New South Wales

Legislation

Cancer is a notifiable disease in NEW SOUTH WALES under the *Public Health Act 1991* and the Public Health (General) Regulation 2002. All hospitals, including radiation oncology departments, are required to notify cases. Under the regulation, hospitals and radiation oncology departments are required to notify using the 'Cancer Notification Form' published by the Cancer Institute NEW SOUTH WALES. Pathologists are only required to send in a copy of the pathology report; no information on Indigenous status is required. The Registrar of Births, Deaths and Marriages must forward a notification of death in the approved form, which includes Indigenous status, to the cancer registry.

Sources of information

Information on cancer notifications comes mainly from hospitals, including radiotherapy and medical oncology departments, pathology laboratories and the Registrar of Births Deaths and Marriages. Data are also received from nursing homes but not from BreastScreen NEW SOUTH WALES or the NEW SOUTH WALES Pap Test Register.

Indigenous status and other demographic data are usually only recorded in hospital records or death registrations. These records must be matched to the other sources of registrations, primarily pathology reports, to produce a complete record for an individual.

The New South Wales Central Cancer registry estimates that 14% of cancer notifications do not have pathology information provided and thus are from sources, and 1.3% of notifications come from the death certificate only.

Notification mechanisms

Cancer cases are notified electronically by public and private hospitals, private day surgeries, some public outpatient departments, public radiotherapy departments and the Registry of Births, Deaths or Marriages (either through the cancer notification portal, Health Information Exchange or disk). Pathology laboratories, aged care facilities, some public and private outpatient departments, and private radiotherapy departments notify cancer cases by paper form.

Notification of Indigenous cases

The Cancer Institute NEW SOUTH WALES form includes the standard Indigenous status question and response categories, but also includes a category for 'Declined to respond'.

Recording of Indigenous data in registry information system

The standard Indigenous status format is used. A category for 'Declined to respond' is also included.

Transmission of data for national collation

Unit record files (identified) are sent by the registry to the AIHW electronically for national collation.

Completion rate

The registry estimates that 19% of cancer notifications do not have Indigenous status recorded.

Victoria

Legislation

The Cancer Council Victoria collects information under the *Cancer Act 1958*, which obligates hospitals and pathology laboratories to report diagnoses of cancer. The Cancer (Reporting) Regulations 2002 list required items for hospital and pathology reports. The hospital report includes a mandatory field for 'Aboriginal or Torres Strait Islander' but the pathology form does not.

Sources of information

Notifications come mainly from hospital and pathology reports. Information on deaths from cancer is obtained from the Victoria Registrar of Births, Deaths and Marriages; receiving records from multiple sources for each individual serves to improve data quality by cross-checking. Only notifications from death certificates are intensively followed up.

Demographic data, including Indigenous status, come from hospital notifications and death certificates (Cancer Council Victoria 2002 pp4-5). For pathology reports received, the registry populates the Indigenous status field with 'not stated' temporarily until it can be automatically over-ridden with information from the hospital or death certificate.

Notification mechanisms

The nine large laboratories accounting for most notifications send data to the registry electronically. There are many smaller labs which mostly use paper forms. Reports may be sent monthly, fortnightly or weekly.

Some hospitals, if they have the capacity, can create an electronic file which is sent directly to the registry. Information is drawn from the hospital patient information system and non-routine clinical data. Cases are sent over a secure website.

Notification of Indigenous cases

Victoria does not use a standard notification form. Hospital and pathology reports are sent directly to the Victoria Cancer Council. Most hospital records use a format similar to the standard format for Indigenous status (instead of 'not stated/inadequately described, they have added two response categories 'question unable to be asked' and 'patient refused to answer'.

Recording of Indigenous data in registry information system

The Cancer Council Victoria does not use the standard Indigenous status format. The five standard categories are used, with an additional category of 'Aboriginal and/or Torres Strait Islander (unspecified)'.

Transmission of data for national collation

Unit record files (identified) are sent by the registry to the AIHW electronically for national collation. Data have recently been transmitted via a secure internet porthole. Information can also be sent via encrypted files. The AIHW has an account with the registry so there is a two-way exchange of information.

Completion rate

The completion rate in 2006 was 77% (AIHW unpublished data).

Queensland

Legislation

Notification of cancer is a statutory requirement for all public and private hospitals, nursing homes and pathology services. Queensland's Public Health Act 2005 requires pathology laboratories and hospitals (both public and private) to notify diagnoses of cancer. The Act requires notifications to be in the 'approved form', which includes the standard Indigenous status question and recording categories.

Only hospitals and nursing homes use the approved form. Pathologists provide a copy of the pathology report which may or may not include Indigenous status. Legislative changes may be needed for collection of Indigenous status by pathologists to be made mandatory and in the approved form.

Sources of information

Notifications are received for all persons with cancer separated from public and private hospitals and nursing homes. Queensland laboratories provide copies of pathology reports for cancer specimens. Data on all persons who die of cancer or cancer patients who die of other diseases are abstracted from the mortality files of the Registrar of Births, Deaths and Marriages and linked to hospital and pathology data (Queensland Cancer Registry 2007 p5).

Indigenous status is sourced from hospital data in the majority of cancer notifications (estimated to be around 85% by Qld Health).

Notification mechanisms

A standard notification form or a variation of it with the same data elements is used. Pathology services notify cases by sending a copy of the pathology report.

Notification of Indigenous cases

The notification form includes the standard Indigenous status question format (Queensland Cancer Registry 2007 p50).

Recording of Indigenous data in registry information system

National standards are complied with.

Transmission of data for national collation

Unit record files (identified) are sent on a compressed CD which is zipped and encrypted to the AIHW for national collation.

Completion rate

The completion rate in 2006 was 83% (AIHW unpublished data).

Western Australia

Western Australian hospitals are not required to notify about cancer diagnoses but they provide data to the Western Australian Cancer Registry on request. New regulations require the notification of non-pathologically-diagnosed cases by hospitals.

Pathology reports can collect 'race' in the normal course of business, and its inclusion in notifications to the registry is not specifically mandated in the Health (Notification of Cancer) Regulations 1981. Under the regulations, pathologists and radiation oncologists are required to send reports. The new draft regulations will specify that this item is to be sent even if not part of the routine "report". Medical practitioners may be required to give extra information from a schedule which includes 'race'. The new draft regulations have replaced 'Race' with 'Indigenous Status'. No further changes are thought to be required in order to mandate the collection of Indigenous status.

Sources of information

Most cancer notifications are obtained from pathology laboratories and radiation oncologists. Data are kept by the Western Australian Cancer Registry.

Pathology and mortality data files are linked to create new records, or to update information from pathology records. Additional demographic information, including Indigenous status, is obtained from periodic extracts from Morbidity Data System files or online from a Patient Master Index in Perth Metropolitan Area public hospitals. Where information is insufficient to allow complete registration, active follow-up may be undertaken by contacting treating doctors, pathology laboratories or hospitals (Threlfall and Thompson 2007 pA1-2).

Notification mechanisms

Pathology laboratories provide data electronically via delimited files.

Hospitals do not notify the registry as data is accessed via HMDS data; this is subject to change in the new draft regulations.

Notification of Indigenous cases

There is no standard notification form for cancer notifications. Information is sent directly from hospitals and pathology labs.

Public hospitals use the standard Indigenous question except in rural hospitals where there are no 'not stated/inadequately described' or 'Neither Aboriginal nor Torres Strait Islander' categories. Both these categories are coded as 'Other'. Metropolitan hospitals allow for these two categories separately but the information is combined as 'Other'.

Recording of Indigenous data in registry information system

The standard Indigenous status format is not used. Data are recorded according to the following:

1= Aboriginal but not Torres Strait Islander

4= Neither Aboriginal nor Torres Strait Islander

5= Aboriginal +/or Torres Strait Islander (unspecified)

Transmission of data for national collation

Unit record files (identified) are sent electronically for national collation. Data is provided in dbf or ascii fixed-width files either zipped-encrypted or on a CD.

Completion rate

The completion rate in 2006 was 98% (AIHW unpublished data).

South Australia

Legislation

Under the South Australian Health Care Regulations 2008, Part 6 (Reporting of Cancer), hospitals or health services that incorporate a radiotherapy clinic must report Indigenous status, race and ethnicity. Pathology laboratories need only provide a copy of their report to the South Australian Cancer Registry within three months. There is no regulation for the report to include Indigenous status.

Sources of information

Cancer notifications come from pathology laboratories, hospitals and radiation clinics. The Registrar of Births, Deaths and Marriages is another important source of cancer data. A minimum data set is collected for each case which includes race (South Australian Cancer Registry 2007 p8).

Notification mechanisms

Various mechanisms are used, including a standard notification form, paper forms, fax and electronically.

Notification of Indigenous cases

A standard cancer notification form is used which distinguishes Aboriginal, Torres Strait Islander, and both Aboriginal and Torres Strait Islander. This form is generally used by medical practitioners and hospitals, but not by pathology labs.

Information is sent directly from hospitals and pathology labs to the registry.

Public hospitals use the standard Indigenous status question with a 'not stated/inadequately described' category permitted. Private hospitals also mostly use the standard Indigenous question.

Recording of Indigenous data in registry information system

National standards are complied with.

Transmission of data for national collation

Unit record files (identified) are sent electronically for national collation.

Completion rate

The completion rate in 2006 was 83% (AIHW unpublished data).

Tasmania

Legislation

In Tasmania, The Public Health Act 1997 specifies that a notification must be made in accordance with any relevant guidelines. The 'Guidelines for Notification of Notifiable Diseases Human Pathogenic Organisms and Contaminants' list Indigenous status as one of the data items to be provided by hospitals but not by laboratories. Legislative changes would be needed to mandate the collection of Indigenous status by pathology.

The confidentiality section of the guidelines allows for data to be exchanged between registries (e.g. the cancer registry, the breast cancer registry and the cervical registry).

Sources of information

Data is obtained from pathology laboratories, radiation oncology clinics, hospitals and the Registrar of Births, Deaths and Marriages. Most cases included a pathology report and a hospital service (either as an inpatient or at a radiation oncology clinic). Data are matched and cross checked.

The registry estimates that 9% of notifications rely on pathology information without hospital notes; 4% rely on results of clinical investigation or clinical assessment as well as hospital notes; 0.9% rely on results of clinical investigation or clinical assessment without hospital notes; and 1.3% are from death certificate only. The remainder (80-85%) rely on information from the pathology report, where the request is coming from the specialist or hospital.

Notification mechanisms

Only one public hospital and a radiotherapy centre provide notifications electronically, while several are moving towards this format. Other hospitals complete cancer registration abstract sheets which are mailed as paper copies. One pathology company provides notifications electronically, while others send a paper copy. Pathology reports which are specifically requested by registry staff may be faxed.

Notification of Indigenous cases

No standard notification form is used. Information is sent directly from hospitals and pathology labs.

Public hospitals and the Registrar of Births, Deaths and Marriages use the standard Indigenous status format when notifying the registry.

Recording of Indigenous data in registry information system

National standards are complied with.

Transmission of data for national collation

Unit record files (identified) are encrypted, zipped and sent electronically for national collation.

Completion rate

The completion rate in 2006 was 39% (AIHW unpublished data).

Australian Capital Territory

The NEW SOUTH WALES Cancer Registry undertakes data management and coding on behalf of the ACT Cancer Registry. This reflects both the considerable resources required to collect, code and process cancer registry data, and cross-border use of medical services.

Legislation

The Public Health Regulations 2000 require pathology services, hospitals and nursing homes to notify the ACT Cancer Registry about cancer diagnoses. The regulations do not specify what information is to be collected. No legislative changes are required to mandate the collection of Indigenous status.

Sources of information

The ACT Cancer Registry receives information on cancer notifications from hospitals, nursing homes, pathology labs, the electoral roll and the Registry of Births, Deaths and Marriages. If information is missing, a letter requesting the missing information is sent to the patient's GP.

Notification mechanisms

Pathology laboratories and nursing homes use paper forms, and hospitals use a mix of paper and electronic forms.

Notification of Indigenous cases

The standard Indigenous status question is used.

Recording of Indigenous data in registry information system

National standards are complied with.

Transmission of data for national collation

The NEW SOUTH WALES Cancer Registry sends unit record files (identified) to the ACT Registry which is then passed onto the AIHW for national collation in electronic form as an encrypted zip file on CD.

Northern Territory

Legislation

It is compulsory to notify the Northern Territory Cancer Registry when a pathological diagnosis of cancer is made or where cancer is mentioned as a cause of death on a death certificate. The NT Cancer (Registration) Act 1988 was replaced by the Cancer (Registration) Act 2009. While the 1998 Act (Cancer (Registration) Regulations 1991) specifies that pathology notifications should include 'ethnic group', the 2009 Act makes it mandatory for pathology laboratories, hospitals and the Registrar of Births, Deaths and Marriages to report information that is on the pathology form, including 'Indigenous status'. It also allows the Registrar General to seek additional information from doctors. Both Acts contain a provision that pathology services do not need to provide data that is not reasonably available to them.

Sources of information

Details missing from a pathology report, including Indigenous status, are obtained from the laboratory, treating hospital or doctor. Additional information is obtained from other State cancer registries and cancer screening programs (Condon et al. 2004b p5). This has resulted in an estimated 98% accuracy for Indigenous status in the NT Cancer Registry (based on a recent hospital audit). Computerised death registration data are obtained from the Registrar of Births, Deaths and Marriages on a monthly basis.

It is estimated that 85% of cancer notifications source information from pathology laboratories and 15% from death certificates. This will include some overlap with hospital data.

Notification mechanisms

Pathology laboratories notify cases in paper form by mail. Hospitals may notify in paper form, fax or electronic.

Notification of Indigenous cases

The standard Indigenous status format is used.

Recording of Indigenous data in registry information system

National standards are complied with.

Transmission of data for national collation

Unit record files (identified) are sent electronically for national collation.

Completion rate

The completion rate in 2006 was 97% (AIHW unpublished data).

Appendix G Cervical screening registries

New South Wales

In New South Wales, the *Public Health Act 1991* stipulates what personal information can be collected by the NSW Pap Test Register. The register made a submission to the NSW Public Health Bill 2010 requesting the addition of Indigenous status as a data item and this was accepted. The amended *Public Health Act 2012* permits the collection and storage of Indigenous identification on the NSW Pap Test Register.

Sources of information

The NSW Pap Test Register receives all test results from pathology laboratories.

Notification mechanisms

Pathology records are sent electronically. Some very small histology labs (4 currently) send hard copies.

Notification of Indigenous cases

There is no data item for Indigenous status on pathology forms. The NSW Pap Test Register therefore does not obtain any information on Indigenous Status.

Recording of Indigenous data in registry information system

The NSW Pap Test Register is building the capability to record Indigenous status information.

Transmission of data for national collation

A secure portal is used.

Victoria

Legislation

The Victorian Cervical Cytology Registry (VCCR) operates under the Cancer Act 1989. The Act does not specify what items are to be collected. Indigenous status can be collected but changes would be required for it to be made mandatory. The Breastscreen Registry operates under the same Act and collects Indigenous status.

Sources of information

All histology data is obtained from pathology forms. All cytology data are in coded format; the VCCR does not receive the actual laboratory request form. The only exception to this is a few small laboratories which send in the actual laboratory form.

Notification mechanisms

Pathology forms are received via paper, and cytology results via paper, fax or electronic.

Notification of Indigenous cases

A small proportion of records have Indigenous status recorded as part of the Victorian Cytology Service Pilot Study (see section 1.2 for details).

Recording of Indigenous data in registry information system

An Indigenous indicator that complies with national standards can be collected.

Transmission of data for national collation

Data are transmitted electronically via Excel spreadsheets in aggregated form (i.e. de-identified).

Queensland

Legislation

The Queensland Pap Smear Register is governed by the Public Health Act 2005. The Act does not enable ethnicity to be recorded but is seeking amendment to Part 3, Section 251 for the inclusion of ethnicity (and potentially Indigenous status following legal advice) to subsection (d) which is for 'other information prescribed under a regulation'. This will enable Indigenous status information to be made mandatory.

Sources of information

All test results come from pathology labs, an estimated 40% from public labs and 60% from private.

Notification mechanisms

The Queensland Pap Smear Register receives less than 1% of results via paper forms from laboratories. These are generally interstate results. The rest are received electronically and contain the woman's details along with a coded summary of the pathology report.

Notification of Indigenous cases

About 5% of records have Indigenous status recorded. Although the two main laboratories (Queensland Medical Laboratory and Sullivan and Nicolaides) do not collect Indigenous status, Queensland Pathology collects Indigenous status information on its pathology form. It is not mandatory, however, and is often overlooked. About 10,000 Indigenous persons are on the register.

Recording of Indigenous data in registry information system

Indigenous status can be recorded according to the national standard.

Transmission of data for national collation

Data are transmitted electronically via Excel spreadsheets in aggregated form (i.e. de-identified).

Western Australia

Legislation

Regulation 9 of the *Health (Cervical Cytology Register) Regulations 1991* (WA) provides that a person in charge of a laboratory must forward the results or a copy of the results of a cervical cancer test to the Chief Executive Officer (CEO) of Health in a form approved by the CEO of Health. The 'approved form' has a field to indicate Indigenous status but it is optional and cannot be made mandatory until such time as the information is available from laboratories. It is preferred practice that laboratories provide optional data when available.

Sources of information

The Cervical Cytology Registry receives WA Death Registry data, limited electoral roll data, limited WA Cancer Registry data and has manual access to public hospital records. Some of these sources include Indigenous status data but the registry does not make use of this information. Only pathology request form data are used.

Notification mechanisms

Laboratories are required to send an encrypted and signed email with test results attached. This ensures they can only be decrypted and read by the Cervical Cytology Registry, that the registry can verify the sender of the results is the laboratory, and that the results have not been altered in transit. Test results must be sent within 60 days of completion of the test by the laboratory.

Notification of Indigenous cases

Some public hospital laboratories can supply Indigenous data but it is not consistent with the standard format for Indigenous status and cannot be mapped to the required categories. It is not recorded by the registry. Of the nine laboratories contributing data, the four public hospital laboratories (PathWest) are able to record Indigenous status as part of a pilot project (see section 1.2 for more details).

Recording of Indigenous data in registry information system

Indigenous status can be recorded according to the national standard.

Transmission of data for national collation

Data are transmitted electronically via Excel spreadsheets as email attachments, in aggregated form (i.e. de-identified).

South Australia

Legislation

The SA Cervix Screening Program operates under the Public & Environmental Health (Cervical & Related Cancer Screening) Regulations 2006. The pathology laboratory must provide various details—name, address, date of birth, Medicare number and any other identifying particulars. It is not mandatory for Indigenous status information to be provided.

Sources of information

All information is received from pathology labs. Although some records are sent to laboratories from hospitals, the registry does not receive records directly from hospitals. Work is underway to reconcile cancer and cervical screening data with data from the Registrar of Births, Deaths and Marriages.

Notification mechanisms

All test records, including test results from pathology laboratories, are received electronically. Electronic data is not received direct into the database from GPs, service providers or hospitals. Some data is received in response to reminders from GPs/service providers, and once verified, the information is loaded into the registry. GP reminder letters do not usually include Indigenous status.

Notification of Indigenous cases

There is no data item for Indigenous status on pathology forms. Indigenous status information is therefore not obtained.

Recording of Indigenous data in registry information system

Indigenous status information is not collected, but has the capacity to receive and store this information according to the national standard.

Transmission of data for national collation

Data is sent electronically via Excel spreadsheets, however a secure data exchange facility has been requested. This will allow external users such as the AIHW and other registries temporary access, to a secure web portal where data can be uploaded and/or downloaded.

Tasmania

Legislation

The *Tasmanian Public Health Act 1997* (Part 7- Cervical Screening Register) specifies that information in the Cervical Screening Register may be obtained from (a) the person; (b) a medical practitioner or registered nurse engaged by the person; (c) a person in charge of a laboratory engaged by, or on behalf of, the person; (d) the person responsible for keeping the National HPV Vaccination Program Register; (e) a person responsible for keeping a corresponding register; (f) Medicare Australia.

The *Personal Information Protection Act 2004* contains a clause providing for the collection of "sensitive information" but this is only for specific purposes and in certain circumstances.

Legislative changes are needed to enable the collection of Indigenous status. Drafting of a proposed amendment will be carried out by the Tasmanian Cervical Cancer Prevention Program and the legal representative from Population Health. It may be that the Act will either extend the definition of personal information to include indigenous status or add it to the list at section 137A (recording information).

Sources of information

All test records are received from two private pathology laboratories and two public hospitals. The majority of test results come from the public hospital laboratories.

Notification mechanisms

Data is received electronically via encrypted email attachments. It comes in two parts: client demographic information is received first (which triggers a patient history to be returned to the laboratory so a recommendation can be made to the patient's clinician about appropriate follow-up). This is then followed by the result data.

A small percentage of results are received on paper format and are manually entered.

The register can also manually print and mail patient histories on request from a laboratory, client or cervical cancer test provider.

Notification of Indigenous cases

Indigenous status will be recorded if it is included in the electronic file. The format of the demographic data file is designed so that Indigenous status can be included by the pathology laboratory (providing it has the capability). There is no provision on the pathology request forms to record Indigenous status information. Therefore the information cannot be transmitted to the electronic file sent to the registry.

Recording of Indigenous data in registry information system

The register can, but does not, collect Indigenous status in the national standard format.

Transmission of data for national collation

De-identified data is transmitted electronically in Excel spreadsheets.

Australian Capital Territory

Legislation

A regulatory change was made in 2008 to enable the collection of Indigenous status by the ACT Cervical Screening Register. Collection is not mandatory.

Sources of information

All cervical cytology, histology and HPV-DNA results are received from pathology labs.

Notification mechanisms

All data items are electronically received from contributing laboratories, which in turn receive them from screening practitioners through pathology request forms. Data are sent to the register under a strict protocol agreed to by all labs and the register.

Notification of Indigenous cases

There is no data item for Indigenous status on pathology forms. Laboratories therefore do not receive Indigenous status data.

Recording of Indigenous data in registry information system

An Indigenous indicator complying with national standards can be collected. Most women are recorded as "not stated/inadequate description".

Transmission of data for national collation

Data are transmitted electronically via Excel spreadsheets as email attachments, in aggregated form (i.e. de-identified).

Northern Territory

Legislation

Indigenous status can be collected under the NT Public Health (Cervical Cytology Register) Regulations. These specify that 'the person in charge of a laboratory within the Territory must, within 60 days of receiving test results relating to a woman, provide the register with any details entered on the request form by a health practitioner under regulation 6(5)'. This regulation specifies that 'aboriginality' is one of the personal details a health practitioner must enter on the request form for women who have had a cervical examination, but only to the extent to which the health practitioner is able to ascertain those details. This implies that aboriginality is a mandatory item to be collected under the regulation, but is not collected because there is no field to record it on the request form. The regulations do not specify in what format aboriginality is to be collected.

Section 4(e) of the regulations specifies conditions for provision of data. It does not allow for data matching of cervical screening data with other data collections such as the NT hospital client master index to better capture client personal details.

Sources of information

Cytology data is received electronically direct from laboratories: Royal Darwin Hospital for histology (text which is coded by a consultant and manually entered), and interstate laboratories which process all cervical cytology taken in the NT. Most cytology results come from private labs; 80% of histology results come from the Royal Darwin Hospital.

Notification mechanisms

Data are encrypted from laboratories to a generic e-mail account. Data comes from Royal Darwin Hospital by e-mail attachment.

The NT Register can send patient histories to laboratories on request, to assist with reporting on current tests, but because laboratories have not modified their systems to enable this information exchange, the software is not installed on the NT Register.

Notification of Indigenous cases

There is no data item for Indigenous status on pathology forms. The Northern Territory therefore does not receive Indigenous status information. All data received are stored as '9=Not stated/inadequately described'.

Recording of Indigenous data in registry information system

Indigenous status can be recorded according to the national standard.

Transmission of data for national collation

Data are transmitted electronically via Excel spreadsheets as email attachments, in aggregated form (i.e. de-identified).

Appendix H Example pathology request form which includes an Indigenous identifier

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List of tables

List of figures

Under the National Indigenous Reform Agreement in 2008, the Council of Australian Government agreed to data quality improvements which are focussed on improving Indigenous identification in key data sets. This report outlines work towards the inclusion of Indigenous status on pathology request forms as a way to improve Indigenous identification in national cancer, communicable disease and cervical screening registries.