Evaluation of Indigenous status completeness in vaccine preventable disease notification data in the NNDSS

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Authors and acknowledgments

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Survey participants and informants

We thank all jurisdictional public health authority staff who participated in our survey and provided additional information.

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Contents

Glossary

ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
AIR	Australian Immunisation Register
ARIA+	Accessibility/Remoteness Index of Australia Plus
CDNA	Communicable Diseases Network Australia
GP	General practice/practitioner
Hib	*Haemophilus influenzae* type b
IMD	Meningococcal disease (invasive)
IPD	Pneumococcal disease (invasive)
NACCHO	National Aboriginal Community Controlled Health Organisation
NATSIHP	National Aboriginal and Torres Strait Islander Health Protection Sub-Committee of the Australian Health Protection Principal Committee
NCIMS	Notifiable Conditions Information Management System (NSW Health)
NCIRS	National Centre for Immunisation Research and Surveillance
NIP	National Immunisation Program
NNDL	National Notifiable Diseases List
NNDSS	National Notifiable Diseases Surveillance System
NSW	New South Wales
NT	Northern Territory
PHU	Public Health Unit
Qld	Queensland
SA	South Australia
Tas	Tasmania
Vic	Victoria
VPD	Vaccine preventable disease
WA	Western Australia

Executive summary

Background

Reliable Indigenous status identification in health datasets is key to greater understanding of the health needs of Aboriginal and Torres Strait Islander peoples and continuing progress towards Closing the Gap targets, via policy development, service delivery improvements and effective monitoring of services and programs. The National Notifiable Diseases Surveillance System (NNDSS) was established in 1990 under the auspices of the Communicable Diseases Network Australia (CDNA) to collect and store surveillance data for nationally notifiable diseases in Australia. While the eight states and territories (jurisdictions) of Australia are primarily responsible for public health action, national-level surveillance through the NNDSS is important for a range of purposes, including to: describe national epidemiology and identify national trends; guide policy development and resource allocation; monitor the need for, and impact of, national disease control programs; and inform a coordinated response to multi-jurisdictional outbreaks.

Data on a range of vaccine preventable diseases (VPDs) are collected in the NNDSS, with a disproportionately higher burden of most VPDs in Aboriginal and Torres Strait Islander peoples. Under the National Immunisation Program, some vaccines are funded for Aboriginal and Torres Strait Islander people alone, or with expanded age eligibility. High quality Aboriginal and Torres Strait Islander status (recorded as 'Indigenous status' in the NNDSS and referred to respectfully hereafter as such) data in the NNDSS allow better evaluation of these existing programs and consideration of new or expanded program initiatives. A 2004 evaluation of the NNDSS identified that Indigenous status was one of the most poorly completed data fields, and in 2009 CDNA, as part of its own Closing the Gap strategy, set targets of 95% Indigenous status completeness in the NNDSS for 18 priority diseases, including eight VPDs (*Haemophilus influenzae* type b [Hib], hepatitis A, newly acquired hepatitis B , measles, invasive meningococcal disease [IMD], pertussis <5 years, and invasive pneumococcal disease [IPD] <5 years and ≥50 years) and 80% completeness for other diseases (including diphtheria, unspecified hepatitis B, laboratory confirmed influenza, pertussis [≥5 years], IPD [≥5 to <50 years], rotavirus, rubella and tetanus). In 2016–2019 Indigenous status completeness at the national level was over 90% for most VPDs in the NNDSS, but lower for influenza (37.4%), pertussis (59.2%) and rotavirus (69.7%), all of which are high incidence diseases either fully or predominantly notified by laboratories, with some variation by jurisdiction and age group. We aimed to undertake a comprehensive evaluation of factors influencing the quality and completeness of Indigenous status for VPDs in the NNDSS.

Methods

The framework for this evaluation was provided by the data quality attribute of the United States Centers for Disease Control and Prevention's *Updated guidelines for evaluating public health surveillance systems*. Evaluation methodology consisted of three modules: 1) review of published and grey literature; 2) analysis of NNDSS VPD data from 2010 to 2019 (the most recently available data at study commencement) by year of notification, sex, age, jurisdiction and remoteness, with comparison to relevant CDNA targets; and 3) stakeholder engagement including consultation with the National Aboriginal Community Controlled Health Organisation and an online survey of key

jurisdictional surveillance staff. Findings informed recommendations to improve the completeness of NNDSS Indigenous status data.

Results/Discussion

Trends in NNDSS Indigenous status completeness

For VPDs where the CDNA target is 95%, national-level Indigenous status completeness was above the target in all years from 2012 onwards for measles, IMD, IPD in both the <5 and ≥50 years age groups, and Hib disease, and within four percentage points for hepatitis A, pertussis (<5 years age group) and newly acquired hepatitis B. For VPDs with a target of 80%, Indigenous status completeness was above this in most years for rubella, diphtheria and tetanus, reaching 100% in the majority of years but with fluctuations due to small numbers of notifications. Completeness increased substantially for mumps, from 60% in 2010 to above 90% from 2013 onwards, likely due to increased public health follow-up related to large multi-jurisdictional outbreaks in remote Aboriginal communities. Completeness was below the 80% target in all years between 2012 and 2019 for IPD in the ≥5 to <50 years age group (range 72%–79%), and between 2010 and 2019 for rotavirus (59%–79%), pertussis (≥5 years age group; 61%–69%), unspecified hepatitis B (48%–62%) and laboratory confirmed influenza (43%–63%). However, there was substantial variation by jurisdiction, with the Northern Territory (NT) and Western Australia (WA) above the CDNA targets for all VPDs for the 2010 to 2019 period, and South Australia (SA) above the CDNA targets for all VPDs except laboratory confirmed influenza (75%). Completeness was ≥95% for NT for all VPDs except unspecified hepatitis B (92%) and for WA for all except laboratory confirmed influenza (89%), unspecified hepatitis B (92%) and rotavirus (94%). For all VPDs assessed, Indigenous status completeness increased with increasing remoteness. This could be due to a combination of greater capacity for public health follow-up due to fewer notifications, better identification of Indigenous status due to higher proportions of Aboriginal and Torres Strait Islander people in communities, and a greater role of Aboriginal Community Controlled Community Health Services, known to have more complete identification of Aboriginal and Torres Strait Islander clients than mainstream general practice (GP) settings.

Barriers, enablers and strategies to improve Indigenous status completeness

The main barriers identified by most jurisdictions were: 1) the absence of an Indigenous status field in most pathology request forms, leading to missing Indigenous status identification in laboratory notifications; and 2) limited public health authority resource capacity to follow up missing data, either through case follow-up or indirectly by cross-checking other health datasets such as hospitalisations, particularly for high incidence diseases. These issues likely explain the low Indigenous status completeness observed in most jurisdictions for unspecified hepatitis B, laboratory confirmed influenza, rotavirus and pertussis (≥5 years age group), all of which are high incidence diseases predominantly notified by laboratories only. However, Indigenous status completeness was high for these VPDs in NT and WA. The high completeness in NT is attributable to routine public health follow-up of all notifications with manual cross-checking of hospital databases where Indigenous status is missing. NT also reports undertaking retrospective updating of missing Indigenous status through annual manual data cleaning. The high Indigenous status completeness in WA is attributable in large part to the high level of clinician reporting of all VPDs, along with manual cross-checking of hospital databases by public health and reference laboratory

staff where Indigenous status is missing. Manual cross-checking of other databases, as undertaken in NT and WA, is a resource intensive activity, which may not be feasible in all jurisdictions. WA also mandates inclusion of an Indigenous status field in pathology request forms, although completeness of this field is low. WA also undertakes annual linkage with other health datasets, although this is currently only used to enhance Indigenous status completeness in COVID-19 notification data and Indigenous status completeness in WA VPD notification data in 2021 was reported to have been approximately 97% prior to data linkage. Mandated inclusion of an Indigenous status field on pathology request forms, which was supported by most jurisdictions when surveyed, would seem a key medium to long term strategy to improve Indigenous status completeness. However, based on the WA experience, this would need to be complemented by work to ensure effective transfer of Indigenous status data between primary care and pathology software systems. A nationally coordinated and consistent approach, developed in collaboration with jurisdictions, would be preferable given many pathology services operate across jurisdictional borders.

Data linkage is another strategy that the stakeholders surveyed all perceived as potentially useful for improving Indigenous status completeness. Data linkage may be particularly useful in those jurisdictions where Indigenous status completeness in NNDSS is lower, either overall or for specific diseases, with consistency of methods across jurisdictions desirable. While data linkage is technically complex to establish initially, it is likely a less resource intensive strategy once operational compared with manually cross-checking for missing Indigenous status information in other data systems, particularly for high incidence diseases. The innovation in data usage achieved during the COVID-19 response may provide an opportunity to enhance data for other notifiable diseases, including through data linkage. Jurisdictions recently gained access to population-level Australian Immunisation Register (AIR) data for public health activity, thus providing access to Indigenous status as reported to Medicare or to the AIR by immunisation providers. Aboriginal and Torres Strait Islander stakeholders should be consulted around data linkage methodologies for population health purposes, including how best to deal with inconsistencies in recorded Indigenous status of individuals within and between datasets.

However, accurate identification of Indigenous status at the point of service, whether GP, hospital or laboratory, should be the ultimate and universal goal, along with accurate transmission between services and to public health authorities through the notification process, rather than needing data linkage to mitigate inadequate collection and transfer practices.

Current CDNA targets for Indigenous status completeness in NNDSS data have remained unchanged since introduced in 2009. The majority of jurisdictions surveyed thought targets should be raised for rubella, tetanus, mumps and diphtheria, half thought targets should be raised for IPD (5 to <50 years) and rotavirus, and a minority that targets should be raised for influenza, pertussis (≥5 years) and unspecified hepatitis B. There is a strong argument for increasing targets for those VPDs with a current target of 80% where the target is already being achieved in all jurisdictions (diphtheria and tetanus), as these have small numbers of notifications, are followed up by all jurisdictions and are of considerable public health significance. However, targets for all VPDs should be reviewed and increased where appropriate based on factors including the importance of complete Indigenous status data to inform timely and effective public health action. Consideration should be given to the introduction of targets for other VPDs of contemporary relevance, such as

COVID-19, Japanese encephalitis, mpox and respiratory syncytial virus, and other notifiable diseases without completeness targets that are not vaccine preventable. The National Aboriginal and Torres Strait Islander Health Protection Sub-committee of the Australian Health Protection Principal Committee (NATSIHP) should be consulted in the review of targets and in the consideration of diseases for which Indigenous status completeness should be monitored. Regular reporting of progress against targets to key stakeholders would also be of benefit to raise awareness and promote ongoing improvement efforts. Inclusion of Indigenous status completeness targets as a reportable indicator under the National Partnership for Streamlined Agreements – Vaccine Preventable Diseases Surveillance Program Schedule, potentially aligned to CDNA targets, should also be considered, with appropriate review of accompanying financial contributions.

We identified inconsistencies between jurisdictions in how Indigenous status reporting categories are completed and mapped to NNDSS data specifications, particularly in relation to missing data. Consistency of coding would enhance interpretation of national-level Indigenous status data in the NNDSS, and ideally allow understanding of reasons for incomplete data (e.g. refused response versus truly missing data), to inform actions to increase data completeness.

Conclusion

To optimise Indigenous status completeness for VPDs, and for other notifiable diseases in the NNDSS, a mix of strategies are needed to ensure accurate identification and recording at all relevant levels (primary care, hospital, laboratory and public health authority) and effective transfer between these services. The development, implementation and evaluation of all initiatives should be led by Aboriginal and Torres Strait Islander peoples wherever possible, and their expertise and experience utilised to optimise appropriateness and effectiveness. Driving and supporting a nationally consistent approach to address the recommendations in this report may fall within the remit of the forthcoming Australian Centre for Disease Control as the focal point for disease surveillance data collation, coordination of laboratory data collection, reporting and analysis.

Recommendations

Inclusion of Indigenous status on pathology request forms

- The Australian Government Department of Health and Aged Care (the Department) should work with relevant stakeholders and national networks, including CDNA and the Public Health Laboratory Network, to develop a nationally consistent approach to ensure inclusion of an Indigenous status field on pathology request forms, complemented by work to ensure effective transfer of Indigenous status data between primary care and pathology software systems.

Coordinated use of data linkage between notification data and other health datasets to enhance Indigenous status completeness

- The Department and jurisdictional health departments should work together to identify coordinated and consistent approaches to data linkage for improving Indigenous status completeness and quality.

Targets for Indigenous status completeness in notifiable disease data

- CDNA should review its current targets for Indigenous status completeness in notifiable disease data and increase these where appropriate, in consultation with NATSIHP.
- CDNA, with NATSIHP, should consider whether Indigenous status targets should be introduced for other diseases in the NNDSS – for example, COVID-19, Japanese encephalitis, mpox.
- The Department should consult with jurisdictional health authorities about potential inclusion of Indigenous status completeness as a reportable indicator under the National Partnership for Streamlined Agreements – Vaccine Preventable Diseases Surveillance Program, with targets potentially aligned to CDNA targets and review of accompanying financial contributions.
- The Department and jurisdictional health departments should continue to work with relevant stakeholders to optimise the collection of Indigenous status in primary care and hospital settings.

Standardised use of reporting categories in notifiable disease surveillance systems

- The Department and jurisdictional health departments should work together to implement standardised and consistent categories for reporting Indigenous status in jurisdictional notifiable disease surveillance systems and mapping of this information to the NNDSS.

Education and training

- The Department and jurisdictional health departments should continue to support and expand training initiatives for healthcare staff regarding the importance and procedural aspects of collecting Indigenous status, including in cases of notifiable disease.
- Jurisdictional health departments should continue to support and expand education and training for public health staff on the importance of Indigenous status reporting in notifiable disease data, and promote checking of Indigenous status during case follow-up.

Aboriginal and Torres Strait Islander oversight

- Development, implementation and evaluation of all initiatives to improve Indigenous status collection, recording, reporting and evaluation should be led by Aboriginal and Torres Strait Islander peoples wherever possible, and their expertise and experience used to optimise appropriateness and effectiveness.

Introduction

A range of initiatives aiming to improve health and wellbeing outcomes for Aboriginal and Torres Strait Islander peoples have been a cornerstone of the Australian Government's 'Closing the Gap' strategy, introduced in December 2007. However, disproportionate rates of many health conditions, including communicable diseases, persist,[1] and where improvements have occurred, the gap has not always narrowed, due to similar or greater improvements in non-Indigenous people.[2]

Reliable identification of Aboriginal and Torres Strait Islander status in health datasets is key to greater understanding of the health needs of Aboriginal and Torres Strait Islander peoples and continuing progress towards Closing the Gap targets. This informs health service decision making, including policy development and service delivery improvements, and facilitates effective monitoring of health services and programs.[3] At an individual level, benefits of collecting and recording Aboriginal and Torres Strait Islander status include upholding the rights of individuals to self-report their status at health service encounters and enabling Aboriginal and Torres Strait Islander clients to be offered information and services designed to meet their needs.[3,4] Aboriginal and Torres Strait Islander people are known to be under-identified in health datasets, which led to the development of the *National best practice guidelines for collecting Indigenous status in health data sets* by the Australian Institute of Health and Welfare (AIHW) in 2010.[3]

The NNDSS was established 33 years ago in 1990 under the auspices of the Communicable Diseases Network Australia (CDNA) to collect and store surveillance data for nationally notifiable diseases in Australia. These are diseases that present a risk to public health, are of particular concern nationally and are included under legislation in the National Notifiable Disease List (NNDL).[5] While the eight states and territories ('jurisdictions') of Australia are primarily responsible for public health action, the role of national-level surveillance through the NNDSS includes:[6]

- describing national epidemiology and identifying national trends
- providing guidance for policy development and resource allocation
- monitoring the need for, and impact of, national disease control programs
- informing the response to national or multi-jurisdictional outbreaks
- meeting international reporting requirements, such as to the World Health Organization
- supporting human biosecurity emergency measures under the *Biosecurity Act 2015*.

Aboriginal and Torres Strait Islander people experience a disproportionately higher burden of many vaccine preventable diseases (VPDs) for which vaccination is funded under the National Immunisation Program (NIP).[1,7] Under the NIP, some vaccines are funded for Aboriginal and Torres Strait Islander people alone, or with expanded age eligibility. High quality Aboriginal and Torres Strait Islander status data in the NNDSS (reported in the NNDSS as 'Indigenous status' and referred to respectfully hereafter as such) allows better evaluation of these existing programs and consideration of new or expanded program initiatives.

A 2004 evaluation of the NNDSS identified that Indigenous status was one of the most poorly completed data fields.[8] In 2009 the CDNA, as part of its own 'Closing the Gap' strategy, set targets

of 95% Indigenous status completeness in the NNDSS for 18 priority diseases, including eight VPDs (Hib, hepatitis A, newly acquired hepatitis B, measles, IMD, pertussis [<5 years], IPD [<5 years and ≥50 years]) and 80% completeness for other diseases (including diphtheria, unspecified hepatitis B, laboratory confirmed influenza, pertussis [≥5 years], IPD [≥5 to <50 years], rotavirus, rubella and tetanus).[6] A review of NNDSS data from 1991–2011 found that although completeness of Indigenous status had improved over time, these targets had not been met.[9]

In 2016–2019 Indigenous status completeness at the national level was over 90% for most VPDs in the NNDSS, but much lower for laboratory confirmed influenza (37.4%), pertussis (59.2%) and rotavirus (69.7%), with some variation by jurisdiction and age group necessitating exclusion of some influenza, pertussis and rotavirus notification data from analyses.[1] Completeness of Indigenous status in the NNDSS should ideally be sufficient to avoid exclusion of data, which can result in bias and inaccurate estimates of national incidence.

Aims

We aimed to undertake a comprehensive evaluation of factors influencing the quality and completeness of Indigenous status for VPDs reported to the NNDSS, with specific objectives to:

1. describe Indigenous status notification processes, encompassing reporting to the different jurisdictional notifiable disease surveillance systems and then transfer to the NNDSS
2. assess Indigenous status completeness for VPDs reported to the NNDSS between 2010 and 2019 at the national and jurisdictional levels, over time, by remoteness and by age group
3. assess the contribution to unknown Indigenous status of 'not stated' response versus blank data fields, by jurisdiction
4. assess the appropriateness of current CDNA targets for Indigenous status completeness for notifiable VPDs
5. identify barriers to completeness and successful initiatives used by states and territories that have improved Indigenous status data in notifiable disease surveillance systems
6. make recommendations for best practice to help improve Indigenous status completeness in notifiable disease surveillance systems of jurisdictions and in the NNDSS.

Methods

The framework for this evaluation was provided by the 'data quality' attribute of the United States Centers for Disease Control and Prevention's *Updated guidelines for evaluating public health surveillance systems*,[10] which is defined as the 'completeness and validity of the data recorded in a public health surveillance system'.

This evaluation focuses on assessing completeness of the Indigenous status field, as recorded in the NNDSS, along with measures of Indigenous status data quality provided by assessment of data collection and data management.[10] Assessment of validity of these data would require comparison with the 'true' Aboriginal and Torres Strait Islander status through data linkage or patient interviews,[10] and was beyond the scope of this evaluation. Evaluation methodology

consisted of three modules: literature review; NNDSS data analysis; and stakeholder engagement, including an online survey, with findings from all components used to inform recommendations for improving the completeness of NNDSS Indigenous status data.

Module 1: Literature review

A review of published and grey literature was conducted to identify studies and reports relating to Indigenous status completeness in notifiable disease surveillance systems across Australia. The purpose of the review was to provide an overview of how Indigenous status is collected and reported in jurisdictional surveillance systems; identify the data transmission process to the NNDSS; review differences in jurisdictional reporting mechanisms and requirements; and summarise previously identified barriers, facilitators and strategies for improving Indigenous status completeness. Factors that impact collection of Indigenous status at the point of service (i.e. at GP, hospital or laboratory level) were predominantly summarised through the literature review. Databases searched were Google Scholar, Ovid MEDLINE and Australian Indigenous Health*InfoNet*, along with the websites of relevant Commonwealth and jurisdictional government organisations. The search was restricted to Australian literature from 2000 onwards.

Module 2: NNDSS data analysis

A descriptive analysis of Indigenous status completeness in NNDSS data, from 1 January 2010 to 31 December 2019 (the most recently available data at study commencement), was conducted for 14 VPDs, namely: diphtheria, Hib, hepatitis A, newly acquired hepatitis B, unspecified hepatitis B, laboratory confirmed influenza, measles, IMD, mumps, pertussis, IPD, rotavirus infection,[*] rubella and tetanus. Poliovirus infection was excluded as there were no notifications during the study period, along with varicella and herpes zoster, diseases caused by varicella-zoster virus, as these are not notifiable in New South Wales (NSW) and have a high proportion not specified as either varicella (chickenpox) or zoster (shingles) in most other jurisdictions.

Indigenous status completeness was compared to the current CDNA targets for the selected VPDs, which include targets for different age groups for pertussis and IPD notifications, resulting in 17 targets for the 14 VPDs analysed. For simplicity, these 17 VPD targets are referred to hereafter as 'VPDs', with specification of age group where relevant. Unless age groups are specified, the analyses reflect VPD notifications for all ages.

Indigenous status completeness was analysed at the national level for each VPD by year of notification, jurisdiction, age group and remoteness of area of residence, as defined by the Accessibility/Remoteness Index of Australia Plus (ARIA+).[11] Further analysis was conducted for each jurisdiction. Indigenous status completeness for individual VPDs was compared with relevant CDNA targets at the national and jurisdictional levels. An assessment of unknown Indigenous status data was also conducted, at the national and jurisdictional levels, comparing the proportion

[*] Rotavirus was added to the National Notifiable Diseases List in October 2016, and became nationally notifiable on 1 January 2017. The national surveillance case definition for rotavirus was implemented from 1 July 2018. Rotavirus became notifiable earlier than 1 July 2018 in some states and territories under individual jurisdictions' public health legislation. NSW, Tasmania, SA, WA, NT and Queensland reported rotavirus to the NNDSS for the full study period 2010–2019; ACT reported to the NNDSS since January 2018; Victoria reported to the NNDSS since August 2018.

of VPD notifications with unknown Indigenous status due to a ‘not stated’ value versus being left blank/reporting ‘NULL’.

Module 3: Stakeholder engagement

Stakeholder survey

A survey of National Surveillance Committee members working in jurisdictional health departments was conducted to further explore Indigenous status reporting and data management for the selected VPDs, initiatives already undertaken, and stakeholder recommendations for improving Indigenous status data quality.

Stakeholders were approached by email and asked to consult with relevant colleagues but to only complete and submit one online self-administered semi-structured Qualtrics survey per jurisdiction. Findings of the literature review and NNDSS data analysis informed development of the survey questions. The survey was open for completion for four weeks from November to December 2022 and included both open (free-text) and closed (binary and Likert scale) questions. Responses to open questions were analysed thematically. Responses to closed questions were analysed by response frequency or jurisdiction specific response. Following analysis, jurisdictional representatives were approached to seek clarification or additional information where needed.

Other stakeholder engagement

NACCHO was consulted and provided feedback on the survey questions and a late-stage draft of the report.

Cultural governance

The NCIRS National Indigenous Immunisation Coordinator provided cultural oversight of the evaluation. The proposal for the study was shared with members of the NCIRS Cultural Governance Group to provide advice on cultural and technical aspects of the evaluation.

Ethical approval

Ethical approval for surveillance evaluations within the Master of Philosophy (Applied Epidemiology) program undertaken by the lead investigator of this study has been provided by the Australian National University Human Research Ethics Committee (HREC) (protocol number 2017_909). An ethical waiver has been provided by Sydney Children’s Hospitals Network HREC for the use of de-identified surveillance data in projects conducted under the NCIRS funding agreement with the Australian Government Department of Health and Aged Care.

Results

Description of the NNDSS

Each jurisdiction in Australia collects notifiable disease data under its own public health legislation and using its own surveillance systems.The *National Health Security Act 2007* provides the legislative basis and authorisation for the exchange of this information with the Australian Government for diseases included in the NNDL.[6] Jurisdictions provide de-identified data to the NNDSS on a daily basis, relating to new cases of nationally notifiable diseases that meet CDNA surveillance case definitions.[12] The NNDSS is a dynamic system and notification data may be updated by jurisdictions at a later time.

The population under surveillance by the NNDSS is the entire Australian population, but several factors influence the representativeness of NNDSS data. The NNDSS is a passive surveillance system that relies on disease notification by jurisdictions, and each jurisdiction uses its own predominantly passive surveillance methods relying on disease notification by medical practitioners and laboratories, in accordance with their own legislation. Surveillance methods may also change over time. Other factors influencing representativeness of NNDSS data include patient access to health care, severity of illness and health-seeking behaviours, and clinician and laboratory diagnostic and reporting practices.[6,8] NNDSS notifications therefore represent a proportion (the 'notified fraction') of the total incidence or prevalence of disease in the population, which can vary by jurisdiction, by disease and over time.[6,8]

Indigenous status data field specifications

NNDSS data fields

The NNDSS core dataset is used for every case of a notifiable disease and includes both mandatory and non-mandatory data fields for completion by jurisdictional health authorities prior to data transfer to the NNDSS. The Indigenous status data field is a non-mandatory field and is defined as 'a single character field indicating the Indigenous status of the individual'.[13] Possible Indigenous status data field codes and corresponding definitions are shown in Table 1.

Table 1. NNDSS Indigenous status data field codes and definitions

Data field code	Definition
1	Indigenous (Aboriginal but not Torres Strait Islander origin)
2	Indigenous (Torres Strait Islander but not Aboriginal origin)
3	Indigenous (Aboriginal and Torres Strait Islander origin)
4	Not Indigenous (not Aboriginal or Torres Strait Islander origin)
9	Not stated
NULL or left blank	No information provided

National guidelines for collecting and recording Indigenous status in health datasets

The AIHW's *National best practice guidelines for collecting Indigenous status in health data sets* (the 'National Guidelines') were developed to improve the collection and recording of Indigenous status in national health datasets, and provide a systematic, nationally consistent approach to asking the Indigenous status question and recording this information.[3]

Members of the National Indigenous Health Equality Council Peak Body Reference Group and National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data provided feedback on the guidelines, the development of which was informed by interviews and surveys of front-line health care personnel, data managers and administrators of national data collections.[3] Under the National Indigenous Reform Agreement 2011, jurisdictions committed to implementation of these guidelines across the health sector by December 2012.[14]

The National Guidelines consist of three parts: Part A (instructions on how to ask the Indigenous status question); Part B (how to record responses); and Part C (practical advice on how to deal with scenarios where circumstances prevent the question from being answered or a response being recorded), as outlined below.

Part A: Asking the question:

The standard Indigenous status question and standard response options should be used as follows:

'Are you [is the person] of Aboriginal or Torres Strait Islander origin?'

☐ No

☐ Yes, Aboriginal

☐ Yes, Torres Strait Islander

For clients of both Aboriginal and Torres Strait Islander origin, both 'Yes' boxes should be ticked.

Alternatively, a fourth option can be provided:

☐ Yes, both Aboriginal and Torres Strait Islander

The National Guidelines also provide the following advice for healthcare providers:

- Clients should be asked the Indigenous status question when they first register with the respective service by the staff who is responsible for registering the client.
- All clients should be asked the question.
- If a form is returned, and the question has not been answered by the client, it should be followed up with the client.

Part B: Recording responses

Error! Reference source not found. summarises how the National Guidelines stipulate information systems should record Indigenous status responses using national categories, and

how various response scenarios should be coded. Additional advice is provided in the National Guidelines as follows:

- Recording a response, and coding category respectively should be a mandatory requirement when a client is first registered; registration should not be able to be completed until an Indigenous status response is entered into the system.
- Local information systems should be able to distinguish between situations where Indigenous status was coded as category 9 due to the client's refusal to respond versus where it was impossible to ask the question, or other situations where the response was left blank or incomplete. The latter scenarios require follow-up.
- If any other categories are used in a local data system, they must be mapped to the national categories before providing the records to the state, territory or national data custodians.

Table 2. Recording responses to the Indigenous status question as per National Guidelines[3]

National coding category	National categories for recording Indigenous status	Response scenario/s
1	Aboriginal but not Torres Strait Islander origin	'Yes, Aboriginal' is ticked but 'Yes, Torres Strait Islander' is not ticked
2	Torres Strait Islander but not Aboriginal origin	'Yes, Torres Strait Islander' is ticked but 'Yes, Aboriginal' is not ticked
3	Both Aboriginal and Torres Strait Islander origin	'Yes, Aboriginal' is ticked and 'Yes, Torres Strait Islander' is also ticked (or, if option provided 'Yes, both Aboriginal and Torres Strait Islander' is ticked)
4	Neither Aboriginal nor Torres Strait Islander origin	'No' is ticked
9	Not stated/inadequately described	• Client is capable of responding but declines to respond following prompting/follow-up. • 'No' is ticked and either or both 'Yes, Aboriginal', and 'Yes, Torres Strait Islander' are ticked. • It is impossible for the question to be asked during the contact period. • Response to the question has been left blank or is incomplete.

Consistency of NNDSS Indigenous status specifications with the National Guidelines

The NNDSS does not strictly use the recommended national Indigenous status coding categories of the National Guidelines, as it allows for blank and 'NULL'-coded entries if no information has been provided, while under the National Guidelines this should be coded as 9 – 'not stated/inadequately described'. However, the NNDSS is a national dataset that aggregates the data provided by states and territories. Inspecting NNDSS data it is clear that some jurisdictions have consistently only provided coding category 9 for unidentified Indigenous status, while others have provided both 9 and 'NULL' codes (see Appendix Table A4).

Indigenous status completeness of VPD notifications in the NNDSS: national overview

Overall national Indigenous status completeness for the 17 VPDs combined was 52% for the period 2010–2019 (Table 3). For the eight VPDs with a CDNA target of 95%, Indigenous status completeness exceeded the target for Hib, measles, IMD and IPD (both <5 and ≥50 years age groups) (Table 3). Completeness was within four percentage points of the 95% target for hepatitis A (94%), newly acquired hepatitis B (91%) and pertussis <5 years (93%). For VPDs with a target of 80%, completeness was ≥90% for diphtheria, mumps, rubella and tetanus, and 80% for IPD in the ≥5 to <50 years age group. The remaining four VPDs, representing 95.9% of total notifications, were substantially below the 80% target: unspecified hepatitis B (54%); laboratory confirmed influenza: (47%); pertussis (≥5 years; 60%); and rotavirus (71%) (Table 3).

Table 3. Number of VPD notifications reported to the NNDSS, relative proportions and Indigenous status completeness in relation to CDNA targets, 2010–2019

Vaccine preventable disease	Number of notifications (n)	Proportion of total VPD notifications (%)	Indigenous status completeness (% of n with known status)
VPDs with CDNA Indigenous status completeness target of 95%			
Hib	182	0.014	98
Hepatitis A	2,221	0.167	94
Hepatitis B (newly acquired)	1,738	0.131	91
Measles	1,601	0.120	97
IMD	2,304	0.173	98
Pertussis <5 years	24,439	1.837	93
IPD <5 years	2,304	0.173	97
IPD ≥50 years	10,190	0.766	97
VPDs with CDNA Indigenous status completeness target of 80%			
Diphtheria	45	0.003	93
Hepatitis B (unspecified)	62,006	4.660	54
Influenza (laboratory confirmed)	996,256	74.873	47
Mumps	3,920	0.295	93
Pertussis ≥5 years	176,940	13.298	60
IPD ≥5 to <50 years	5,333	0.401	80
Rotavirus*	40,738	3.062	71

Rubella	251	0.019	90
Tetanus	38	0.003	92
All diseases	1,330,601	100.000	52

Completeness in orange indicates a gap of ≤5 percentage points from the CDNA target; completeness in red indicates a gap of >5 percentage points from the CDNA target.
** NSW, Tasmania, SA, WA, NT and Queensland reported rotavirus to the NNDSS for the full study period 2010–2019; ACT reported to the NNDSS since January 2018; Vic reported to the NNDSS since August 2018.*

Trends in Indigenous status completeness for VPD notifications

National trends by VPD and year, 2010 to 2019

Overall Indigenous status completeness for the 17 VPDs combined decreased from 63% in 2010 to 47% in 2019; however, this was predominantly due to a decrease for influenza (which comprised the majority of VPD notifications), from 63% in 2010 to 45% in 2019 (

Table 4).

For VPDs where the CDNA target is 95%, Indigenous status completeness for measles, IMD, IPD (both the <5 and ≥50 years age groups) and Hib was above the target in all years from 2012 onwards. Completeness for hepatitis A was above the 95% target from 2010 to 2016 and within five percentage points of it from 2017 to 2019, while for pertussis (<5 years), completeness was above 90% in all years but only reached the 95% target once, in 2013. Completeness for newly acquired hepatitis B increased from 86% in 2010 to 95% in 2019 and has remained at 93% or above since 2014.

For VPDs where the CDNA target is 80%, Indigenous status completeness for rubella, diphtheria and tetanus was above this in most years (ranging from 67% to 100%), with fluctuations likely related to the small numbers of notifications. Completeness for mumps increased from 60% in 2010 to 92% in 2019, and was above 90% from 2013 onwards. Completeness between 2010 and 2019 ranged from 59% to 79% for rotavirus, 56% to 65% for pertussis in the ≥5 years age group and 48% to 62% for unspecified hepatitis B, and from 72% to 79% between 2012 and 2019 for IPD in the ≥5 to <50 years age group.

Table 4. Indigenous status completeness of VPD notifications reported to the NNDSS, in relation to CDNA targets, by year, 2010–2019

Vaccine preventable disease	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
VPDs with CDNA Indigenous status completeness target of 95%										
Hib	100	92	100	95	100	100	100	100	100	95
Hepatitis A	95	96	95	97	96	96	95	94	92	91
Hepatitis B (newly acquired)	86	90	89	87	94	94	96	93	94	95
Measles	94	97	98	97	98	100	96	99	97	97
IMD	97	95	96	97	99	99	99	99	98	98
Pertussis <5 years	92	94	94	95	91	91	93	92	90	92
IPD <5 years	95	95	97	97	97	96	99	99	99	97
IPD ≥50 years	96	94	98	97	97	97	98	96	98	97
VPDs with CDNA Indigenous status completeness target of 80%										
Diphtheria	NC	100*	NC	67*	100*	100*	75*	100*	100	100*
Hepatitis B (unspecified)	51	48	52	53	51	50	56	60	62	59
Influenza (laboratory confirmed)	63	54	56	52	53	49	49	43	52	45
Mumps	60	71	74	93	91	96	98	94	98	92
Pertussis ≥5 years	59	59	56	59	61	60	62	65	60	65
IPD ≥5 to <50 years	85	85	78	77	76	72	73	72	77	79
Rotavirus^	62	67	59	74	71	75	79	73	68	75
Rubella	95	86	86	88	94	88	88	100	78*	95
Tetanus	100*	100*	86*	75*	67*	100*	100*	100*	100*	100*
All diseases	63	60	58	58	56	54	54	46	57	47

Completeness in orange indicates a gap of ≤5 percentage points from the CDNA target; completeness in red indicates a gap of >5 percentage points from the CDNA target.
NC = No cases

^NSW, Tasmania, SA, WA, NT and Queensland reported rotavirus to the NNDSS for the full study period 2010–2019; ACT reported to the NNDSS since January 2018; Vic reported to the NNDSS since August 2018.
** Notification number <10*

Indigenous status completeness of VPD notifications by jurisdiction

Overall Indigenous status completeness (i.e. for all VPDs combined) over the 2010–2019 period was lowest in Tasmania (21%) and Victoria (30%) and highest in the Northern Territory (NT; 98%)

and Western Australia (WA; 91%) (**Error! Reference source not found.**). Completeness was above 90% for all individual VPDs in NT, and for all except laboratory confirmed influenza in WA.

For VPDs where the CDNA target is 95%, Indigenous status completeness over the 2010–2019 period was above this target in all jurisdictions (where there were notifications) for Hib and measles, and for most jurisdictions for IMD (except Victoria [94%]), hepatitis A (except Queensland [92%] and Victoria [91%]) and IPD (both <5 and ≥50 years age groups, except in Victoria [92% in both]) (**Error! Reference source not found.**). Completeness was above 95% in most jurisdictions for pertussis in the <5 years age group (except NSW [92%] and Victoria [82%]), and in four jurisdictions for newly acquired hepatitis B (ranging from 86% to 92% in the other jurisdictions).

For VPDs where the CDNA target is 80%, Indigenous status completeness over the 2010–2019 period was above this target in all jurisdictions (where there were notifications) for diphtheria, rubella and tetanus (**Error! Reference source not found.**). Completeness was above 80% in most jurisdictions for mumps (except Tasmania [74%] and Victoria [79%]) and IPD in the ≥5 to <50 years age group (except NSW [64%] and Victoria [44%]). Completeness was above 80% in five jurisdictions for rotavirus (Queensland, South Australia [SA], the Australian Capital Territory [ACT], WA and NT, ranging from 7% to 47% in the other jurisdictions), four jurisdictions for unspecified hepatitis B (ACT, NT, SA and WA, ranging from 33% to 73% in the other jurisdictions), and for three jurisdictions for pertussis in the ≥5 years age group (NT, WA and SA, ranging from 47% to 73% in the other jurisdictions). Completeness for laboratory confirmed influenza was only above the target in WA (89%) and NT (99%) and was lowest in Tasmania (6%) and Victoria (22%).

Table 5. Indigenous status completeness of VPD notifications reported to the NNDSS by jurisdiction, 2010–2019

	ACT	NSW	NT	Qld	SA	Tas	Vic	WA
VPDs with CDNA Indigenous status completeness target of 95%								
Hib	NC	97	100	100	100	100*	96	100
Hepatitis A	100	97	95	92	100	100	91	100
Hepatitis B (newly acquired)	100	88	100	86	100	87	92	100
Measles	100	96	99	98	100	100	96	100
IMD	100	98	100	98	100	97	94	100
Pertussis <5 years	98	92	99	99	97	96	82	97
IPD <5 years	100	97	100	100	100	100	92	100
IPD ≥50 years	100	97	100	100	99	99	92	100
VPDs with CDNA Indigenous status completeness target of 80%								
Diphtheria	NC	100*	100*	91	100*	NC	100*	100
Hepatitis B (unspecified)	97	33	92	64	99	73	49	92

Influenza (laboratory confirmed)	54	36	99	59	75	6	22	89
Mumps	95	81	100	94	99	74	79	100
Pertussis ≥5 years	73	54	95	50	87	47	51	95
IPD ≥5 to < 50 years	100	64	100	99	100	99	44	100
Rotavirus^	94	47	99	81	85	11	7	94
Rubella	100*	91	NC	84	100	100*	84	100
Tetanus	NC	89*	NC	82	100*	NC	100*	100
All diseases	62	41	98	60	78	21	30	91

Completeness in orange indicates a gap of ≤5 percentage points from the CDNA target; completeness in red indicates a gap of >5 percentage points from the CDNA target.
NC = No cases
^NSW, Tasmania, SA, WA, NT and Queensland reported rotavirus to the NNDSS for the full study period 2010–2019; ACT reported to the NNDSS since January 2018; Vic reported to the NNDSS since August 2018.
** Notification number <10*

Indigenous status completeness of VPD notifications by remoteness

Nationally, for all VPDs combined Indigenous status completeness increased with increasing remoteness, ranging from 49% in major cities to 95% in very remote areas. For individual VPDs the greatest differences in completeness between major cities and remote/very remote areas were for influenza, ranging from 45% in major cities to 94% in very remote areas, unspecified hepatitis B (50% to 98%), pertussis in the ≥5 years age group (58% to 91%), rotavirus (69% to 97%) and IPD in the ≥5 to <50 years age group (70% to 100%). Completeness for mumps ranged from 86% to 100%, increasing with remoteness. There was less difference for other VPDs, ranging from 14 percentage points (mumps and tetanus) to two percentage points (IMD). Further detail on completeness by remoteness categories at the national level is provided in the Appendix (Table A1). A similar pattern was seen in most jurisdictions (Appendix **Table A2**).

Indigenous status completeness of VPD notifications by age group

Indigenous status completeness nationally for all VPDs combined was highest in the 0–4 years age group (61%) and lowest in the ≥50 years age group (47%). When analysed by individual VPD, the greatest ranges in completeness between age groups were for: pertussis (from 54% in the ≥50 years age group to 93% in the 0–4 year age group); unspecified hepatitis B (from 48% in ≥50 years to 76% in 5–14 years); and rotavirus (from 58% in 25–49 years to 78% in 0–4 years). Completeness for IPD was 97% for the 0–4 and ≥50 years age groups, but ranged from 77% to 87% in other age groups, while completeness for influenza was low across all age groups (43%–56%). Further detail on completeness by age group is provided in the Appendix (Table A3).

Reporting of unknown Indigenous status in VPD notifications by jurisdiction

Analysis of Indigenous status in the NNDSS showed that some jurisdictions (NT, SA and Victoria) report only code 9 ('not stated') where Indigenous status is unknown, as per the National Guidelines, whereas the others use both code 9 and 'NULL' values/blank fields. In ACT, NSW and WA the majority of notifications with unknown Indigenous status were reported to NNDSS as 'NULL'/blank, while in Queensland and Tasmania only a few were (Appendix Table A4).

Indigenous status notification processes

Previously identified factors impacting Indigenous status completeness

Previous reports[3,15–17] have identified a range of factors impacting Indigenous status completeness and quality in aggregated national notifiable disease data, including:

- differences in jurisdictional public health legislation regarding a mandated requirement to collect and report Indigenous status in notifications
- inconsistent use between jurisdictions of the national standard Indigenous status question in notification forms and in the standard recording format of notifiable disease registries
- the proportion of diseases notified by doctors or laboratories or both (dual notification systems)
- the level of Indigenous status completeness in the databases of primary healthcare providers
- whether Indigenous status is included as a data field on pathology request forms, and the level of completeness of this field if it is present
- the level of data matching or sharing between systems.

Summary of survey responses

Stakeholders from all eight jurisdictions responded to the online survey. The roles of respondents included managers in epidemiology, surveillance and data teams, senior epidemiologists, and surveillance coordinators. Jurisdictional representatives reported using Indigenous status from VPD notifications to inform policy and program development, for program evaluation and outbreak detection, to monitor trends among Aboriginal and Torres Strait Islander people, and to check completeness and data quality.

Table 6 provides a summary of key survey findings, with the overall completeness of Indigenous status for VPDs in each jurisdiction included for reference.

Table 6. Summary of Indigenous status identification processes for VPDs* by jurisdiction

	NT	WA	SA	ACT	Qld	NSW	Vic	Tas
Completeness of Indigenous status for VPDs	98%	91%	78%	62%	60%	41%	30%	21%
Legislation in place to mandate reporting of Indigenous status in VPD notifications	X	X	X	X	X	Unsure	✓	✓
Mandatory inclusion of Indigenous status field on pathology forms	X	✓ (2013)	X	X	X	X	X	X
Number of VPDs where public health follow-up occurs for all cases	14/14	11/14	10/14	11/14	10/14	9/14	10/14	12/14
Frequency of checking Indigenous status during public health follow-up	All cases	All cases	All cases	Most cases	Some cases	Unsure	Most cases	Most cases
Data linkage with other administrative health datasets	X	✓ (approx. 2007)	X	X	✓ (2022)	X	✓ (2022)	X
Manual check of other administrative data sources	✓	✓	✓	✓	✓	✓	✓	✓
Auditing of Indigenous status completeness	Annually	Fortnightly	Monthly	Quarterly	Weekly	Quarterly	Monthly	Unsure
Source of notifications^	Majority dual (10/14 VPDs)	All dual	Majority dual (13/14 VPDs)	All dual	Majority lab only (9/14 VPDs)	All dual	Majority dual (13/14 VPDs)	Majority lab only (11/14 VPDs)

* *Diphtheria,* Haemophilus influenzae *type b, hepatitis A, hepatitis B (newly acquired), hepatitis B (unspecified), influenza (laboratory confirmed), measles, invasive meningococcal disease, mumps, pertussis, invasive pneumococcal disease, rotavirus, rubella and tetanus*

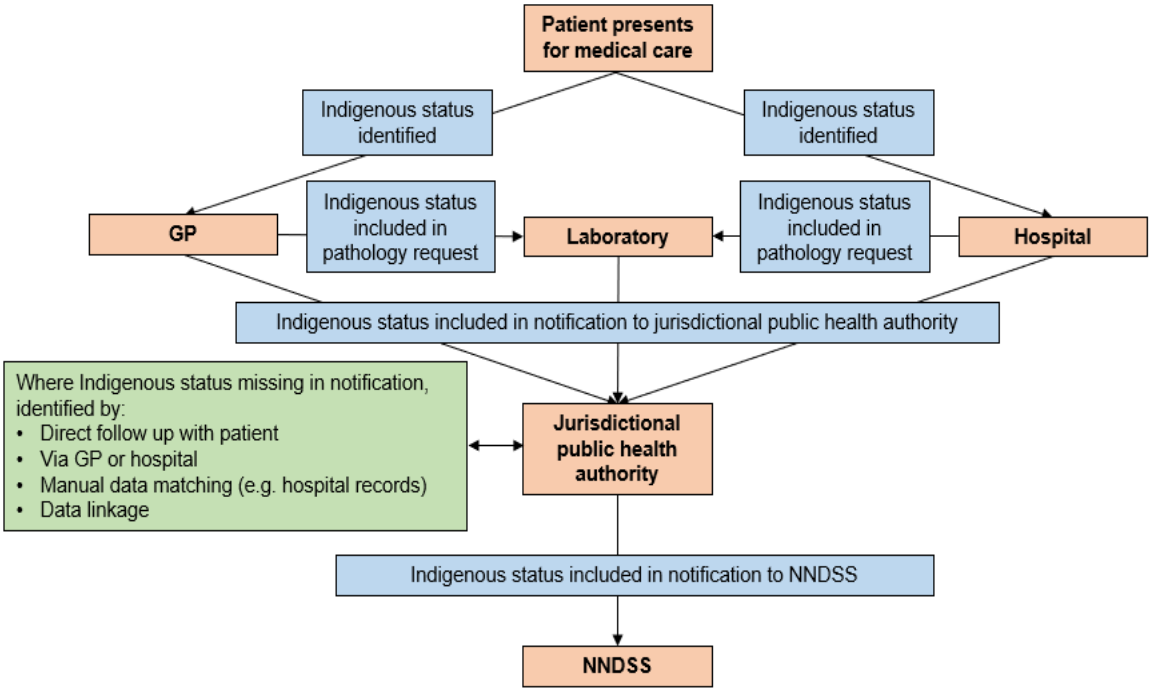
^ *Dual = notifications are received from both laboratories and clinician*

Mechanisms of reporting Indigenous status in notification data

Flow of notification data to the NNDSS

Indigenous status can be potentially collected at multiple points, ranging from the presentation of a patient for medical care to the notification being reported to the NNDSS. The flow of notifications and information collection is demonstrated in Figure 1.

Figure 1. Flow of notification data to the NNDSS including potential Indigenous status collection points



Indigenous status categories

Literature review

The standardisation of the Indigenous status question and recording categories across public health datasets and jurisdictions has been part of the public health policy discussion since 1997.[18] The 2010 National Guidelines provide a standard national approach to asking the question and categories for recording responses.[3] In 2013 not all jurisdictions were reported to be using the standard format to record Indigenous status in their disease notification forms and communicable disease registries.[15]

Disease notification forms for seven of eight jurisdictions were obtained from jurisdictional health department websites (ACT,[19] NSW,[20] NT,[21] Queensland,[22] SA,[23] Victoria,[24] WA[25]). All available forms included a field for Indigenous status with some differences in how the information is collected and/or categorised; however, most forms contained either the standard Indigenous status question or standard recording categories as per the National Guidelines. The use of these notification forms varies by jurisdiction – for example, they may be used by clinicians but not by laboratories, and only for particular notifiable diseases.

Stakeholder survey

Some jurisdictions reported having separate online notification forms with different options for Indigenous status data entry, and that the fields and categories on the paper or online form do not necessarily represent the fields used in their notifiable disease register.

All jurisdictions reported that their notifiable disease register uses the Indigenous status categories 'Aboriginal', 'Torres Strait Islander', 'both Aboriginal and Torres Strait Islander' and either 'not Indigenous' or 'not Aboriginal or Torres Strait Islander'.

Categories for missing Indigenous status information varied between jurisdictions. Not all jurisdictions use a 'not stated' category, and not all use a 'NULL' category or blank field (Appendix Table A5). Some jurisdictions use other categories which are not used in the NNDSS and map to either 'not stated' or 'NULL'/blank category in NNDSS (Appendix Table A6).

Mandatory reporting of Indigenous status with notifications

Literature review

In 2004 the multi-agency Improving Indigenous Identification in Communicable Disease Reporting Project Steering Committee recommended legislating mandatory collection and reporting of Indigenous identification in communicable disease health policies and notifications.[17] In 2013, five jurisdictions (NSW, Victoria, WA, Tasmania and NT) were reported to have legislation to mandate provision of Indigenous status with disease notifications.[15] This was reported to apply to both medical practitioners and laboratories in NSW, WA, Tasmania and NT, and to medical practitioners only in Victoria.[15] In WA and NSW the requirement to provide Indigenous status information with disease notifications applied only if the information was known or available to the notifier.[15]

Stakeholder survey

Only two jurisdictions (Tasmania[26] and Victoria[27]) reported having current legislation that mandates the reporting of Indigenous status with disease notifications, with some jurisdictions unsure or reporting absence of legislation which was inconsistent with literature review findings.

Source of notifications

Literature review

Jurisdictional public health authorities can be notified of VPDs by medical practitioners (usually GPs or hospital clinicians) or by laboratories, with notification requirements varying by jurisdiction and disease.[6] The predominance of laboratory notifications in Australia has long been recognised as a barrier to Indigenous status completeness in the NNDSS, due to the limited patient information provided and need for follow-up to obtain additional information, with associated significant resourcing implications,[17] particularly for high incidence diseases.

Stakeholder survey

ACT, NSW and WA reported that all VPDs can be notified to public health authorities by both clinicians and laboratories (dual notification system), while other jurisdictions reported a combination of laboratory only or dual notification depending on the disease. Measles, IMD and

tetanus were notified through dual notification in all jurisdictions, while notification methods for other diseases varied by jurisdiction. WA reported a high level of clinician notification across all VPDs and credited this as a key reason for their high Indigenous status completeness. Further detail on the method of notifications by jurisdiction is provided in Table A7 in the Appendix.

Collection of Indigenous status by clinicians and laboratories

Collection of Indigenous status in general practice and hospital settings

Literature review

Indigenous status is recorded for over 95% of clients seen at Aboriginal Community Controlled Health Services (ACCHSs),[28] but has been poorly collected in mainstream GP settings,[29–31] although we could not identify any recent (since 2012) studies assessing this. Strategies to improve collection of Indigenous status in mainstream GP settings were explored in the 2013 AIHW report *Taking the next steps: identification of Aboriginal and Torres Strait Islander status in general practice,*[16] with barriers to collection in these settings identified to include:[16,17,31,32]

- lack of GP and practice staff awareness of the reasons for, and importance of, identifying Indigenous status
- staff discomfort with asking the question (e.g. concern about causing offence)
- practice environments that are not culturally safe
- the onus is placed on patients to self-disclose their Indigenous status without being asked
- an assumption that the practice has no, or few, Aboriginal and Torres Strait Islander patients
- a belief that Aboriginal and Torres Strait Islander patients do not want to disclose their Indigenous status
- a belief that Indigenous status can be ascertained from physical appearance alone
- a belief that all patients should be treated equally, with services based on Indigenous status not being justified
- deficiencies in practice software in relation to collection and recording of Indigenous status.

Strategies identified at the practice level for improving collection of Indigenous status in mainstream GP settings have included:[16,17,31,33,34]

- education for GPs and practice staff on cultural awareness, how to ask about Indigenous status and why the question is important
- asking the question respectfully and with an explanation of how the information will be used
- improving cultural safety of the practice, preferably involving the local Aboriginal and Torres Strait Islander community in this process; measures could include employing Aboriginal and Torres Strait Islander staff and displaying flags, posters and pamphlets
- improvements to administrative strategies such as including Indigenous status in new patient registration forms, and having processes to follow up missing data, including updating the Indigenous status of existing patients
- use of clinical software that supports best practice – for example, it allows both administrative and clinical staff to collect and record Indigenous status; ensures Indigenous status is a

mandatory field; and can differentiate between a patient declining to provide their Indigenous status and the question not being asked.

In relation to hospital settings, 88% of Aboriginal and Torres Strait Islander patients nationally were estimated to be accurately identified in public hospital admission records for 2011–2012, ranging from 58% in ACT to 98% in NT and from 77% in major cities to 99% in very remote areas.[35]

Collection of Indigenous status by pathology laboratories

Literature review

The inclusion of Indigenous status information in pathology request forms and systems was recommended by the Improving Indigenous Identification in Communicable Disease Reporting Project Steering Committee in 2004.[17] Given an increasing predominance of laboratory notifications, the limited capacity for transfer of Indigenous status information between requesting clinicians, pathology laboratories and public health authorities was identified as a key factor contributing to underreporting of Indigenous status in communicable disease reporting systems.[17]

The 2013 AIHW report *The inclusion of Indigenous status on pathology request forms* identified that pathology request forms in most jurisdictions still did not include an Indigenous status field, and if they did it was often not completed.[15] This report also noted that the National Advisory Group for Aboriginal and Torres Strait Islander Health Information and Data had advocated for Indigenous status to be a mandatory field in the Australian Standard governing electronic pathology messaging, and recommended jurisdictions progress the inclusion of Indigenous status on pathology request forms through a range of mechanisms.[15]

Stakeholder survey

WA was the only jurisdiction to report mandating inclusion of an Indigenous status field on pathology request forms, since approximately 2013, although completeness of the field was reported to be low. All other jurisdictions except Queensland thought that mandating inclusion of an Indigenous status field on pathology request forms would be either extremely useful (NT, ACT, Victoria), very useful (Tasmania) or moderately useful (NSW, SA). It was also suggested that a nationally coordinated approach would be useful.

Education and training

Literature review

Education and training for health professionals, including raising cultural awareness, increasing understanding of best practice methods for collecting Indigenous status, and enhancing awareness of the benefits of Indigenous status data collection, have long been recognised as important to increase Indigenous status identification in health data systems.[3,16,17,36] A variety of resources are available to assist with education and training of health professionals, along with resources tailored to patients.[37]

Financial support and other incentives

Literature review

Various financial incentives under the Practice Incentives Program for GPs may indirectly contribute to improved Indigenous status identification, including the Indigenous Health Incentive[38] and the e-Health Incentive.[39] Indigenous status identification is also a component of accreditation for GP practices[40] and hospitals.[41]

Collection of Indigenous status by public health authorities

Level of follow-up by public health authorities

Literature review

Notifiable diseases that are followed up by public health authorities to collect supplementary information generally have higher Indigenous status completeness as missing information can be obtained during follow-up.[15,17] The CDNA Series of National Guidelines provide nationally consistent guidance for jurisdictions on the public health follow-up required for notifiable diseases.[42] Of the VPDs assessed in this study, national guidelines are available for Hib,[43] hepatitis A,[44] hepatitis B,[45] influenza,[46] measles,[47] IMD[48] and pertussis[49] (see Appendix Table A8 for further details). Jurisdictional guidelines are also used, including for notifiable diseases where there are no national guidelines, although these are not publicly accessible in most jurisdictions.

Stakeholder survey

All jurisdictions reported that they follow up every notification of diphtheria, Hib, hepatitis A, newly acquired hepatitis B, measles, IMD and tetanus. All jurisdictions reported following up mumps (but only some age groups in SA); pertussis (but only some age groups in Queensland, SA, Victoria and WA); and IPD (but only <5 and ≥50 years in NSW, and <5 and ≥65 years in Queensland). All jurisdictions except NSW reported following up rubella notifications (although congenital rubella requires follow-up as per the NSW control guideline[50]). Unspecified hepatitis B is followed up by all jurisdictions except NSW and ACT (with Victoria unsure), while reported follow-up of rotavirus and influenza is quite variable, with only NT following up all notifications in all age groups. Further detail on public health follow-up reported in each jurisdiction is provided in the Appendix (Table A9).

Where public health follow-up occurs, this was reported to include follow-up of incomplete Indigenous status for all cases in WA, NT and SA, most cases in Victoria, ACT, NSW and Tasmania, and some cases in Queensland. Follow-up practices were reported to have remained the same between 2010 and 2019 for ACT, NT, SA, NSW, Tasmania and WA, with the other two unsure. All jurisdictions reported that public health follow-up is useful to improve Indigenous status completeness (rated extremely useful by ACT and Queensland, very useful by WA and SA and moderately useful by NSW, Victoria and Tasmania). Victoria noted that as of 2022, local Public Health Units (PHUs) have taken over follow-up of some conditions, with extra staffing capacity that should lead to increased follow-up and Indigenous status completeness.

Auditing of completeness/quality control

Stakeholder survey

Seven jurisdictions reported undertaking regular audits of Indigenous status completeness (with Tasmania unsure), at frequency ranging from weekly in Queensland to fortnightly in WA, monthly in Victoria and SA, quarterly in ACT and NSW, and yearly in NT. Victoria noted that to assist in improving completeness of Indigenous status, they have flags for missing data in their notifiable disease surveillance system.

Manual check of other data systems

Stakeholder survey

All eight jurisdictions noted that they use manual processes to cross-check with other data systems (e.g. AIR or hospital data) to increase Indigenous status completeness. NT reported cross-checking hospital data for all cases, and credit this as the primary reason for their high Indigenous status completeness. WA reported that PHUs routinely check other administrative health data for Indigenous status during case follow-up, and that its reference laboratory also checks Indigenous status in their hospital patient information systems before notifying cases.

Automated data linkage

Literature review

Data linkage can improve identification of Aboriginal and Torres Strait Islander peoples in health data,[51] and improve the accuracy of notification rate estimates.[52–54] Other potential benefits include assessing the extent of under-identification of Indigenous status in health datasets and reducing the need for follow-up to obtain missing information.[15]

The 2012 AIHW *National best practice guidelines for data linkage activities relating to Aboriginal and Torres Strait Islander people* were developed to provide nationally consistent guidance on methodology for managing missing or inconsistent Indigenous status information when linking datasets.[55] These guidelines outline a number of considerations, including the need to conduct data linkage in accordance with the core values and ethics of Aboriginal and Torres Strait Islander people.[55] Privacy and confidentiality concerns also need to be addressed when considering data linkage.[15,55]

A 2017–2018 review reported that no jurisdiction was routinely using data linkage to improve completeness of notifiable disease surveillance data, although jurisdictional stakeholders identified use of data linkage to improve completeness of Indigenous status as a priority.[56]

Stakeholder survey

Three jurisdictions (WA [2007–current], Queensland [2022–current] and Victoria [2022–current, but yet to be fully validated]) reported using linkage with other administrative health datasets to improve Indigenous status completeness in their notifiable disease registers. WA reported that a data linkage unit has linked notification data to other datasets, including hospitalisations, deaths and births since at least 2007, usually annually although more ad hoc during the COVID-19

pandemic, but that these linked data are currently only used to update Indigenous status in relation to COVID-19 notifications. All jurisdictions indicated data linkage would be useful to improve Indigenous status completeness (rated extremely useful by Queensland and SA, very useful by NSW, Victoria, WA, Tasmania and ACT, and slightly useful by NT). Three jurisdictions noted plans to link notification data in 2023: Queensland to datasets including hospitalisations; SA to AIR data; and Victoria to emergency department, hospitalisation, death and AIR data).

Automated data matching within a jurisdictional notifiable disease system

Analysis conducted for this study identified that Indigenous status completeness in NSW had notably increased compared to NNDSS data extracted approximately 15 months prior.[1] The observed increases in completeness for high incidence VPDs are shown in Table 7. NSW Health stakeholders attributed this increase to follow-up of large numbers of COVID-19 cases during the intervening time period, predominantly through an SMS survey, which included a question on Indigenous status. The NSW Notifiable Conditions Information Management System (NCIMS) links Indigenous status information to a person, rather than to a single notification event. When Indigenous status is completed for a notification, it automatically updates in NCIMS for all other disease notifications received for the same person. As this was an incidental finding during analysis, the stakeholder survey did not explore whether similar processes occur in other jurisdictions.

Table 7. Indigenous status completeness (%) for pertussis, unspecified hepatitis B and laboratory confirmed influenza notifications in NSW, 2010–2019 – comparison of NNDSS datasets as of 1 February 2021 and 4 May 2022

	Indigenous status completeness (%)	
	NNDSS dataset 1 February 2021	**NNDSS dataset 4 May 2022**
Pertussis	45	60
Hepatitis B (unspecified)	18	33
Influenza (laboratory confirmed)	16	36

Financial incentives for public health authorities

Literature review

The Improving Indigenous Identification in Communicable Disease Reporting Project Steering Committee made several recommendations in its 2004 report regarding incentives for Indigenous status identification, including a recommendation for the Australian Government to ensure funding is linked to satisfactory and sustained gains in Indigenous status identification in communicable disease reporting.[17]

The Commonwealth provides some financial support to jurisdictions for surveillance and reporting of nationally notifiable VPDs covered by the NIP, under the Vaccine Preventable Diseases Surveillance Program component of the National Partnership for Streamlined Agreements.[57] The

current Agreement, which is in place until 30 June 2024, specifies that jurisdictions have a responsibility to implement improvements to data quality, such as improved reporting of Indigenous status in notifications that require follow-up.[57] Under the Agreement, jurisdictions are required to produce annual reports which detail their achievement of a variety of pre-determined indicators in order to receive funding. While improving Indigenous status completeness is included as a high-level goal in the Agreement, it is not included in the reporting requirements as an indicator, nor are targets specified.

Barriers to collection of Indigenous status at the public health authority level

Stakeholder survey

Identified barriers to collection of Indigenous status included resourcing issues, with follow-up being disease dependent and less likely for high incidence conditions where follow-up with clinicians or manual cross-checking of other databases (e.g. hospitalisations) is required. However, NT and WA reported manually cross-checking hospitalisation data for all VPD notifications where Indigenous status missing, although information may not be available in a small proportion (e.g. for new arrivals from interstate).

CDNA targets for Indigenous status completeness

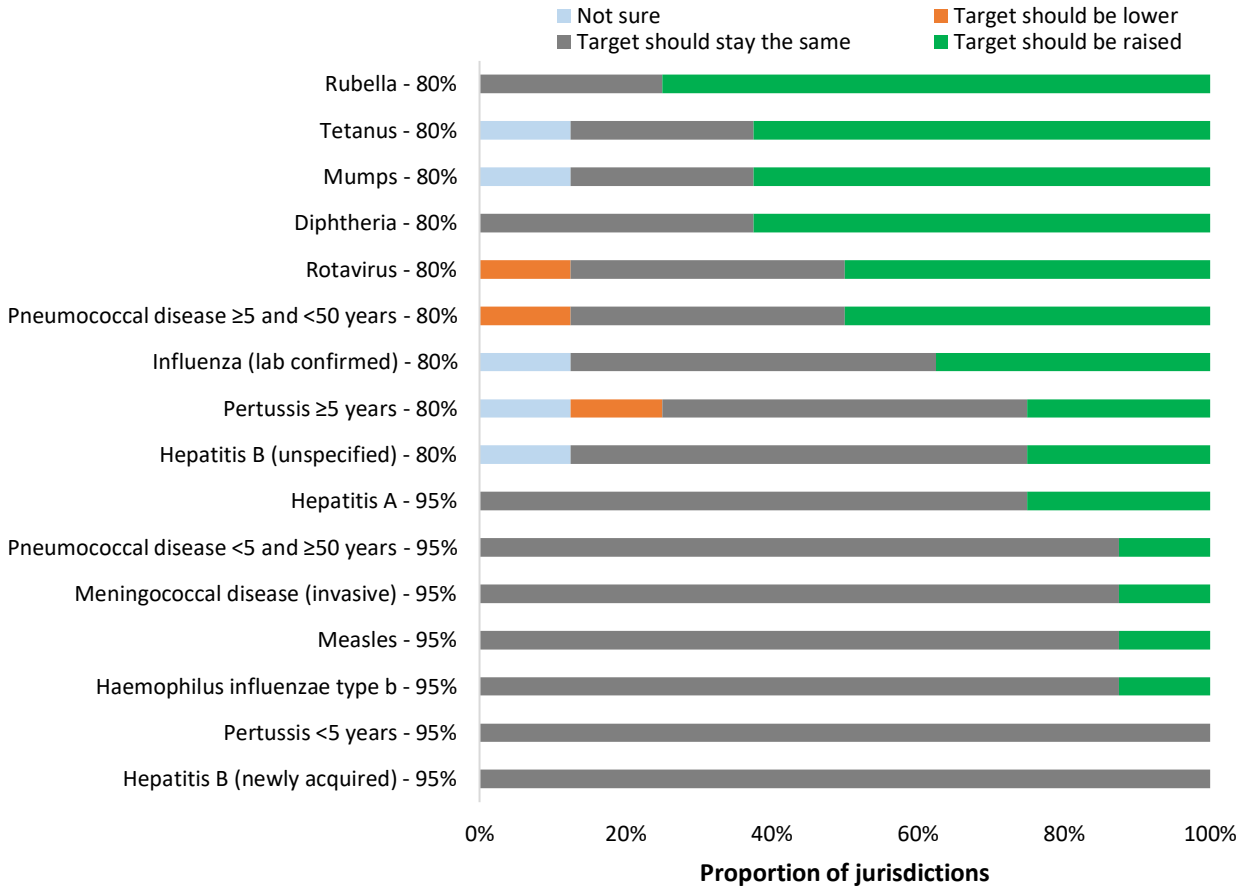
Stakeholder survey

For VPDs with a current CDNA target for Indigenous status completeness of 80%, the majority of jurisdictions thought targets should be raised for rubella, tetanus, mumps and diphtheria, half that they should be raised for IPD (5 to <50 years age group) and rotavirus, and a minority (2–3) that they should be raised for influenza, pertussis (≥5 years) and unspecified hepatitis B (

Figure 2). For VPDs with a current target of 95%, the majority of jurisdictions thought targets should remain the same, although a minority (1–2) thought targets should be increased for hepatitis A, IMD, IPD, measles and Hib (

Figure 2).

Figure 2. Perceived appropriateness of CDNA targets for Indigenous status completeness by VPD



Discussion

Trends in NNDSS Indigenous status completeness

For VPDs where the CDNA target is 95%, national-level Indigenous status completeness was above the 95% CDNA target in all years from 2012 onwards for measles, IMD, IPD (both the <5 and ≥50 years age groups) and Hib, and within three percentage points for hepatitis A, pertussis (<5 years age group) and newly acquired hepatitis B. For VPDs with a CDNA target of 80%, Indigenous status completeness was above this in most years for rubella, diphtheria and tetanus, reaching 100% in the majority of years but with fluctuations due to the small numbers of notifications. Completeness increased substantially for mumps, from 60% in 2010 to above 90% from 2013 onwards, likely due to increased public health follow-up related to large multi-jurisdictional outbreaks in remote Aboriginal communities.[58,59] Completeness was below the 80% target in all years between 2012 and 2019 for IPD in the ≥5 to <50 years age group (range 72%–79%), and between 2010 and 2019 for rotavirus (59%–79%), pertussis (≥5 years age group; 61%–69%), unspecified hepatitis B (48%–62%) and laboratory confirmed influenza (43%–63%). However, there was substantial variation by jurisdiction for these latter VPDs, with NT and WA above the CDNA targets for all VPDs for the 2010–2019 period, and SA for all except laboratory confirmed influenza (75%). Completeness was ≥95% for NT for all VPDs except unspecified hepatitis B (92%), and for WA for all except laboratory confirmed influenza (89%), unspecified hepatitis B (92%) and rotavirus (94%). For all VPDs assessed, Indigenous status completeness increased with increasing remoteness. For most VPDs the differences were small (3–14 percentage points) but larger differences of 29–49 percentage points between major cities and very remote areas were identified for unspecified hepatitis B, laboratory confirmed influenza, pertussis (≥5 years) and rotavirus. Higher Indigenous status completeness in remote areas could be related to greater capacity for public health follow-up due to fewer notifications, better knowledge and identification of Indigenous status due to higher proportions of Aboriginal and Torres Strait Islander people in communities, and a greater role of ACCHSs. Considerably higher completeness was also identified for age groups prioritised for public health follow-up under national and jurisdictional guidelines.

Barriers, enablers and strategies to improve Indigenous status completeness

The two main barriers to Indigenous status completeness identified by most jurisdictions were: 1) the absence of an Indigenous status field in most pathology request forms, leading to missing Indigenous status identification in laboratory notifications; and 2) limited public health authority resource capacity to follow up missing data, either directly with the case or via the treating clinician/hospital, or indirectly by cross-checking other datasets such as hospitalisations or AIR, particularly for high incidence diseases. These issues likely explain the low Indigenous status completeness observed in most jurisdictions for unspecified hepatitis B, laboratory confirmed influenza, rotavirus and pertussis (≥5 years age group), all of which are high incidence diseases

predominantly notified by laboratories. However Indigenous status completeness was high for these VPDs in NT and WA.

The high Indigenous status completeness for all VPDs in NT can be attributed to routine public health follow-up of all notifications, with manual cross-checking of hospital databases for all cases where Indigenous status is missing. NT also reports undertaking retrospective updating of missing Indigenous status through annual manual data cleaning. The high Indigenous status completeness in WA is attributable in large part to high levels of clinician notification of all VPDs, along with manual cross-checking of hospital databases by public health and reference laboratory staff where Indigenous status is missing. Manual cross-checking of other databases, as undertaken in NT and WA, is a resource intensive activity. WA also mandates inclusion of an Indigenous status field in pathology request forms, although completeness of this field is poor. While WA undertakes annual data linkage, by a designated data linkage unit with access to multiple health datasets, this is currently only used to enhance Indigenous status completeness in COVID-19 notification data. Indigenous status completeness in WA VPD notification data in 2021 is also reported to have been approximately 97% even prior to data linkage (Paul Saunders, personal communication, May 2023). Mandated inclusion of an Indigenous status field on pathology request forms, which was supported by most jurisdictions surveyed, would seem to be a key medium to long term strategy to improve Indigenous status completeness. However, based on the WA experience, this would need to be complemented by work to ensure effective transfer of Indigenous status data between primary care and pathology software systems. A nationally coordinated and consistent approach, developed in collaboration with jurisdictions, would be preferable given many pathology services operate across jurisdictional borders.[15] Consideration could also be given to incorporation of recording and reporting of Indigenous status into laboratory accreditation standards. While some jurisdictions (Victoria, Tasmania) also mandate provision of Indigenous status in disease notifications, this was not associated with higher Indigenous status completeness, suggesting that legislation of this nature is insufficient in the absence of robust compliance mechanisms and other complementary strategies and systems.

Data linkage is another strategy that the stakeholders surveyed all perceived as potentially useful for improving Indigenous status completeness in their notifiable disease systems. Data linkage may be particularly useful in those jurisdictions where Indigenous status completeness is lower, either overall or for specific diseases, with consistency of methods across jurisdictions desirable. While data linkage is technically complex to establish initially, and barriers previously identified include data security, privacy, infrastructure and capability,[56] once operational it is likely a less resource intensive strategy than manually cross-checking for missing Indigenous status information in other data systems, particularly for high incidence diseases. The public health response to the COVID-19 pandemic led to innovative uses of health data in Australia,[60] in particular data linkage both nationally and within jurisdictions.[61,62] These approaches could be applied more broadly to achieve sustainable flow-on benefits for other notifiable diseases. Jurisdictions recently gained access to population-level AIR data to inform public health activities, thus providing access to Indigenous status as reported to Medicare or to the AIR by an immunisation provider, noting that Indigenous status was missing in only 0.7% of AIR records in 2021.[63] However, Aboriginal and Torres Strait Islander stakeholders should be consulted around data linkage methodologies for population health purposes of this nature, including how best to deal with inconsistencies in recorded Indigenous status of individuals within and between datasets,

which may reflect variation in the quality of data collected between datasets and over time but also the legitimate choice of whether or not to identify as Aboriginal and/or Torres Strait Islander on specific occasions and in specific settings.[64]

Accurate identification of Indigenous status at the point of service, whether GP, hospital or laboratory, should be the ultimate and universal goal, along with accurate transmission between services and to public health authorities through the notification process, rather than needing data linkage to mitigate inadequate collection and transfer practices. Along with the population health level benefits, accurate real-time identification of Indigenous status enables optimal patient management to be provided and can provide other health and wellbeing benefits for individuals.

Current CDNA targets for Indigenous status completeness in NNDSS data have remained unchanged since they were introduced in 2007. The majority of jurisdictions surveyed thought the targets should be raised for rubella, tetanus, mumps and diphtheria; half thought they should be raised for IPD (5 to <50 years age group) and rotavirus; and a minority (two to three jurisdictions) thought they should be raised for influenza, pertussis (≥5 years) and unspecified hepatitis B. There is a strong argument for increasing the targets for those VPDs with a current target of 80% where the target is already being achieved in all jurisdictions (i.e. diphtheria and tetanus), as these have small numbers of notifications, are routinely followed up by all jurisdictions and are of considerable public health significance. However, targets for all VPDs should be reviewed and increased where considered appropriate, based on relevant factors such as the importance of complete Indigenous status data to inform timely and effective public health action, or to track progress towards achieving national disease control targets, such as for hepatitis B.[65] The National Aboriginal and Torres Strait Islander Health Protection Sub-committee of the Australian Health Protection Principal Committee should be consulted in the review of targets and conditions for which monitoring of Indigenous status completeness is indicated.

Consideration should also be given to whether Indigenous status targets should be introduced for other notifiable VPDs of contemporary importance such as COVID-19, Japanese encephalitis, mpox and respiratory syncytial virus (a high incidence disease for which vaccination may be introduced),[66] and other notifiable diseases that are not vaccine preventable. Regular reporting of progress against completeness targets to key stakeholders would also likely be of benefit to raise awareness and promote ongoing improvement efforts. Inclusion of Indigenous status completeness targets as a reportable indicator under the National Partnership for Streamlined Agreements – Vaccine Preventable Diseases Surveillance Program Schedule should also be considered, potentially with targets aligned to CDNA targets and review of accompanying financial contributions.

We identified inconsistencies between jurisdictions in how Indigenous status reporting categories are completed and mapped to NNDSS data specifications, particularly in relation to missing data. Consistency of coding and systems across jurisdictions would enhance the interpretation of national-level Indigenous status data in the NNDSS, and ideally allow understanding of reasons for incomplete data (e.g. refused response versus truly missing data) to inform actions to increase data completeness. Education and training should also be provided for public health staff regarding the importance of checking for missing Indigenous status information during case follow-up, and appropriate processes to follow.

Limitations

This evaluation has several limitations. Stakeholder responses may not be fully representative of jurisdictional perspectives and there were some gaps in responses, which we attempted to address via direct follow-up with jurisdictions where possible. Factors contributing to Indigenous status collection and recording at the point of care were obtained from the literature review, with most information sourced from key AIHW guidelines/reports released in the early 2000s,[3,16] so we may not have identified all currently relevant factors; further assessment and consultation with stakeholders in this area may be of benefit. Technical details around systems and processes necessary for data transmission to and from laboratories were beyond the scope of this evaluation; further consultation with laboratory stakeholders, including the Public Health Laboratory Network, would be useful to explore and address relevant issues. We also assessed Indigenous status completeness in NNDSS data for the 2010–2019 (i.e. pre-pandemic) period, so may not have captured all improvements resulting from pandemic-related system enhancements, but consider that this would be unlikely to materially affect our conclusions and recommendations. We found that in NSW Indigenous status data collected during COVID-19 case follow-up were applied to all other notifications for the relevant individual, leading to retrospective improvement in overall Indigenous status completeness. A similar effect may have occurred in other jurisdictions. Finally, the scope of our evaluation was limited to VPDs; however, many of the issues identified are likely relevant more broadly, so further exploration in relation to other notifiable diseases may be of benefit.

Conclusion

To optimise Indigenous status completeness for VPDs, and for other notifiable diseases in the NNDSS, a mix of strategies and system-based approaches are needed to ensure accurate identification and recording at all relevant levels (primary care, hospital, laboratory and public health authority) and effective transfer between these services. Development, implementation and evaluation of all initiatives to improve Indigenous status collection, recording, reporting and evaluation should be led by Aboriginal and Torres Strait Islander people wherever possible, and their expertise and experience utilised to optimise appropriateness and effectiveness. Driving and supporting a nationally consistent approach to address the recommendations in this report may fall within the remit of the forthcoming Australian Centre for Disease Control as the focal point for disease surveillance data, coordination of laboratory data collection, reporting and analysis.[67]

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Appendix. Additional tables and figures

Table A1. Indigenous status completeness (%) of VPD notifications reported to the NNDSS by ARIA+ categories (2010–2019)[#]

Vaccine preventable disease	Major city	Inner regional	Outer regional	Remote	Very remote
VPDs with CDNA Indigenous status completeness target of 95%					
Hib	97	100	97	100*	100
Hepatitis A	94	97	96	90	100
Hepatitis B (newly acquired)	91	90	95	94	100*
Measles	97	97	99	100*	100*
IMD	98	96	99	100	100
Pertussis <5 years	93	91	95	99	99
IPD <5 years	97	97	99	100	100
IPD ≥50 years	97	97	98	100	100
VPDs with CDNA Indigenous status completeness target of 80%					
Diphtheria	96	83	100*	100*	NC
Hepatitis B (unspecified)	50	68	77	88	98
Influenza (laboratory confirmed)	45	46	63	86	94
Mumps	86	88	97	99	100
Pertussis≥5 years	58	60	69	88	91
IPD ≥5 to < 50 years	70	80	94	99	100
Rotavirus^	69	66	80	93	97
Rubella	91	76	80*	100*	NC
Tetanus	86	100	100*	NC	100*
All diseases	49	51	67	88	95

*Completeness in orange indicates a gap of ≤5 percentage points from the CDNA target; completeness in red indicates a gap of >5 percentage points from the CDNA target. NC = No cases; * Notification number <10*

^NSW, Tasmania, SA, WA, NT and Queensland reported rotavirus to the NNDSS for the full study period 2010–2019; ACT reported to the NNDSS since January 2018; Vic reported to the NNDSS since August 2018.

 # There is no major city category in NT or Tasmania; no inner regional category in NT; no outer regional category in ACT; no remote category in ACT; and no very remote category in ACT or Victoria

Table A2. Indigenous status completeness (%) of VPD notifications (all diseases combined) reported to the NNDSS by jurisdiction and ARIA+ categories (2010–2019)[#]

Jurisdiction	Major city	Inner regional	Outer regional	remote	Very remote
ACT	62	61	–	–	–
NSW	39	48	51	62	73
NT	–	–	95	99	100
Qld	57	59	70	84	89
SA	77	82	82	86	88
Tas	–	20	24	31	37
Vic	30	33	33	22	–
WA	90	88	96	97	98
Australia	49	51	67	88	95

 # There is no major city category in NT or Tasmania; no inner regional category in NT; no outer regional category in ACT; no remote category in ACT; and no very remote category in ACT or Victoria.

Table A3. Indigenous status completeness (%) of VPD notifications reported to the NNDSS by age group (2010–2019)

Vaccine preventable disease	0–4 years	5–14 years	15–24 years	25–49 years	≥50 years
VPDs with CDNA Indigenous status completeness target of 95%					
Hib	98	100	100*	100	98
Hepatitis A	96	97	96	93	92
Hepatitis B (newly acquired)	86	100	95	91	91
Measles	98	97	97	97	100
IMD	98	98	98	98	97
Pertussis <5 years	93	–	–	–	–
IPD <5 years, ≥50 years	97	–	–	–	97
VPDs with CDNA Indigenous status completeness target of 80%					
Diphtheria	NC	100*	100	100	86
Hepatitis B (unspecified)	55	76	62	54	48
Influenza (laboratory confirmed)	50	50	56	46	43
Mumps	95	97	95	91	85
Pertussis >5 years	–	67	63	55	54
IPD ≥5 to < 50 years	–	87	81	77	–
Rotavirus^	78	71	69	58	59
Rubella	100*	100*	89	89	87
Tetanus	100*	100*	100*	86*	91
All diseases	61	56	58	49	47

Completeness in orange indicates a gap of ≤5 percentage points from the CDNA target; completeness in red indicates a gap of >5 percentage points from the CDNA target.

NC = No cases

^NSW, Tasmania, SA, WA, NT, and Queensland reported rotavirus to the NNDSS for the full study period 2010–2019; ACT reported to the NNDSS since January 2018; Victoria reported to the NNDSS since August 2018.

** Notification number <10*

Table A4. Proportions and notifications of known, 'not stated' and 'not provided' Indigenous status in VPD notifications by jurisdiction, 2010–2019

Jurisdiction		Indigenous status		
		Known	Not stated (Code 9)	No information provided ('NULL'/blank)
ACT	**%**	**62**	**11**	**27**
	n	11,700	2,121	5,112
NSW	**%**	**41**	**13**	**45**
	n	192,906	62,114	212,245
NT	**%**	**98**	**2**	**0**
	n	14,189	321	0
Qld	**%**	**60**	**40**	**0 (0.01)**
	n	187,957	12,4835	17
SA	**%**	**78**	**22**	**0**
	n	114,776	32,767	0
Tas	**%**	**21**	**79**	**0 (0.02)**
	n	3,749	13,870	3
Vic	**%**	**30**	**70**	**0**
	n	76,722	176,402	0
WA	**%**	**91**	**1**	**8**
	n	90,071	612	8,112
Australia	**%**	**52**	**31**	**17**
	n	692,070	413,042	225,489

Table A5. Indigenous status categories used by jurisdictions for VPD notifications

NNDSS data fields	ACT	NSW	NT	Qld	SA	Tas	Vic	WA
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	✓	✓	✓	✓	✓	✓	✓	✓
9 – Not stated	✓∞	✓#	✓	✓	✓	✓	✓^	X
NULL or left blank - No information provided	✓	✓	X*	✓	X*	✓	✓	✓
Above categories used between 2010–2019	✓	✓	✓	X	✓	✓	Unsure	✓
Other fields used	X	X	X	X	✓	✓	✓	✓

** 'not stated' used instead of 'NULL'/blank if no response has been given for Indigenous status*

∞ Defined as 'not stated/inadequately described' in ACT

^ Defined as 'missing/not stated' in Vic

 # Defined as 'not stated/unknown' in NSW

Table A6. Other Indigenous status categories used by jurisdictions and how they map to NNDSS categories

	Other category used	Mapped to NNDSS as 'not stated'	Mapped to NNDSS as 'NULL'/blank
SA	Question not able to be asked	✓	
	Declined to answer	✓	
WA	Unknown	✓	
Tas	Unknown		✓
Vic	Declined to answer	Unsure	Unsure
ACT	–	–	–
NSW	–	–	–
NT	–	–	–
Qld	–	–	–

Table A7. Method of notifications by VPD and jurisdiction*

	ACT	NSW	NT	Qld	SA	Tas	Vic	WA
Diphtheria	Dual	Dual	Dual	Lab only	Dual	Lab only	Dual	Dual
Hib	Dual	Dual	Dual	Lab only	Dual	Lab only	Dual	Dual
Hepatitis A	Dual	Dual	Lab only	Lab only	Dual	Lab only	Dual	Dual
Hepatitis B (newly acquired)	Dual	Dual	Dual	Lab only	Dual	Lab only	Dual	Dual
Hepatitis B (unspecified)	Dual	Dual	Dual	Lab only	Dual	Lab only	Dual	Dual
Influenza (laboratory confirmed)	Dual	Dual	Lab only	Lab only	Lab only	Lab only	Lab only	Dual
Measles	Dual	Dual	Dual	Dual	Dual	Dual	Dual	Dual
IMD	Dual	Dual	Dual	Dual	Dual	Dual	Dual	Dual
Mumps	Dual	Dual	Dual	Dual	Dual	Lab only	Dual	Dual
Pertussis	Dual	Dual	Dual	Lab only	Dual	Lab only	Dual	Dual
IPD	Dual	Dual	Lab only	Lab only	Dual	Lab only	Dual	Dual
Rotavirus	Dual	Dual	Lab only	Lab only	Dual	Lab only	Dual	Dual
Rubella	Dual	Dual	Dual	Dual	Dual	Lab only	Dual	Dual
Tetanus	Dual	Dual	Dual	Dual	Dual	Dual	Dual	Dual

** Dual includes notifications being received from both laboratories and clinicians.*

Lab = laboratory; Hib = Haemophilus influenzae type b; IMD = invasive meningococcal disease; IPD = invasive pneumococcal disease

Table A8. Recommended public health follow-up of vaccine preventable diseases as per national guidelines

	Recommended public health follow-up
Hib	Within 24 hours of notification of a confirmed case
Hepatitis A	As soon as possible, generally within one working day of notification of a probable or confirmed case
Hepatitis B	• Newly acquired hepatitis B: within three working days of notification of a confirmed case • Unspecified hepatitis B: timing at discretion of the Public Health Unit
Influenza (laboratory confirmed)	• Novel subtype or untypable isolate: as soon as possible, within 24hrs • Outbreaks in high risk settings (e.g. residential care facilities, Aboriginal and Torres Strait Islander communities): as soon as possible, within one working day • Individual cases in most community settings: as part of routine duties
Measles	Same day of notification of a suspected, probable or confirmed case
IMD	Same day of notification of a probable or confirmed case
Pertussis	As soon as possible, generally within one working day. Highest priority should generally be given to cases who are nucleic acid test/culture confirmed and: • if the case is aged <5 years, follow up the younger cases (<2 years) before the older cases • women known to be in the last month of pregnancy • known to be in contact with infants aged <6 months or women in last month of pregnancy • known to attend or work in a setting with likely contact with infants aged <6 months or women in last month of pregnancy

Hib = Haemophilus influenzae type b; IMD = invasive meningococcal disease

Table A9. Jurisdictional public health follow-up of vaccine preventable diseases as reported by stakeholders

	ACT	NSW	NT	Qld	SA	Tas	Vic	WA
Diphtheria	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hib	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hepatitis A	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hepatitis B (newly acquired)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hepatitis B (unspecified)	No	No	Yes	Yes	Yes	Yes	Unsure	Yes
Influenza (laboratory confirmed)	RACF only	RACF only	Yes	No	No	No	At risk settings	No
Measles	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
IMD	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Mumps	Yes	Yes	Yes	Yes	Some age groups*	Yes	Yes	Yes
Pertussis	Yes	Yes	Yes	<5 years only	Some age groups*	Yes	<10 years only	Some age groups*
IPD	Yes	<5 years and ≥50 years	Yes	<5 years and ≥65 years	Yes	Yes	Yes	Yes
Rotavirus	Some age groups*	RACF only	Yes	No	Some age groups*	Cases born ≥2007	At risk settings	Some age groups*
Rubella	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
Tetanus	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

**Age groups unspecified*
Hib= Haemophilus influenzae type b; RACF = Residential aged care facility; IMD = invasive meningococcal disease; IPD = invasive pneumococcal disease