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

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Abstract

Background

High quality Indigenous status data for vaccine preventable diseases (VPDs) in the National Notifiable Diseases Surveillance System (NNDSS) is important for evaluation of immunisation programs and ultimately for improving health outcomes for Aboriginal and Torres Strait Islander peoples. We evaluated Indigenous status completeness, and factors influencing it, for VPDs in the NNDSS.

Methods

Literature review (published and grey); descriptive analysis of NNDSS data for selected VPDs over the 2010–2019 period; standardised online survey (containing closed- and open-ended questions) of key informants; semi-structured follow-up interviews.

Results

National level Indigenous status completeness for those VPDs with a Communicable Diseases Network Australia (CDNA) target of 95% was above that target for *Haemophilus influenzae* type b, measles, invasive meningococcal disease and invasive pneumococcal disease (IPD: < 5 and \geq 50 years); and was within four percentage points for hepatitis A, newly acquired hepatitis B and pertussis (< 5 years).

For VPDs with an 80% target, completeness was \geq 90% for diphtheria, mumps, rubella and tetanus; \geq 80% for IPD (\geq 5 to < 50 years); and below target for unspecified hepatitis B (54%), laboratory confirmed influenza (47%), pertussis (\geq 5 years; 60%) and rotavirus (71%). However, completeness was above 90% for all VPDs in the Northern Territory, and all except laboratory confirmed influenza (89%) in Western Australia. Key barriers to Indigenous status completeness include the absence of an Indigenous status field on most pathology request forms and limited public health authority resource capacity to follow up missing data, particularly for high incidence diseases.

Conclusion

National level Indigenous status completeness is high for most VPDs but low for others, particularly for high incidence diseases predominantly notified by laboratories. Completeness is uniformly high for all VPDs in the Northern Territory and Western Australia; however, this is due to the resource-intensive public health follow-up of all notifications and manual cross-checking of other databases when Indigenous status is missing. To more efficiently optimise Indigenous status completeness in the NNDSS across all jurisdictions, a mix of additional strategies is needed to ensure accurate identification and recording in primary care, hospital, laboratory and public health settings, and effective transfer between them.

Keywords: vaccine preventable diseases; notifiable diseases; Indigenous status; Aboriginal and Torres Strait Islander status

Introduction

Rates of many health conditions are higher in Aboriginal and Torres Strait Islander peoples in Australia, compared to the non-Indigenous population, including for many vaccine preventable diseases (VPDs) for which vaccination is funded under the National Immunisation Program (NIP).^{1,2} This is due to the ongoing effects of colonisation, dispossession and inter-generational social disadvantage.³ Accurate identification of Aboriginal and Torres Strait Islander status in health datasets is crucial to better understand health needs, and to ensure that these needs can be effectively addressed.⁴ This is particularly important for VPDs, as under the NIP some vaccines are funded for Aboriginal and Torres Strait Islander people alone, or with expanded age eligibility, based on higher incidence or worse outcome data.¹ High quality Aboriginal and Torres Strait Islander status data in the National Notifiable Diseases Surveillance System (NNDSS), reported 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.

The 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.⁵ A 2004 evaluation identified Indigenous status as one of the most poorly completed data fields in the NNDSS.⁶ In 2009, CDNA set targets of 95% Indigenous status completeness in the NNDSS for 18 priority diseases, including eight VPDs (*Haemophilus influenzae* type b [Hib] disease, hepatitis A, newly acquired hepatitis B, measles, invasive meningococcal disease [IMD], pertussis [< 5 years], invasive pneumococcal disease [IPD; < 5 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).⁷ A review of NNDSS data from 1991–2011 found that completeness of Indigenous status had improved but these targets had not been met.⁸

Indigenous status completeness in the NNDSS at national level over the 2016–2019 period was above 90% for most VPDs, but much lower for laboratory confirmed influenza (37.4%), pertussis (59.2%) and rotavirus (69.7%), with some variation by jurisdiction and age group.² We aimed to comprehensively evaluate factors influencing the quality and completeness of Indigenous status for VPDs reported to the NNDSS, and to make recommendations for improvement.

Methods

This evaluation comprised multiple components, as described below.

Literature review

We undertook a focused review of published and grey literature to identify information relating to how Indigenous status is collected and reported in jurisdictional surveillance systems and then transmitted to the NNDSS, differences in jurisdictional reporting mechanisms and requirements along with 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 the general practice [GP], hospital or laboratory level) were predominantly summarised through the literature review. We searched Google Scholar, Ovid MEDLINE and Australian Indigenous HealthInfoNet,ⁱ with the search restricted to Australian literature from 2000 onwards, along with the websites of relevant Commonwealth and jurisdictional government organisations.

NNDSS data analysis

We undertook descriptive analyses of Indigenous status completeness (calculated as the percentage of notifications with known Indigenous status) in NNDSS data over the 10-year period prior to the coronavirus disease 2019 (COVID-19) pandemic (i.e. 1 January 2010 to 31 December 2019) for diphtheria, Hib disease, hepatitis A, newly acquired hepatitis B,

i <https://healthinonet.ecu.edu.au/>.

unspecified hepatitis B, laboratory confirmed influenza, measles, IMD, mumps, pertussis (separate for < 5 and ≥ 5 year age groups), IPD (separate for < 5, ≥ 5 to < 50 and ≥ 50 years age groups), rotavirus, rubella and tetanus. We did not include poliovirus infection, as there were no notifications during the study period, or varicella-zoster infections, as these are not notifiable in New South Wales and a high proportion in most other jurisdictions are not specified as either varicella (chickenpox) or zoster (shingles) when reported. Indigenous status completeness was assessed for the selected VPDs with comparison to current CDNA targets, which differ by age group for pertussis and IPD notifications, and analysed at 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+).⁹ Similar analyses were conducted for each jurisdiction. Unknown Indigenous status data were also analysed, at national and jurisdictional levels, comparing the proportion of notifications with an unknown Indigenous status recorded as 'not stated' versus those with a 'NULL' or missing value.

Stakeholder survey/engagement

An online survey of recent National Surveillance Committee members working in jurisdictional health departments, using Qualtrics (Provo, Utah), was conducted in late 2022. This survey explored each jurisdiction's Indigenous status reporting and data management, initiatives undertaken and recommendations for improving Indigenous status data quality. Survey question development was informed by literature review and NNDSS data analysis findings and included both open (free-text) and closed (binary, multiple choice and Likert scale) questions, developed in an iterative process involving consultation and piloting with individuals with experience in disease surveillance. Invitees, identified using information supplied by the Australian Government Department of Health and Aged Care, were approached by email and asked to consult with relevant colleagues but to only submit one online response per jurisdiction. 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 via email, or to conduct a semi-structured interview for additional information where relevant.

The National Aboriginal Community Controlled Health Organisation (NACCHO) was consulted and provided feedback on study methods and interpretation of results.

Cultural governance

The National Centre for Immunisation Research and Surveillance (NCIRS) National Indigenous Immunisation Coordinator provided cultural oversight of the evaluation, with the study proposal reviewed by the NCIRS Cultural Governance Group.

Ethical approval

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

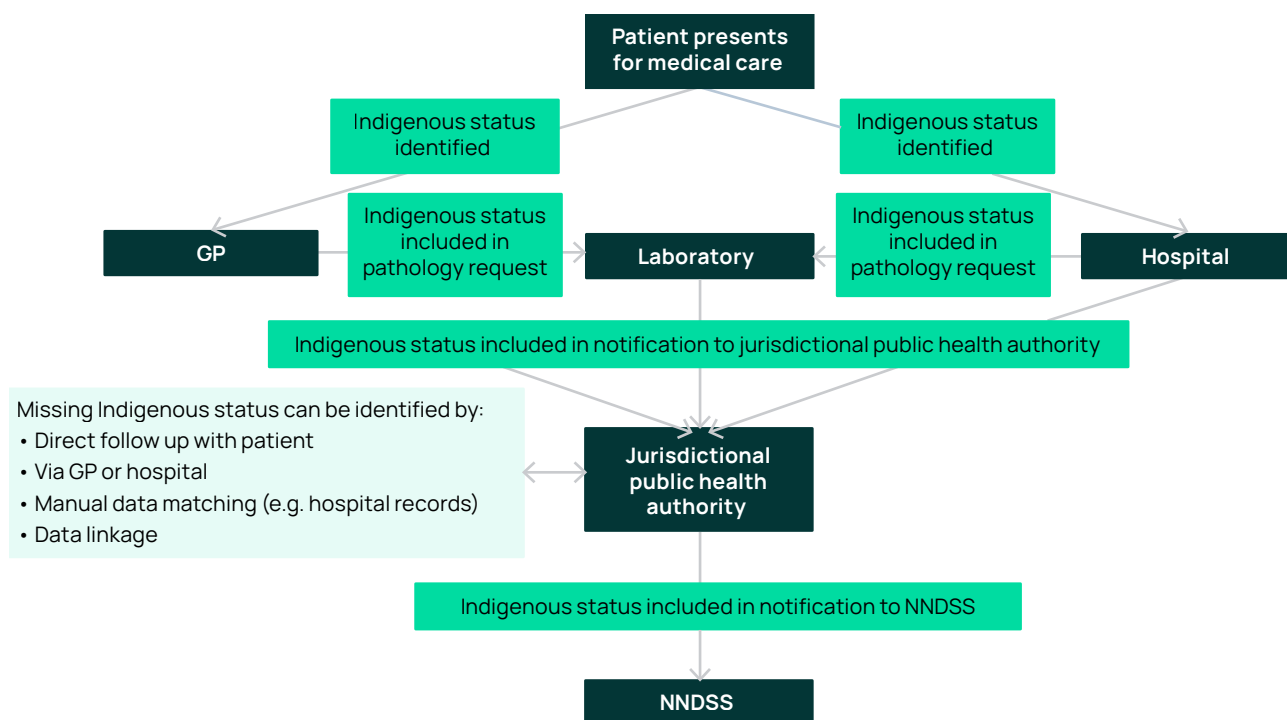
Results

Literature review

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 for transfer of this information to the Australian Government for diseases included in the National Notifiable Diseases List.⁷ Jurisdictions provide de-identified data to the NNDSS on a daily basis for cases that meet CDNA surveillance case definitions.¹⁰ The NNDSS is a dynamic system and notification data may subsequently be updated by jurisdictions.

The NNDSS is a passive surveillance system that relies on notification by jurisdictions, and each jurisdiction uses its own predominantly passive surveillance methods that rely largely on notification by medical practitioners (predominantly in primary health care or hospital settings) and laboratories. Indigenous status can be collected at multiple points, ranging from patient presentation for medical care to reporting of the notification to the NNDSS (Figure 1).

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



The predominance of laboratory notifications in Australia has long been recognised as a barrier to Indigenous status completeness in the NNDSS, due to often limited patient information included and need for follow-up to obtain additional information, in context of limited resource capacity,¹¹ particularly for high incidence diseases. The inclusion of Indigenous status information in pathology request forms and electronic data systems has been recommended in reports dating back to 2004.^{11,12} Studies conducted before 2012 found Indigenous status to be better collected in hospital settings¹³ than in mainstream GP settings,^{14,15} although we did not identify any more recent studies.

Australian Institute of Health and Welfare (AIHW) best practice guidelines were published in 2010, aiming to improve Indigenous status recording in national health datasets and to provide a nationally consistent approach to asking about and recording Indigenous status.⁴ The coding categories recommended in these guidelines are summarised in Table 1. For monitoring and auditing purposes, local information systems should be able to distinguish between situations where Indigenous status was coded as category 9 (not stated/inadequately described) due to a client’s refusal to respond, versus situations where it was impossible to ask the question during initial contact, or other situations where the response was left blank or incomplete, which should be followed up.⁴

The NNDSS core dataset includes mandatory and non-mandatory data fields for completion by jurisdictional health authorities prior to data transfer to the NNDSS, with the Indigenous status data field being a non-mandatory field.¹⁶ Possible Indigenous status data field codes and corresponding definitions are shown in Table 2. The NNDSS does not strictly use the AIHW recommended coding categories, as it allows for blank and ‘NULL’-coded entries. Disease notification forms for seven of the eight jurisdictions were obtained from jurisdictional health department websites.¹⁷⁻²³ While most forms contained the standard Indigenous status question or standard recording categories, depending on the jurisdiction they may be used only by clinicians or for particular notifiable diseases.

Table 1: Recording responses to Indigenous status question as per AIHW national guidelines⁴

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	<ul style="list-style-type: none"> 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.

Table 2: NNDSS Indigenous status data field codes and definitions¹⁶

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

Previous reports have identified a range of factors impacting Indigenous status completeness and quality in national notifiable disease data, including: the proportion of diseases notified by doctors, laboratories or both; 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 the field if present; the limited capacity for transfer of Indigenous status information between requesting clinicians, pathology laboratories and public health authorities; and the level of data matching or sharing between systems.^{4,11,12,24}

The National Advisory Group for Aboriginal and Torres Strait Islander Health Information and Data previously advocated for Indigenous status to be a mandatory field in the Australian Standard governing electronic pathology messaging.¹²

Notifiable diseases that are routinely followed up by public health authorities for disease control and prevention purposes have previously been shown to often have higher Indigenous status completeness, as missing information can be obtained during follow-up.^{11,12} Data linkage can also improve Indigenous status completeness.²⁵ AIHW national best practice guidelines for data linkage activities relating to Aboriginal and Torres Strait Islander people provide guidance on managing missing or inconsistent Indigenous status information when linking datasets, along with key ethical concerns.²⁶

The Commonwealth provides some financial support to jurisdictions (approximately \$1,000,000 per year in total across all jurisdictions) for surveillance and reporting of nationally notifiable VPDs covered by the NIP, under the Vaccine Preventable Diseases Surveillance Program component of the Federated Funding Agreement for Health.²⁷ The current Agreement specifies a responsibility to improve data quality, including Indigenous status in notifications that require follow-up.²⁷ While improving Indigenous status completeness is a high-level goal in the Agreement, it is not included as an indicator under the reporting requirements, nor are targets specified.²

NNDSS data analysis

National level Indigenous status completeness for VPDs with a CDNA target of 95% was above the target for the 2010–2019 period at 97–98% for Hib, measles, IMD and IPD (both < 5 and ≥ 50 years age groups) and ≥ 91% for the other VPDs (hepatitis A, newly acquired hepatitis B and pertussis [< 5 years]; Table 3).

For VPDs with a target of 80%, completeness was ≥ 90% for diphtheria, mumps, rubella and tetanus, and ≥ 80% for IPD (≥ 5 to < 50 years) but was below the target for 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 and Indigenous status completeness (%) in relation to CDNA targets, Australia, 2010–2019

Indigenous status completeness target	Vaccine preventable disease	Number of notifications	Indigenous status completeness (% with known status)
95%	Hib	182	98
	Hepatitis A	2,221	94
	Hepatitis B (newly acquired)	1,738	91
	Measles	1,601	97
	IMD	2,304	98
	Pertussis < 5 years	24,439	93
	IPD < 5 years	2,304	97
	IPD ≥ 50 years	10,190	97
80%	Diphtheria	45	93
	Hepatitis B (unspecified)	62,006	54
	Influenza (laboratory confirmed)	996,256	47
	Mumps	3,920	93
	Pertussis ≥ 5 years	176,940	60
	IPD ≥ 5 to < 50 years	5,333	80
	Rotavirus ^a	40,738	71
	Rubella	251	90
Tetanus	38	92	

a New South Wales, Tasmania, South Australia, Western Australia, the Northern Territory and Queensland reported rotavirus to the NNDSS for the full 2010–2019 period; the Australian Capital Territory reported from January 2018 and Victoria from August 2018.

Indigenous status completeness at the national level increased with increasing remoteness of area of residence, with the greatest differences observed for influenza, ranging from 45% in major cities to 94% in very remote areas; unspecified hepatitis B (50% to 98%); pertussis (≥ 5 years; 58% to 91%); rotavirus (69% to 97%); and IPD (≥ 5 to < 50 years; 70% to 100%; Appendix A, Table A.1). The difference for other VPDs ranged from 14 percentage points (mumps and tetanus) to two percentage points (IMD).

Indigenous status completeness at the national level was broadly similar by year across the 2010–2019 period for most VPDs (Appendix A, Table A.2). Notable improvements, where completeness reached the CDNA target by the end of the 10-year period,

were seen for newly acquired hepatitis B (from 86% in 2010 to 95% in 2019) and mumps (from 60% in 2010 to $> 90\%$ from 2013 onwards). Completeness for rubella, diphtheria and tetanus was above the 80% target in most years, ranging from 67% to 100% with large fluctuations likely related to very small numbers of notifications.

At the jurisdictional level, Indigenous status completeness for VPDs with a CDNA target of 95% was above this target for the 2010–2019 period in all jurisdictions (where there were notifications) for Hib and measles, in most jurisdictions for hepatitis A, IMD, IPD (< 5 and ≥ 50 years) and pertussis (< 5 years), and in half of the states and territories (4/8) for newly acquired hepatitis B (Table 4).

Table 4: Indigenous status completeness (%) of notifications reported to the NNDSS, in relation to CDNA targets, by vaccine preventable disease and jurisdiction, Australia, 2010–2019

Indigenous status completeness target	Vaccine preventable disease	Jurisdiction ^{a,b}							
		ACT	NSW	NT	Qld	SA	Tas.	Vic.	WA
95%	Hib	NC	97	100	100	100	100 ^c	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
80%	Diphtheria	NC	100 ^c	100 ^c	91	100 ^c	NC	100 ^c	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 ^d	94	47	99	81	85	11	7	94
	Rubella	100 ^c	91	NC	84	100	100 ^c	84	100
Tetanus	NC	89 ^c	NC	82	100 ^c	NC	100 ^c	100	

a ACT: Australian Capital Territory; NSW: New South Wales; NT: Northern Territory; Qld: Queensland; SA: South Australia; Tas: Tasmania; Vic.: Victoria; WA: Western Australia.

b NC: no cases.

c < 10 notifications.

d New South Wales, the Northern Territory, Queensland, South Australia, Tasmania and Western Australia reported rotavirus to the NNDSS for the full 2010–2019 period; the Australian Capital Territory reported from January 2018 and Victoria from August 2018.

For VPDs with a CDNA target of 80%, completeness was above the target in all jurisdictions (where there were notifications) for diphtheria, rubella and tetanus, and in most jurisdictions for mumps and IPD (≥ 5 to <50 years). Completeness was above 80% in five jurisdictions for: rotavirus (the Australian Capital Territory, the Northern Territory, Queensland, South Australia and Western Australia), ranging from 7% to 47% in the others; in four jurisdictions for unspecified hepatitis B (the Australian Capital Territory, the Northern Territory, South Australia and Western Australia), ranging from 33% to 73% in the others; and in three for pertussis (≥ 5 years) (the Northern Territory, South Australia and Western Australia), ranging from 47% to 73% in the others. Completeness for laboratory confirmed influenza was above the target only in the Northern Territory (99%) and Western Australia (89%), ranging from 6% to 75% in the others.

Analysis showed that some jurisdictions (the Northern Territory, South Australia and Victoria) reported only code 9 ('not stated') where Indigenous status is unknown, as per AIHW national guidelines, while the others also reported 'NULL' values/blank fields. In the Australian Capital Territory, New South Wales, and Western Australia, the majority of notifications with unknown Indigenous status were reported to the NNDSS as 'NULL'/blank, while in Queensland and Tasmania only a few were (Appendix A, Table A.3).

Stakeholder survey

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, and to monitor trends among Aboriginal and Torres Strait Islander people.

The Australian Capital Territory, New South Wales and Western Australia 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. Western Australia reported a high level

of clinician notification across all VPDs and credited this as a key reason for their high Indigenous status completeness.

All jurisdictions reported that they follow up every notification of diphtheria, Hib, hepatitis A, newly acquired hepatitis B, measles, IMD and tetanus. Most reported following up all mumps, rubella and IPD notifications. Only NT reported following up all influenza and rotavirus notifications. Where public health follow-up occurs, this was reported to include follow-up of incomplete Indigenous status for all cases in the Northern Territory, South Australia and Western Australia, most cases in the Australian Capital Territory, New South Wales, Tasmania and Victoria, and some cases in Queensland.

All eight jurisdictions reported using manual processes to cross-check with other data systems (e.g. the Australian Immunisation Register [AIR] or hospital data) to increase Indigenous status completeness. The Northern Territory reported cross-checking hospital data for all cases and credited this as the primary reason for their high Indigenous status completeness. Western Australia reported that public health units 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.

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'. Only the Northern Territory and South Australia reported not using a 'NULL' category or blank field. Some jurisdictions use other categories which are not used in the NNDSS and map to either 'not stated' or 'NULL'/blank category in NNDSS.

The main barriers identified to collection of Indigenous status were absence of Indigenous status field in most pathology request forms, leading to missing Indigenous status identification in laboratory notifications, and limited public health authority resources to follow up missing data, particularly for high incidence diseases.

Western Australia 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, and the categories used in the reference

laboratory request form ('is patient of Aboriginal descent? [Yes/No]) do not align with national guidelines. All other jurisdictions except Queensland thought that mandating inclusion of an Indigenous status field on pathology request forms would be useful, with a nationally coordinated approach suggested.

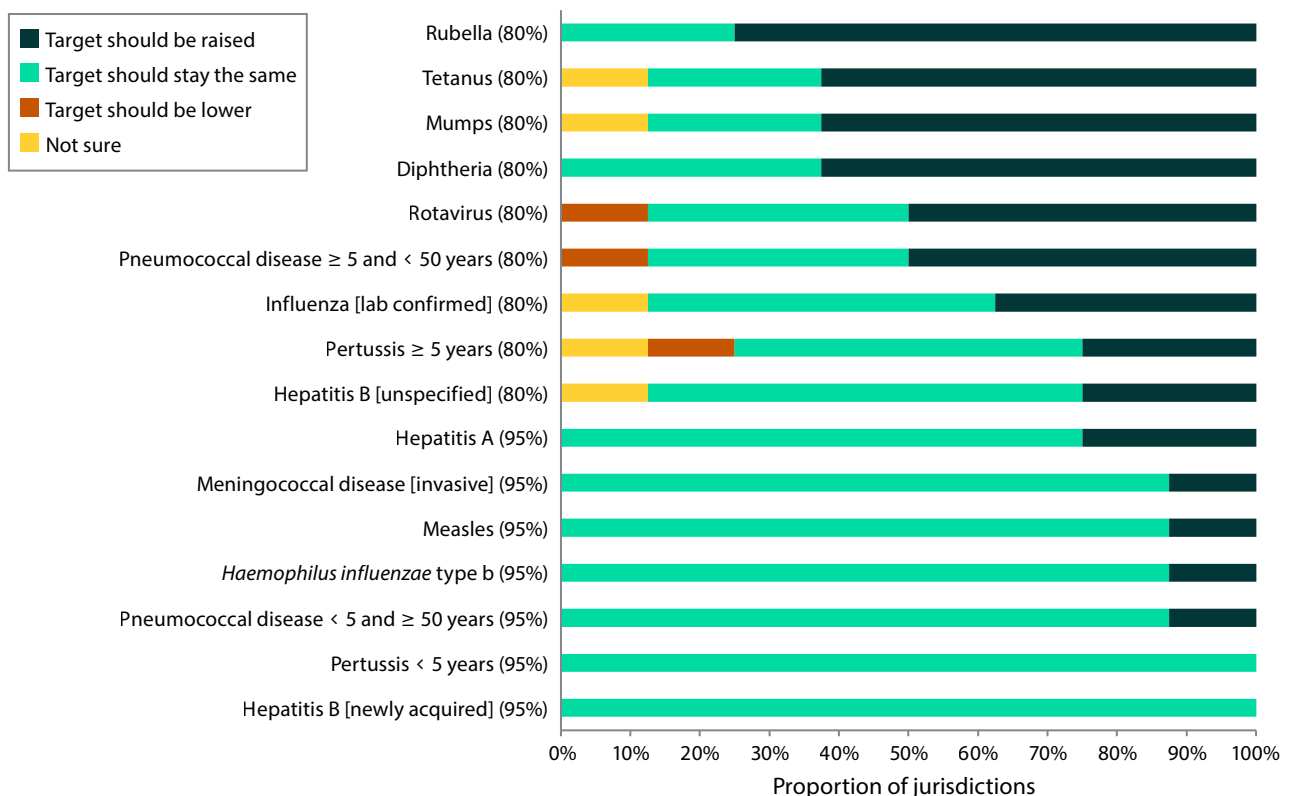
Three jurisdictions (Western Australia [2007 onwards], Queensland [2022 onwards] and Victoria [2022 onwards]) reported using linkage with other administrative health datasets to improve Indigenous status completeness in their notifiable disease registers. Western Australia reported that a data linkage unit has linked notification data to other datasets, including hospitalisations, deaths, and births since at least 2007, usually annually, 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.

An incidental finding from our study was that Indigenous status completeness in New South Wales had increased compared to NNDSS data for the same period but extracted approximately 15 months earlier:² from 45% to 60% for pertussis; 18% to 33% for unspecified hepatitis B; and 16% to 36% for

laboratory confirmed influenza (data not shown). New South Wales Health stakeholders attributed this increase to follow-up of COVID-19 cases in the intervening time period through an SMS survey, which included a question on Indigenous status. The New South Wales 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. It was not explored whether similar processes may exist in other jurisdictions.

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 thought they should be raised for IPD (≥ 5 to < 50 years age group) and rotavirus, and a minority (2–3) thought 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^a



^a CDNA target shown in parentheses.

Discussion

For VPDs with a CDNA target of 95%, we found that national-level Indigenous status completeness was above this target in all years from 2012 onwards for measles, IMD, IPD (< 5 and \geq 50 years age groups) and Hib, and \geq 90% for hepatitis A, pertussis (< 5 years age group) and newly acquired hepatitis B from 2014 onwards. For VPDs with a CDNA target of 80%, Indigenous status completeness was above this in most years for rubella, diphtheria and tetanus, 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.^{28,29} Completeness was below the 80% target in all years during the 2010–2019 period for rotavirus (59–79%), pertussis (\geq 5 years; 56–65%), unspecified hepatitis B (48–62%) and laboratory confirmed influenza (43–63%), and from 2012 to 2019 for IPD in the \geq 5 to < 50 years age group (72–79%). However, there was substantial variation by jurisdiction, with overall completeness for the 2010–2019 period \geq 95% for the Northern Territory for all VPDs except unspecified hepatitis B (92%), and for Western Australia for all except laboratory confirmed influenza (89%), unspecified hepatitis B (92%) and rotavirus (94%).

For all VPDs assessed, national-level 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 (\geq 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 Aboriginal Community Controlled Health Services.

The two main barriers to Indigenous status completeness identified by 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, 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 (\geq 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 the Northern Territory and Western Australia.

Based on our study findings, the high Indigenous status completeness for all VPDs in the Northern Territory 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. The high Indigenous status completeness in Western Australia is attributable 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 the Northern Territory and Western Australia, is a resource intensive activity. Western Australia also mandates inclusion of an Indigenous status field in pathology request forms, although completeness of this field was reported to be poor. While Western Australia undertakes annual data linkage, this is currently only used to enhance Indigenous status completeness in COVID-19 notification data. Indigenous status completeness in Western Australia VPD notification data was also noted to be high even prior to data linkage (approximately 97% in 2021).ⁱⁱ Mandated inclusion of an Indigenous status field on pathology request forms, which was supported by most jurisdictions surveyed, would seem a key medium to long term strategy to improve Indigenous status completeness. However, 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 would be preferable, given many pathology services operate across jurisdictional borders.¹² Recording and reporting of Indigenous status could also be incorporated into laboratory accreditation standards.

ii source: Western Australia follow-up interview, May 2023.

Data linkage may be useful in 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,³⁰ 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,³¹ including linkage at both national and jurisdictional levels.^{32,33} These approaches could be applied more broadly to other notifiable diseases. Jurisdictions now have access to population-level AIR data for public health purposes, thus providing potential to match notifications with 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 2021.³⁴ 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.³⁵

Accurate identification of Indigenous status (at least as far as possible in context of legitimate choices regarding self-identification) 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 may enable more optimal patient management, for example recommendation of vaccinations funded on the National Immunisation Program specifically for Aboriginal and Torres Strait Islander people.

The rationale for why CDNA originally set a 95% Indigenous status completeness target for some VPDs in NNDSS, and 80% for others, is not in the public domain. There is a strong argument for increasing those targets currently set at 80%, given the considerable advances in data and information

systems and technology since the targets were established in 2009. This is particularly the case for diphtheria and tetanus where the number of notifications is small, and they are routinely followed up and of considerable public health significance.² However, targets for all VPDs, and indeed all notifiable conditions, should be reviewed and increased where appropriate. Optimal Indigenous status completeness is important to monitor the effectiveness of immunisation and other public health programs; to track progress towards key national disease control targets, such as for hepatitis B;³⁶ and to inform timely and effective public health actions, including development and implementation of new Closing the Gap policy and program initiatives. Introduction of Indigenous status targets should also be considered for other important vaccine-preventable notifiable conditions such as COVID-19, Japanese encephalitis, mpox and respiratory syncytial virus (a high incidence disease for which immunisation programs are likely to be introduced at some point). The National Aboriginal and Torres Strait Islander Health Protection Subcommittee of the Australian Health Protection Committee should be closely involved in the review and consideration of completeness targets. Regular assessment and reporting of progress against targets are needed to raise awareness and promote ongoing improvement efforts. Indigenous status completeness targets could also be included as a reportable indicator under the Federated Funding Agreement for Health, Vaccine Preventable Diseases Surveillance Program Schedule, with targets potentially aligned to CDNA targets and review of accompanying financial contributions. However, increased funding for VPD surveillance activities such as public health follow-up is not sufficient in isolation, and needs to be complemented by measures to improve accurate identification and recording of Indigenous status at all levels and effective transfer between services, as noted above.

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.

In terms of study limitations, we assessed Indigenous status completeness in NNDSS data for the 2010–2019 period so may not have captured all improvements resulting from pandemic-related system enhancements. For example, we found that in New South Wales, 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. Prospective improvements in completeness may also have occurred, emphasising the importance of ongoing monitoring and reporting of completeness data. While our analysis was limited to VPDs, many of the issues identified are likely relevant more broadly to other conditions.

To optimise Indigenous status completeness for VPDs, and other notifiable conditions, 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, to optimise appropriateness and effectiveness. Driving and supporting a nationally consistent approach may fall within the remit of the Australian Centre for Disease Control as the focal point for disease surveillance data, coordination of laboratory data collection, reporting and analysis.³⁷

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Appendix A

Table A.1: Indigenous status completeness (%) in NNDSS, in relation to CDNA targets, by VPD and ARIA+ category,^a Australia, 2010–2019

Indigenous status completeness target	Vaccine preventable disease	ARIA+ remoteness category					
		Major city	Inner regional	Outer regional	Remote	Very remote	
95%	Hib	97	100	97	100 ^b	100	
	Hepatitis A	94	97	96	90	100	
	Hepatitis B (newly acquired)	91	90	95	94	100 ^b	
	Measles	97	97	99	100 ^b	100 ^b	
	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	
	Diphtheria	96	83	100 ^b	100 ^b	NC ^c	
	Hepatitis B (unspecified)	50	68	77	88	98	
80%	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 ^d	69	66	80	93	97	
	Rubella	91	76	80 ^b	100 ^b	NC ^c	
	Tetanus	86	100	100 ^b	NC ^c	100 ^b	
	All diseases	—	49	51	67	88	95

^a There is no major city category in the Northern Territory or Tasmania; no inner regional category in the Northern Territory; no outer regional category in the Australian Capital Territory; no remote category in the Australian Capital Territory; and no very remote category in the Australian Capital Territory or Victoria.

^b Notification number < 10.

^c NC: no cases.

^d New South Wales, Tasmania, South Australia, Western Australia, the Northern Territory and Queensland reported rotavirus to the NNDSS for the full 2010–2019 period; the Australian Capital Territory reported from January 2018 and Victoria from August 2018.

Table A.2: Indigenous status completeness (%) in NNDSS, in relation to CDNA targets, by VPD and year, Australia, 2010–2019

Indigenous status completeness target	Vaccine preventable disease	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
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	97	98	96	98
	Diphtheria	NC ^a	100 ^b	NC ^a	67 ^b	100 ^b	100 ^b	75 ^b	100 ^b	100	100 ^b
	Hepatitis B (unspecified)	51	48	52	53	51	50	56	60	62	59
80%	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 ^c	62	67	59	74	71	75	79	73	68	75
	Rubella	95	86	86	88	94	88	88	100	78 ^b	95
	Tetanus	100 ^b	100 ^b	86 ^b	75 ^b	67 ^b	100 ^b	100 ^b	100 ^b	100 ^b	100 ^b

a NC: no cases.

b Notification number < 10.

c New South Wales, Tasmania, South Australia, Western Australia, the Northern Territory and Queensland reported rotavirus to the NNDSS for the full 2010–2019 period; the Australian Capital Territory reported from January 2018 and Victoria from August 2018.

Table A.3: Proportions and notifications of known, ‘not stated’ and ‘not provided’ Indigenous status in VPD notifications,^a by jurisdiction, Australia, 2010–2019

Jurisdiction	Indigenous status					
	Known		Not stated (Code 9)		No information provided ('NULL'/blank)	
	n	%	n	%	n	%
Australian Capital Territory	11,700	62	2,121	11	5,112	27
New South Wales	192,906	41	62,114	13	212,245	45
Northern Territory	14,189	98	321	2	0	0
Queensland	187,957	60	124,835	40	17	0 (0.01)
South Australia	114,776	78	32,767	22	0	0
Tasmania	3,749	21	13,870	79	3	0 (0.02)
Victoria	76,722	30	176,402	70	0	0
Western Australia	90,071	91	612	1	8,112	8
Australia	692,070	52	413,042	31	225,489	17

a VPDs included: diphtheria, *Haemophilus influenzae* type b, hepatitis A, hepatitis B (newly acquired), hepatitis B (unspecified), influenza, measles, meningococcal disease (invasive), mumps, pertussis, pneumococcal disease, rotavirus, tetanus.