

# **Health Protection NSW**

# **New South Wales RHD Program Surveillance and Register Report**

2016 - 2018



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# **Executive summary**

#### **ARF and RHD notifications**

- There were 67 notifications of acute rheumatic fever (ARF) and 70 notifications of rheumatic heart disease (RHD) made in NSW between 1 January 2016 and 31 December 2018.
- The average crude rate of notification for ARF was 0.3 cases per 100,000 population per year. The rate of ARF notification increased from 0.2 cases per 100,000 population in 2016 and 2017 to 0.4 in 2018 probably due to improvements in case finding and notification.
- The average crude rate of notification for RHD was 0.7 cases per 100,000 population per year in people aged less than 35 years of age.
- The majority of cases were in children and young adults with more than 84 per cent of ARF notifications and 74 per cent of RHD notifications in people aged less than 25 years of age.
- As reported by other Australian states and territories<sup>1</sup>, Aboriginal and Torres Strait Islander people were at substantially higher risk of both ARF and RHD. The average crude rate of notification of ARF in Aboriginal and Torres Strait Islander people was more than 20 times higher than for non-Indigenous people and 10 times higher for RHD.
- Unlike other places in Australia<sup>1</sup>, NSW has a higher proportion of cases in other at risk groups. People reporting Maori and Pacific Island ancestry represented 34 per cent of cases of ARF and 41 per cent of cases of RHD.
- Cases were distributed across both metropolitan and rural and regional local health districts (LHD) in NSW.
   Aboriginal and Torres Strait Islander cases were more commonly reported from rural and regional LHDs. Most cases in people reporting Maori and Pacific Island ancestry reside in metropolitan LHDs.
- Unlike ARF, the highest proportion of cases of RHD was in people reporting Maori and Pacific Island ancestry.
   This may indicate missed diagnosis and the opportunity for secondary prophylaxis has resulted in poorer health outcomes in this population.

#### **RHD Register**

- One hundred and four individuals eligible for inclusion on the NSW RHD Register were identified between the
  establishment of the Register on 20 May 2016 and 31 December 2018, including cases notified prior to the
  establishment of the register and cases not notifiable in NSW. Of these, 54 have provided consent to be included
  on the Register.
- People reporting Aboriginal and Torres Strait Islander (64 per cent) and Maori and Pacific Island ancestry (55 per cent) had the highest proportion of people providing consent. Less than 40 per cent of other groups provided consent for the Register.
- Ninety-one per cent of people on the Register had been prescribed benzathine penicillin G (BPG) for secondary prophylaxis in NSW. The remaining people were either on oral antibiotics or no longer receiving secondary prophylaxis.
- About 50 per cent of people received more than 80 per cent of their scheduled doses of BPG and between 25 30 per cent of cases received less than 50 per cent of their scheduled doses. These proportions remained stable over time.

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<sup>&</sup>lt;sup>1</sup> Australian Institute of Health and Welfare. 2018. *Better Cardiac Care measures for Aboriginal and Torres Strait Islander people: third national report 2017.* Canberra: Australian Institute of Health and Welfare.



# Methodology

## **Notifiable Diseases Data**

ARF in people of any age, and RHD in people aged less than 35 years are notifiable diseases in NSW. They were added to the list of notifiable diseases on 2 October 2015. Notifications of ARF and RHD are based on clinical reports made by doctors and supplemented by active case finding through review of hospitalisation data for ARF and RHD. Notifications received by NSW Health are held in the Notifiable Conditions Information Management System (NCIMS). NCIMS contains epidemiological information, including name, address, sex, date of birth, country of birth, ancestry, Aboriginal and Torres Strait Islander status and date of symptom onset.

This report was produced using data extracted from NCIMS on 17 July 2019. Data was reported by notification date from 1 January 2016 to 31 December 2018. LHD was reported based on place of residence at notification. Country of birth and ancestry is based on the ABS Standard Australian Classification of Countries (1269.0). People from the Pacific Islands were defined as those from Melanesia, Micronesia and Polynesia, excluding Papua New Guinea.

Crude notification rates were calculated using population denominators obtained from the ABS Population by Age and Sex Regions of Australia 2016 (3235.0 28 Aug 2017) and DPE 2011 ASGS LGA & LHD rounded/unrounded projections (20 Jul 2016). Rates for ARF were calculated using the entire population as the denominator. For RHD, the rates were calculated with the same denominator limited to people aged 0-34 years. Population denominators by year, sex, age and state for Aboriginal and Torres Strait Islander people were obtained from ABS catalogue Estimates and Projections, Aboriginal and Torres Strait Island Australians (3238.0).

High-risk groups are those living in communities with high rates of ARF (incidence >30/100,000 per year in 5–14 year olds) or RHD (all-age prevalence >2/1000). In NSW, Aboriginal people and Torres Strait Islanders people, people reporting Maori and Pacific Island ancestry, and immigrants from countries with an RHD prevalence greater than 2 per 1000 population are considered high risk for ARF and RHD.

# **RHD Register Data**

NSW Health established a voluntary register for people diagnosed with ARF and RHD on 20 May 2016. This Register aims to support patients, their families and their healthcare providers to manage the long-term preventive treatment and clinical reviews required to prevent further ARF episodes and cardiac complications. Information on the follow-up and outcomes of people on the Register is collected, including the dates and type of secondary prophylaxis received, dates of visits to specialists and dentists, dates echocardiograms are performed, dates of hospitalisations, surgery dates and types and information on deaths in people on the Register. Register data is also recorded in NCIMS. Cases notified prior to 20 May 2016 are eligible for inclusion on the Register, as are people who move from interstate or overseas who may not be included in the notifiable diseases data.

This report was produced using data extracted from NCIMS on 17 July 2019. People notified or referred to the Register prior to 31 December 2018 were included. People were considered to have consented to the Register if consent had been received by 31 March 2019.

LHD of residence, country of birth and high risk groups were as defined for notifiable diseases data.

# Compliance with benzathine penicillin G (BPG) prophylaxis

BPG is a long-acting antibiotic used to treat bacterial infections. For patients diagnosed with ARF and RHD, it is the recommended agent for secondary prophylaxis and given every 21-28 days to prevent group A streptococcal

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infections and repeat episodes of ARF. The recommended duration of secondary prophylaxis is 10 years or until the person is aged 21 years. Patients may also receive oral penicillin or erythromycin if they are unable to tolerate BPG injections. The proportion of doses of BPG received was based on the number of observed doses received divided by the expected number of doses during a 12 month period or part thereof. The expected number of doses was calculated by rounding down to the nearest number of doses during the period of observation based on a 28 day cycle for patients on a standard schedule. For patients receiving secondary prophylaxis at an increased frequency, a 21 day cycle was used to calculate the expected number of doses. For each year the start date for each patient was either 1 January, the date they consented to the register or the date they were prescribed BPG for patients who had previously been receiving oral penicillin. For each year, the end date for each patient was either 31 December, the date they withdrew consent for the Register, the date they left NSW, the date they commenced oral prophylaxis or the date they were no longer prescribed secondary prophylaxis.

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# **Notifiable Diseases Data**

### **Acute Rheumatic Fever**

#### Acute rheumatic fever notifications

Number of notifications

A total of 67 cases of ARF were notified in NSW between 1 January 2016 and 31 December 2018 (Figure 1). Twentynine cases were notified in 2018, compared to 19 cases in 2017.

The median number of cases per quarter was 4.5 (range, 3 to 13), and was highly influenced by active case finding (Figure 1). The average crude notification rate was 0.3 cases per 100,000 population per year.

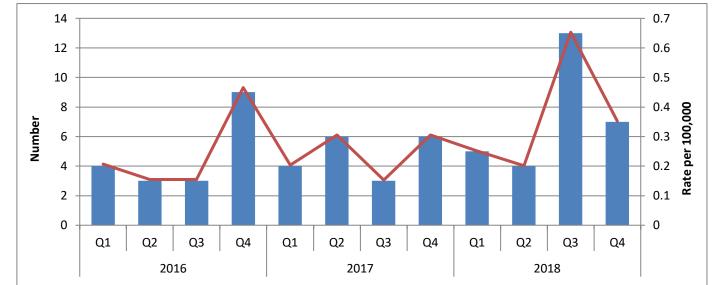


Figure 1: Number and crude rate of notification of ARF by quarter, 2016 - 2018

Western Sydney LHD reported the highest number of cases (25), followed by Hunter New England LHD (9) and Western NSW LHDs (8) (Table 1). Western NSW and Western Sydney LHDs had the highest average crude rates of notification (0.9 per 100,000), followed by Northern NSW LHD (0.6 per 100,000).

Quarter of notification

Crude rate per 100 000

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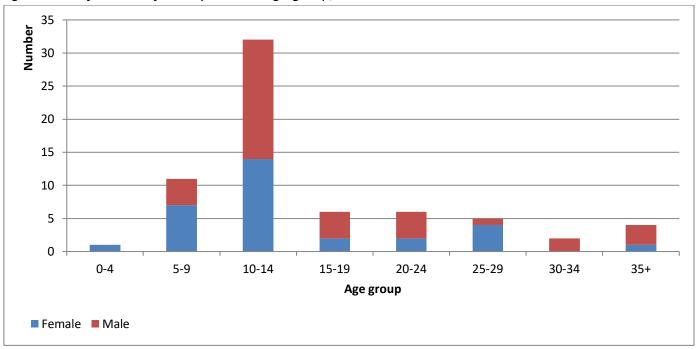
Table 1: Number of ARF notifications by NSW LHD of residence at notification, 2018 compared to 2017 and the average crude notification rate per 100,000 population per year, 2016 to 2018

Local Health District	2018	2017	Total	Average crude rate
			2016-2018	per 100,000
Western Sydney	11	8	25	0.9
Hunter New England	8	1	9	0.3
Western NSW	2	1	8	0.9
South Western Sydney	3	1	8	0.3
Northern NSW	1	4	5	0.6
Northern Sydney	2	0	3	0.1
Mid North Coast	0	1	2	0.3
Murrumbidgee	1	1	2	0.3
Nepean Blue Mountains	0	1	2	0.2
Central Coast	0	0	1	0.1
Illawarra Shoalhaven	0	1	1	0.1
South Eastern Sydney	1	0	1	0.0
Far West NSW	0	0	0	
Southern NSW	0	0	0	
Sydney	0	0	0	
NSW Total	29	19	67	0.3

# **Demographics**

The median age at diagnosis was 13 years, and 84 per cent of notifications were in people aged less than 25 years (Figure 2). Fifty-four per cent of cases were male.

Figure 2: Notifications of ARF by sex and age group, 2016 - 2018



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# NSW GOVERNMENT

## **NSW RHD Program Surveillance and Register Report**

#### **Risk factors**

Forty-three per cent of ARF cases in NSW occurred in Aboriginal and Torres Strait Islander people (Table 2).

Hunter New England LHD and Western NSW LHDs reported the highest number of notifications of ARF in Aboriginal and Torres Strait Islander people (8), followed by Northern NSW LHD (5). The highest rate of notification in Aboriginal and Torres Strait Islander people occurred in Northern NSW LHD (11.0 per 100,000), followed by Western NSW LHD (8.1 per 100,000) and Hunter New England LHD (5.0 per 100,000).

Table 2: Number of ARF notifications and crude notification rate by NSW LHD of residence at notification and Indigenous status, 2016 - 2018

Local Health District	Aboriginal and Torres Strait Islander	Non-Indigenous	Total	Crude rate Aboriginal and Torres Strait Islander
Western Sydney	1	24	25	2.2
Hunter New England	8	1	9	5.0
Western NSW	8	0	8	8.1
South Western Sydney	1	7	8	1.9
Northern NSW	5	0	5	11.0
Northern Sydney	0	3	3	
Mid North Coast	2	0	2	4.9
Murrumbidgee	1	1	2	2.7
Nepean Blue Mountains	1	1	2	2.8
Central Coast	1	0	1	2.7
Illawarra Shoalhaven	0	1	1	
South Eastern Sydney	1	0	1	3.8
Far West NSW	0	0	0	
Southern NSW	0	0	0	
Sydney	0	0	0	
NSW Total	29	38	67	4.2

The average crude notification rate in Aboriginal and Torres Strait Islander people (4.2 per 100,000) was more than 20 times greater than the rate in non-Indigenous people (0.2 per 100,000). The crude rate of notification appeared to be increasing in both Aboriginal and Torres Strait Islander and non-Indigenous population. This likely reflects improvements to case finding and notification rather than an increase in incidence (Table 3).

Table 3: Crude rate of notification per 100,000 population of ARF by Indigenous status and year, 2016 - 2018

Year	•	nd Torres Strait ander	Non-Indigenous		Total	
	Number	Notification rate	Number	Notification rate	Number	Notification rate
2016	8	3.5	11	0.1	19	0.2
2017	8	3.5	11	0.1	19	0.2
2018	13	5.7	16	0.2	29	0.4

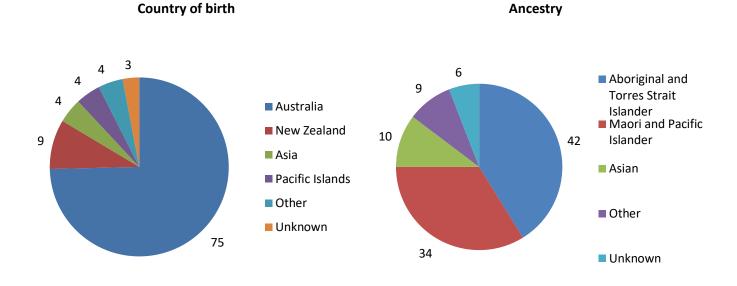
At the time of reporting, country of birth was complete for 97 per cent of cases and ancestry for 94 per cent (Figure 3). Australia was the most commonly reported country of birth (75 per cent), followed by New Zealand (9 per cent), Pacific Island countries and countries in Asia (4 per cent). Over 88 per cent of cases came from populations considered at high risk of RHD: 42 per cent in Aboriginal and Torres Strait Islander people, 34 per cent in people

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reporting Maori and Pacific Islander ancestry, and 12 per cent in people from other countries with a high RHD prevalence.

Figure 3: Proportion of ARF notifications by country of birth and ancestry, 2016 - 2018



The majority of people diagnosed with ARF identifying as an Aboriginal and Torres Strait Islander person lived in regional and remote LHDs (83 per cent). By contrast, 95 per cent of people reporting Maori and Pacific Islander ancestry lived in metropolitan LHDs (Table 4).

Table 4: Number of ARF notifications by NSW LHD of residence and ancestry, 2016 - 2018

Local Health District	Aboriginal and Torres Strait	Maori and Pacific Islander	Other	Unknown	Total
	Islander people	people			
Western Sydney*	1	15	8	2	25
Hunter New England	8	0	1	0	9
Western NSW	8	0	0	0	8
South Western Sydney	0	5	1	2	8
Northern NSW	5	0	0	0	5
Northern Sydney	0	1	2	0	3
Mid North Coast	2	0	0	0	2
Murrumbidgee	1	1	0	0	2
Nepean Blue Mountains	1	1	0	0	2
Central Coast	1	0	0	0	1
Illawarra Shoalhaven	0	0	1	0	1
South Eastern Sydney	1	0	0	0	1
Far West NSW	0	0	0	0	0
Southern NSW	0	0	0	0	0
Sydney	0	0	0	0	0
NSW Total*	28	23	13	4	67

<sup>\*</sup> One person identified as both Aboriginal and Torres Strait Islander and Maori and Pacific Islander

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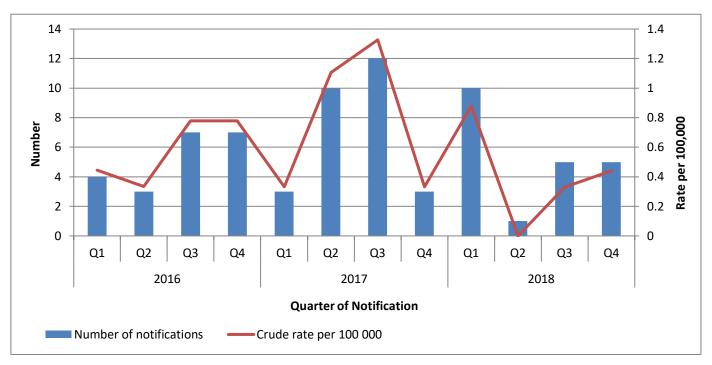
### **Rheumatic Heart Disease**

#### Rheumatic heart disease notifications

A total of 70 cases of RHD were notified in NSW between 1 January 2016 and 31 December 2018 (Figure 4). Twenty-one cases were notified in 2018, compared to 28 cases in 2017.

The median number of cases per quarter was five (range, 1 to 12) and was highly influenced by active case finding (Figure 4). The average crude notification rate was 0.7 cases per 100,000 population per year.

Figure 4: Number and crude rate of notification of RHD in people aged less than 35 years by quarter, 2016 - 2018



Western Sydney LHD reported the highest number of cases (23), followed by South Western Sydney LHD (16) and Mid North Coast LHD (6) (Table 5). Mid North Coast LHD had the highest average crude rate of notification (2.4 per 100,000), followed by Western Sydney (1.5 per 100,000) and Western NSW LHD (1.3 per 100,000).

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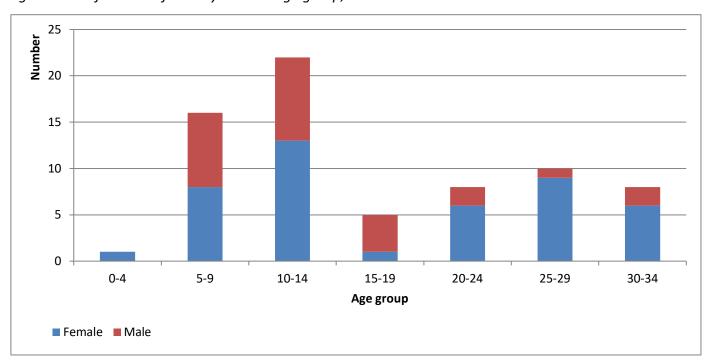
Table 5: Number of RHD notifications by NSW LHD of residence, 2018 compared to 2017 and the average crude notification rate per 100,000 population per year, 2016 to 2018

Local Health District	2018	2017	Total	Average crude rate
			2016-2018	per 100,000
Western Sydney	7	7	23	1.5
South Western Sydney	4	8	16	1.1
Mid North Coast	1	5	6	2.4
Hunter New England	1	2	5	0.4
Western NSW	1	1	5	1.3
South Eastern Sydney	3	0	4	0.3
Northern NSW	0	3	3	0.9
Illawarra Shoalhaven	2	0	2	0.4
Murrumbidgee	1	1	2	0.6
Nepean Blue Mountains	0	1	2	0.4
Northern Sydney	1	0	2	0.2
Central Coast	0	0	0	
Far West NSW	0	0	0	
Southern NSW	0	0	0	
Sydney	0	0	0	
NSW Total	21	28	70	0.6

# **Demographics**

The median age at diagnosis was 12.5 years, and was higher in women (16.5 years) than men (11 years). Seventy-four per cent of notifications were in people aged less than 25 years (Figure 2). By contrast to ARF, only 37 per cent of cases were male. This may reflect RHD being identified in women during pregnancy.

Figure 5: Notifications of RHD by sex and age group, 2016 to 2018



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#### **Risk factors**

Thirty-four per cent of RHD cases in NSW occurred in Aboriginal and Torres Strait Islander people (Table 6).

Mid North Coast and Hunter New England LHDs reported the highest number of notifications of RHD in Aboriginal and Torres Strait Islander people (5), followed by Western NSW LHD (4). The highest rate of notification in Aboriginal and Torres Strait Islander people occurred in Mid North Coast LHD (17.9 per 100,000), followed by Northern NSW LHD (9.7 per 100,000) and Western Sydney LHD (6.2 per 100,000).

Table 6: Number of RHD notifications and crude average notification rate in people aged less than 35 year by NSW LHD of residence at notification and Indigenous status, 2016 - 2018

Local Health District	Aboriginal and Torres Strait Islander people	Non- Indigenous	Total	Crude rate Aboriginal and Torres Strait Islander people
Western Sydney	2	21	23	6.2
South Western Sydney	1	15	16	2.9
Mid North Coast	5	1	6	17.9
Hunter New England	5	0	5	4.6
Western NSW	4	1	5	6.0
South Eastern Sydney	1	3	4	5.8
Northern NSW	3	0	3	9.7
Illawarra Shoalhaven	1	1	2	3.5
Murrumbidgee	1	1	2	3.9
Nepean Blue Mountains	1	1	2	4.1
Northern Sydney	0	2	2	
Central Coast	0	0	0	
Far West NSW	0	0	0	
Southern NSW	0	0	0	
Sydney	0	0	0	
NSW Total	24	46	70	5.1

The average crude notification rate of RHD in Aboriginal and Torres Strait Islander people (5.1 per 100,000) was more than 10 times greater than the rate in non-Indigenous people (0.5 per 100,000). Total notification rates and rates in non-Indigenous people have remained stable over the three year period, but vary in Aboriginal and Torres Strait Islander people due to small numbers of notifications (Table 7).

Table 7: Crude rate of notification per 100,000 population of RHD in people aged less than 35 years by Indigenous status and year, 2016 - 2018

Year	~	d Torres Strait nder	Non-Indigenous		То	otal
	Number	Notification	Number	Notification	Number	Notification
		rate		rate		rate
2016	5	3.2	16	0.5	21	0.6
2017	12	7.6	16	0.5	28	0.8
2018	7	4.5	14	0.4	21	0.6

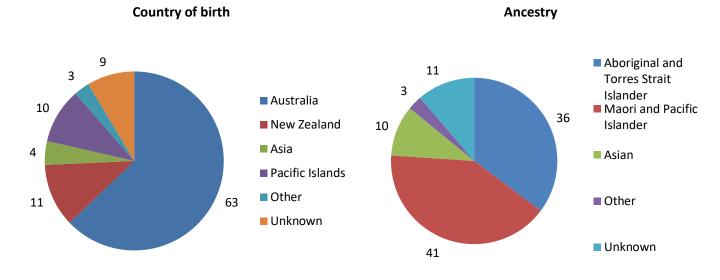
At the time of reporting, country of birth had been collected for 91 per cent of cases and ancestry for 89 per cent (Figure 6). Australia was the most commonly reported country of birth (63 per cent), followed by New Zealand (11 per cent), the Pacific Islands (10 per cent) and Asian countries (4 per cent). However, over 85 per cent of cases came from populations considered at high risk of RHD: 36 per cent in Aboriginal and Torres Strait Islander people, 41 per

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cent in people reporting Maori and Pacific Islander ancestry and 11 per cent in people from countries with a high RHD prevalence. Unlike ARF, the highest proportion of RHD cases was in people reporting Maori and Pacific Island ancestry.

Figure 6: Proportion of notifications of RHD by country of birth and ancestry, 2016 - 2018



The majority of cases diagnosed with RHD (79 per cent) identifying as Aboriginal and Torres Strait Islander people lived in regional and remote LHDs. By contrast, 96 per cent of cases reporting Maori and Pacific Islander ancestry lived in metropolitan LHDs (Table 8).

Table 8: Number of RHD notifications by NSW LHD of residence at notification and ancestry, 2016 - 2018

Local Health District	Aboriginal and	Maori and	Other	Unknown	Total
	<b>Torres Strait</b>	<b>Pacific Islander</b>			
	Islander people	people			
Western Sydney*	3	19	2	0	23
South Western Sydney	1	5	4	6	16
Mid North Coast	5	0	1	0	6
Hunter New England	5	0	0	0	5
Western NSW	4	1	0	0	5
South Eastern Sydney	1	1	1	1	4
Northern NSW	3	0	0	0	3
Illawarra Shoalhaven	1	0	0	1	2
Murrumbidgee	1	1	0	0	2
Nepean Blue Mountains	1	1	0	0	2
Northern Sydney	0	1	1	0	2
Central Coast	0	0	0	0	0
Far West NSW	0	0	0	0	0
Southern NSW	0	0	0	0	0
Sydney	0	0	0	0	0
NSW Total	25	29	17	8	70

<sup>\*</sup> One person identified as both Aboriginal and Torres Strait Islander and Maori and Pacific Islander

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# **RHD Register Data**

# **Enrolment**

There were 114 individuals with ARF or RHD identified by the Register in NSW to 31 December 2018 (Table 9). They included all people notified in NSW from 1 October 2015 and people referred to the Register from other jurisdictions. Of these, 104 were considered eligible for enrolment on the NSW RHD Register. Fifty-four (52 per cent) people have provided consent to be included on the Register to date. Ten people (10 per cent) either refused to provide consent for the Register or were lost to follow-up. Consent for the Register was outstanding for the remaining 40 (38 per cent) people.

Table 9: Number and percentage of people eligible for enrolment on the NSW RHD Register by consent status and total number of people identified, by LHD of residence, by 31 December 2018

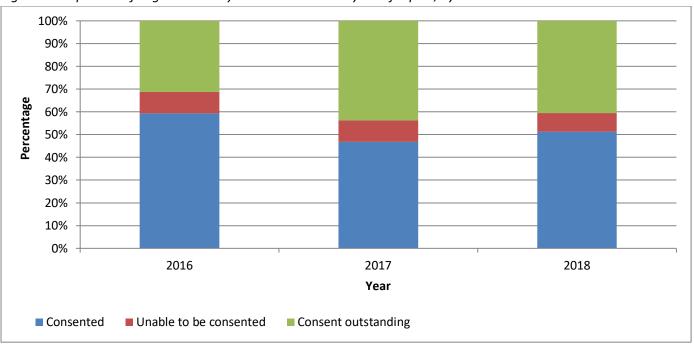
Local Health District		No. (%)	No. (%)	unable	No.	(%) with	Total eligible	Total
	cor	nsented		to be		consent	for register	
			cons	ented*	outs	standing		
Western Sydney	19	(58)	5	(15)	9	(27)	33	34
South Western Sydney	4	(18)	1	(5)	17	(77)	22	22
Hunter New England	10	(91)	0	(0)	1	(9)	11	13
Western NSW	9	(82)	0	(0)	2	(18)	11	13
Mid North Coast	5	(71)	1	(14)	1	(14)	7	7
Northern NSW	1	(17)	1	(17)	4	(67)	6	7
Northern Sydney	2	(100)	0	(0)	0	(0)	2	4
South Eastern Sydney	2	(67	0	(0)	1	(33)	3	4
Illawarra Shoalhaven	1	(33)	2	(67)	0	(0)	3	3
Murrumbidgee	0	(0)	0	(0)	3	(100)	3	3
Nepean Blue Mountains	1	(33)	0	(0)	2	(67)	3	3
Central Coast	0	(0)	0	(0)	0	(0)	0	1
Far West NSW	0	(0)	0	(0)	0	(0)	0	0
Southern NSW	0	(0)	0	(0)	0	(0)	0	0
Sydney	0	(0)	0	(0)	0	(0)	0	0
Total	54	(52)	10	(10)	40	(38)	104	114

<sup>\*</sup> People unable to be consented to the register included six people who refused to provide consent, three people whose primary care doctor refused to talk to them about the NSW RHD Register and one person who was lost to follow-up.

The proportion of people consented for the register declined over time from 59 per cent in 2016 to 51 per cent in 2018 (Figure 7). The proportion of people with consent outstanding increased correspondingly from 31 per cent in 2016 to 41 per cent in 2018, indicating there was a delay in people being consented to the Register. Western Sydney LHD (19) had the highest number of cases consented to the Register. Northern Sydney (100 per cent), Hunter New England (91 per cent) and Western NSW (82 per cent) had highest proportions of people consented to the Register.

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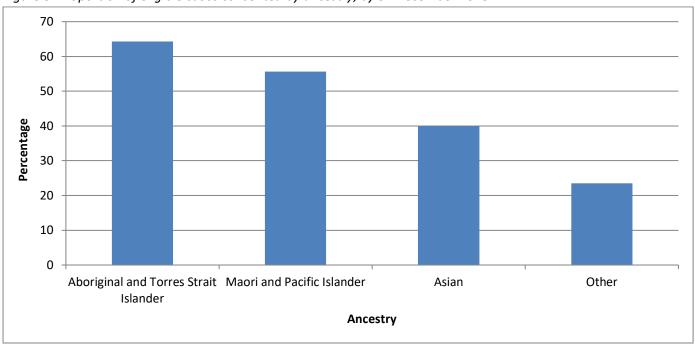
Figure 7: Proportion of eligible cases by consent status and year of report, by 31 December 2018\*



<sup>\*</sup> Data from 2015 not shown due to the small case count.

Aboriginal and Torres Strait Islander people had the highest rate of consent (64 per cent) followed by people reporting Maori and Pacific Island ancestry (Figure 8). Less than 40 per cent of the remaining people provided consent for the Register.

Figure 8: Proportion of eligible cases consented by ancestry, by 31 December 2018



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Cases were most likely to be consented to the Register close to the time they were first identified by the Register. The median time to consent ranged from 1 to 95 days following identification by the Register.

Table 10: Number of eligible cases providing consent and median and interquartile range in days to provide consent for the NSW RHD Register by year of notification, 20 May 2016-31 December 2018

Year	Number	Median days to consent	Quartile 1	Quartile 3
2016*	19	95	5	355
2017	15	78	0	349
2018	19	1	0	38

<sup>\*</sup> Includes people reported prior to the establishment of the Register on 20 May 2016.

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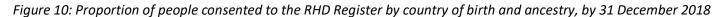
# **Demographics**

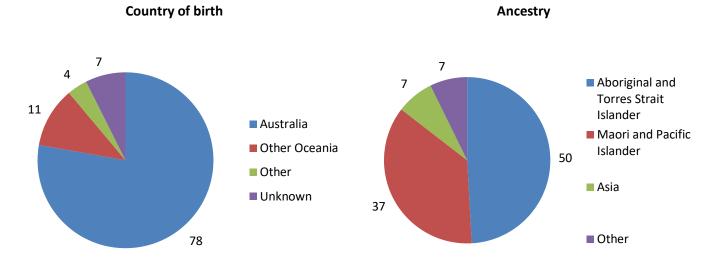
Half of the cases (50 per cent) providing consent for the NSW RHD Register were male. Over 90 per cent of people were aged less than 25 years at the time of enrolment (Figure 10).

30 Number 25 20 15 10 5 0 0-4 5-9 10-14 25-29 30-34 15-19 20-24 35+ Age group ■ Female ■ Male

Figure 9: Number of people consented to the RHD Register by age group and sex, by 31 December 2018

The majority (78 per cent) of people were born in Australia (Figure 11) with a further 11 per cent of people born in other countries in Oceania (Figure 11). Most people were from high risk populations: Aboriginal and Torres Strait Islander (50 per cent), Maori and Pacific Islander (37 per cent) and countries in Asia with high RHD prevalence (7 per cent).





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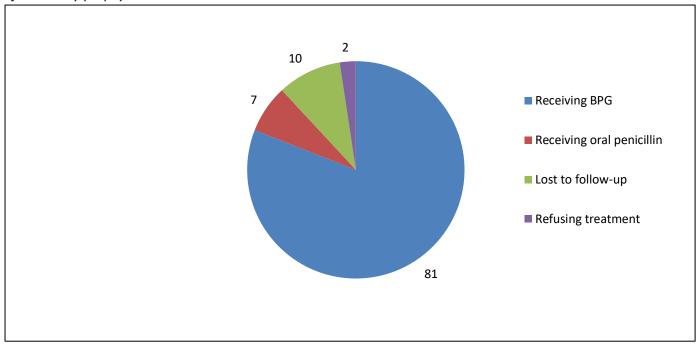




# Follow-up

Seventy-eight per cent of people on the Register were currently receiving secondary prophylaxis in NSW, 7 per cent had left NSW and 15 per cent had not been prescribed secondary prophylaxis while on the NSW RHD Register. Of the 42 people currently being prescribed secondary prophylaxis, the majority (34) were receiving BPG, three were receiving oral prophylaxis, four were lost to follow-up and one person was refusing treatment (Figure 11).

Figure 11: Proportion of people consented to the NSW RHD Register prescribed secondary prophylaxis in NSW by type of secondary prophylaxis received on 31 December 2018



The majority of people in NSW (94 per cent) received their follow-up through primary care services: 48 per cent went to general practitioners, 35 per cent went to Aboriginal Community Controlled Health Services and 10 per cent were managed by Community Health services (Figure 12).

Of the 54 people on the NSW Register, 49 had been prescribed BPG for secondary prophylaxis in NSW. The proportion of people receiving more than 80 per cent of their BPG doses was approximately 50 per cent. This proportion remained stable over time (Figure 13). The proportion of people receiving less than 50 per cent of doses also remained static at approximately 25 per cent of cases. The median proportion of doses was stable at over 80 per cent (Table 11).

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Figure 12: Proportion of people on the NSW RHD Register by type of health service attended for follow-up, 1 January 2016-31 December 2018

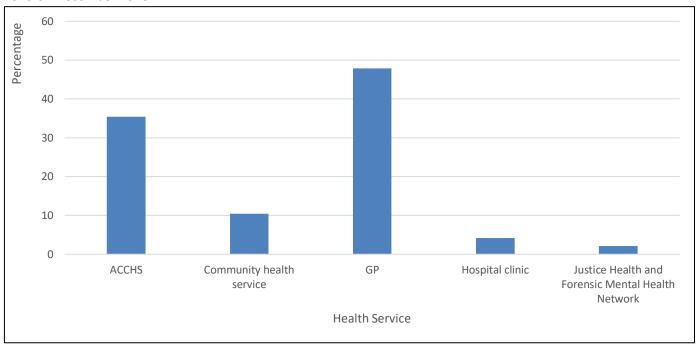
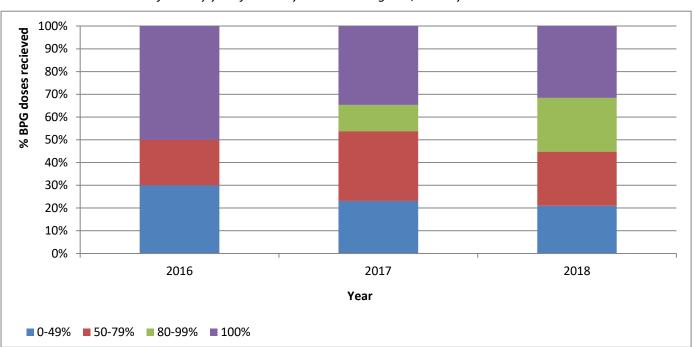


Figure 13: Proportion of BPG doses received for people consented to the NSW RHD Register prescribed BPG due to receive at least one dose of BPG by year for each year on the Register, 20 May 2016-31 December 2018



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Table 11: Number of people on the RHD Register prescribed BPG due to receive at least one dose of BPG and median proportion of doses received by year, 20 May 2016-31 December 2018

Year	Number	Median proportion of doses received		
2016	10	83	39	100
2017	26	81	47	100
2018	38	80	50	98

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# **Glossary**

ARF: Acute rheumatic fever

ARF is an acute illness caused by a generalised inflammatory response to group A Streptococcal infection. The inflammatory response targets specific parts of the body, including joints, skin, brain and heart.

**BPG:** Benzathine penicillin G

BPG is a long-acting antibiotic used to treat bacterial infections. For patients diagnosed with ARF and RHD, it the recommended agent for secondary prophylaxis and given every 21-28 days to prevent group A streptococcal infections and repeat episodes of ARF.

LHD: Local Health District

NSW Health is managed by eight metropolitan LHD, seven rural and regional LHD and three Specialty Networks. They were established to operate public hospitals and institutions and provide health services to communities within geographical areas or a defined patient population for Specialty Networks.

NCIMS: Notifiable Conditions Information Management System

NCIMS is a confidential application used to manage the surveillance and reporting of diseases and conditions notifiable under the NSW Public Health Act 2010.

RHD: Rheumatic heart disease

RHD is the permanent impairment of heart valves caused by an episode of ARF.

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# **RHD Network**

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