

Rheumatic Heart Disease Prophylaxis in Older Patients: A Register-Based Audit of Adherence to Guidelines

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Background. Prevention of rheumatic heart disease (RHD) remains challenging in high-burden settings globally. After acute rheumatic fever (ARF), secondary antibiotic prophylaxis is required to prevent RHD. International guidelines on recommended durations of secondary prophylaxis differ, with scope for clinician discretion. Because ARF risk decreases with age, ongoing prophylaxis is generally considered unnecessary beyond approximately the third decade. Concordance with guidelines on timely cessation of prophylaxis is unknown.

Methods. We undertook a register-based audit to determine the appropriateness of antibiotic prophylaxis among clients aged ≥ 35 years in Australia's Northern Territory. Data on demographics, ARF episode(s), RHD severity, prophylaxis type, and relevant clinical notes were extracted. The determination of guideline concordance was based on whether (1) national guidelines were followed; (2) a reason for departure from guidelines was documented; (3) lifelong continuation was considered appropriate in all cases of severe RHD.

Results. We identified 343 clients aged ≥ 35 years prescribed secondary prophylaxis. Guideline concordance was 39% according to national guidelines, 68% when documented reasons for departures from guidelines were included and 82% if patients with severe RHD were deemed to need lifelong prophylaxis. Shorter times since last echocardiogram or cardiologist review were associated with greater likelihood of guideline concordance ($P < .001$). The median time since last ARF was 5.9 years in the guideline-concordant group and 24.0 years in the nonconcordant group ($P < .001$). Thirty-two people had an ARF episode after age 40 years.

Conclusions. In this setting, appropriate discontinuation of RHD prophylaxis could be improved through timely specialist review to reduce unnecessary burden on clients and health systems.

Keywords. benzathine penicillin G; rheumatic fever; rheumatic heart disease; secondary prophylaxis.

Rheumatic heart disease (RHD) is characterized by immunological destruction of cardiac valves in the setting of episodes of acute rheumatic fever (ARF). ARF episodes occur after exposure to particular strains of the bacterium *Streptococcus pyogenes* (group A streptococcus [GAS]). Most episodes of ARF occur in children between age 5 and 14 years, but they may also occur well into adulthood [1]. Secondary antibiotic prophylaxis has been shown to reduce the risk of ARF recurrences and the development or worsening of RHD [2–4], with intramuscular benzathine penicillin G (BPG) having the most evidence for effectiveness [5]. Much work has been done aiming to improve adherence to BPG injections, especially in Australian Indigenous populations that are disproportionately affected by the disease [6–9]. Notwithstanding this, there are also potentially a number

of clients actually receiving secondary prophylaxis for whom it may no longer be indicated.

The Australian ARF/RHD [10] guideline provides recommendations on duration of prophylaxis depending on time since most recent ARF and severity of RHD. Table 1, adapted from this guideline, summarizes these. Other factors such as living circumstances, estimated local community incidence of GAS infection, presence and severity of carditis during the ARF episode(s), and prior adherence to prophylaxis may influence a clinician's decision about whether to continue penicillin [10].

The consequences of unnecessary continuation of BPG after an age at which ARF risk has fallen can be categorized into patient, health care system, and antimicrobial stewardship factors. Patient factors include the time and commitment required to attend the clinic every 28 days and adverse effects such as administration pain and injection site reactions [11]. Health care system factors include the cost of the injection itself, and the opportunity cost for staff who must dedicate substantial time to patient care including maintaining up-to-date recall systems and administering the injections, potentially detracting from their ability to deliver care to those at higher risk. Antimicrobial stewardship factors include the adverse effects of regular antibiotic administration on the host microbiome (although penicillin G is very narrow-spectrum),

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including the potential for promotion of resistance among colonizing staphylococci, pneumococci, and other organisms.

Clinicians are required to make decisions about the ongoing need for RHD prophylaxis on the basis of guideline recommendations and a subjective assessment of the risk–benefit profile in individual patients. We undertook this audit in the high-burden setting of Australia’s Northern Territory (NT), using the NT RHD Register. Our aims were to determine the proportion of prophylaxis prescriptions that were guideline-concordant in the ≥35 years age group, to ascertain determinants of nonconcordance, and to provide actionable data back to the NT RHD control program.

METHODS

Study Design, Population, and Setting

This is a register-based, cross-sectional, descriptive study. All clients age 35 years and older on secondary prophylaxis with penicillin, or an alternative antibiotic, were identified from the NT RHD Register on July 10, 2017, and relevant client demographic and clinical data were extracted. Further clinical information including any documented reasons for prophylaxis continuation was obtained from the register between July 10 and August 3, 2017. The age of 35 years was chosen as the cutoff point for analysis as, per Australian Guidelines, most patients with RHD can cease prophylaxis by that age unless disease is severe or there has been an episode of ARF in the previous 10 years.

Ethical Approval

This project was approved as a low-risk audit by the chair of the Human Research Ethics Committee (HREC) at the NT Department of Health and Menzies School of Health Research (reference number HREC 2017–2909).

Definitions and Guidelines

ARF episodes were defined as definite, probable, or possible cases. Definite cases fulfilled the Revised Jones Criteria [12] with alternative diagnoses excluded. The Australian guidelines describe “probable” and “possible” ARF as clinical presentations

that fall short by either 1 major or 1 minor manifestation, or the absence of streptococcal serology results, but in which ARF is considered the most likely diagnosis [13]. Three “priority” categories of RHD are recognized for programmatic and clinical purposes [10]: priority 1 (severe RHD), priority 2 (moderate RHD), and priority 3 (mild RHD or ARF alone without RHD). Further definitions of these priority groups and their corresponding recommended durations of secondary prophylaxis are shown in Table 1. Regarding prophylaxis duration for RHD priority 1 patients, the guidelines provide some scope for clinician discretion, stating, “Continue prophylaxis until age 40 years, or longer” [10]. The choice to continue for longer is based on disease severity, the level of cardiac risk posed should another ARF episode occur, and the likelihood of ARF recurrence based on host and environmental factors. The recommended form of secondary prophylaxis is BPG; oral erythromycin is used in the instance of penicillin intolerance.

Data Collection and Assessment

Data for this study were extracted from the NT RHD Register, which is a centralized database maintained by staff at the NT RHD Control Program, NT Government Department of Health. ARF is a notifiable disease in the NT; therefore there is almost complete capture of recognized cases. The NT RHD Register was established in 1997 when patient records held by health services and hospitals in the Top End of the NT were searched for all documented diagnoses of ARF and RHD. In 2001, a similar process was undertaken in the rest of the NT to establish a territory-wide database. Since then, data have been entered manually at the time of diagnosis or service provision, based on clinic letters, discharge summaries, echocardiography reports, and direct communication with clinicians. The data support long-term patient care and enable monitoring of ARF and RHD control strategies in the NT.

Client demographic data extracted directly from the register were patient unique identifier, date of birth, sex, age, ethnicity, RHD priority group, prophylaxis start date, and NT region.

Data collected manually from register records comprised date and age at most recent ARF episode (definite, probable, or

Table 1. Recommended Secondary Prophylaxis Duration, as per RHD Priority Category

Priority Category	Priority Category Definition	Duration of Secondary Prophylaxis
All patients		Minimum 10 y since last episode of ARF ^a
1	Severe RHD, previous valve repairs or prosthetic valves, or symptomatic moderate RHD	Until age 40 y (or longer ^b)
2	Moderate RHD (asymptomatic) with normal left ventricular function	Until age 35 y
3	Mild RHD or no RHD but on secondary prophylaxis after an episode of ARF	Until age 21 y or at least 10 y after last ARF, whichever is longer

Table adapted from Australian ARF/RHD guidelines, 2nd ed. [10].

Abbreviations: ARF, acute rheumatic fever; RHD, rheumatic heart disease.

^aWhere a diagnosis of RHD is made without knowledge of previous ARF, guidelines recommend continuation until age 35 years for patients who are older than age 25 years at the time of RHD diagnosis.

^bPriority 1 patients may be continued on secondary prophylaxis after age 40 years if a specialist deems that this is appropriate (eg, severe disease and risk of further ARF is considered to be high).

possible), form of secondary prophylaxis, last BPG injection, date of RHD diagnosis where applicable, last echocardiogram date, and results of last medical specialist (cardiologist or specialist physician) review. Additionally, specialist letters present in the register and comments entered by RHD Register staff were also searched for information relating to prophylaxis.

Calculation of Adherence to Guidelines

To measure guideline concordance, clients were analyzed according to the RHD priority category to which they were currently allocated in the register. If there was an obvious error in assignment of RHD priority category based on recent echocardiogram findings, such as a recent finding of severe valvular lesions necessitating categorization as priority 1, but the person was categorized as priority 2 or 3, then the priority categorization was amended. Any such corrections to the data were determined by consensus among the study investigators. The determination of guideline concordance was based on whether (1) the national guidelines were followed; (2) the national guidelines were followed, or a reason for departure from guidelines was documented; (3) the national guidelines were followed, or a reason for departure from guidelines was documented, or

lifelong continuation was considered appropriate in all cases of severe RHD. These separate calculations reflect that in addition to standard guidelines, clinical judgement is a consideration in individual decision-making regarding use of secondary prophylaxis, reflected in [Table 1](#).

Calculations and Statistical Analysis

Microsoft Excel (version 14.3.9) and Stata IC 14 (Stata, College Station, TX) were used for data entry and analysis. Figures were created using Microsoft Excel (2016). The Student *t* and Wilcoxon rank-sum tests were used to compare continuous variables, as appropriate, and the chi-square test was used for categorical variables. *P* values $\leq .05$ were considered statistically significant.

RESULTS

Three hundred forty-three clients were identified from the register who still had an active prescription for secondary prophylaxis and were aged ≥ 35 years ([Table 2](#)). Ninety-eight percent of clients were Australian Indigenous peoples of Aboriginal or Torres Strait Islander origin; 68% were female, and the median age (interquartile range) was 42 (37–48) years. BPG injections

Table 2. Characteristics of Study Population

	Priority Group			Total, No. (%)
	1	2	3	
No. of clients	191	56	96	343
No. with RHD	191	56	60	307 (90)
RHD without known ARF	104	21	13	138 (40)
Ethnicity				
Aboriginal	189	55	92	336 (98)
Other	2	1	4	7 (2)
Sex				
Male	70	11	29	110 (32)
Female	121	45	67	233 (68)
Age, median (IQR), y	44 (40–52)	40 (37–43)	39 (36.5–44)	42 (37–48)
Region, by remoteness				
Urban	33	10	38	81 (24)
Rural/remote	158	46	58	262 (76)
Region, by site				
Central region	28	15	42	85 (25)
Northern region	163	41	54	258 (75)
Prophylaxis type				
Benzathine penicillin G	181	56	90	327 (95)
Phenoxymethyl penicillin	10	0	3	13 (4)
Erythromycin	0	0	3	3 (1)
Valve(s) affected by RHD ^a				
Mitral	187	53	35	275 (80)
Aortic	116	24	11	151 (44)
Tricuspid	65	5	2	72 (21)
Pulmonary	6	0	0	6 (2)
Prosthetic heart valve	107			107 (31)
Valve repair	47			47 (14)

Abbreviations: ARF, acute rheumatic fever; IQR, interquartile range; RHD, rheumatic heart disease.

^aAs per the most recent echocardiogram report. Trivial valve changes were not counted in this assessment but may have contributed to a diagnosis of RHD, as valve appearance may have.

were by far the most common form of secondary prophylaxis, at 95%; 16 clients were prescribed oral prophylaxis: 3 erythromycin and 13 phenoxymethylpenicillin (penicillin V).

Overall, 39% of clients (135 of 343) met clear criteria for continuation of their prophylaxis according to the Australian guidelines. This corresponded to 29%, 29%, and 66% of RHD priority categories 1, 2, and 3, respectively (Table 3). On review of echo findings, 2 patients were recategorized from priority 2 to priority 1. An additional 99 clients (234/343, 68%) were intentionally continued on prophylaxis and had a reason for departure from guidelines documented. In 97 instances, this was due to clinician preference, and in 89 of these, the reason provided was that RHD severity was priority 1; lifelong prophylaxis was therefore considered appropriate. In 2 instances, the documented reason was client preference to continue. If all RHD priority 1 clients were considered to have a lifelong indication for secondary prophylaxis, then the overall proportion of clients whose continuation of prophylaxis was classed as being concordant with guidelines would be 82% (280 of 343).

Examples of reasons provided in the clinical notes section for prophylaxis continuation are as below. Of note, “LA Bicillin” is the term commonly used locally to refer to BPG.

- “I have encouraged her to continue LA Bicillin [BPG] for at least another 5 years in view of her children and potential young family in her vicinity.”
- “...has made an informed decision to remain on LA Bicillin therapy, understanding that there is no sufficient evidence about the benefit of this strategy.”
- “...continue BPG for further 2 years given echo findings and high prevalence of ARF in community.”
- “Two attempts of failed withdrawal from LA Bicillin prophylaxis, and the current plan is to continue Bicillin until aged 45.”
- “This lady has a metallic mitral valve and aortic regurgitation, which is at least moderate, and given that she is going to live in communities with a high disease burden, it is reasonable to keep her on Bicillin lifelong.”

The median numbers of years since the most recent cardiologist review and echocardiogram are shown in Figure 1A and B, according to guideline concordance and rheumatic heart disease severity. Factors associated with guideline concordance are

shown in Table 4. For these calculations, the measure of guideline concordance used was that in which either the national guidelines were followed or a reason to depart from the guideline was provided. A shorter period of time since last echocardiogram or cardiologist review was associated with a greater likelihood of guideline concordance ($P < .001$ in both instances) (Table 4). A reason for guideline concordance is ARF within the last 10 years; the median time since most recent ARF was 5.9 years in the guideline-concordant group and 24.0 years in the nonconcordant group ($P < .001$) (Table 4), and as a consequence, age at most recent ARF was older (median, 32.0 years) in the guideline-concordant group (vs 19.4 years in the nonconcordant group; $P < .001$) (Table 4). There were 32 clients who had an ARF episode after age 40 years with a documented indication for ongoing prophylaxis, but there were none in the group without a documented indication to continue. Of these 32 clients, 8 were priority 1, 4 were priority 2, and 20 were priority 3. This study was unable to incorporate adherence data, but based on local unpublished data, ARF occurring in patients prescribed penicillin would almost certainly have been attributable to penicillin nonadherence.

Clients who had no documented indication for prophylaxis continuation appeared less likely to be adherent, as they had a longer median time since their last BPG injection (42 days vs 21 days; $P = .012$) (Table 4).

Regional differences were noted in pattern of disease severity and guideline concordance. Individuals included in the audit from the Northern NT region were more likely to have severe (priority 1) disease (163/258, 63%) than those in the Central region (28/85, 33%; $P < .001$) (Table 2). A small difference in guideline concordance was evident, with greater concordance evident in the Central region (78% vs 68% in the Northern region; $P = .031$) (Table 4).

DISCUSSION

In this register-based audit, we identified that 68% of people aged ≥ 35 years had an appropriate indication to still be receiving secondary prophylaxis against RHD. This means that up to 32% of people staying on active recall lists for ongoing BPG dosing in this setting may not require it. This burden on clients and health care providers could be mitigated through timely expert review of clients at key milestones—such as when they turn 35

Table 3. Proportion of Patients Whose Secondary Prophylaxis Was in Accordance With Guideline Recommendations

Priority Group	Calculations of Guideline Concordance, No. (%)		
	(1) National Guideline Was Followed	(2) Guideline Was Followed, or a Reason for Departure From Guideline Was Documented	(3) 1 and 2 Fulfilled, and Lifelong Continuation Was Considered Appropriate for all Priority 1 Clients
1	56/191 (29)	145/191 (76)	191/191 (100)
2	16/56 (29)	23/56 (41)	23/56 (41)
3	63/96 (66)	66/96 (69)	66/96 (69)
Total	135/343 (39)	234/343 (68)	280/343 (82)

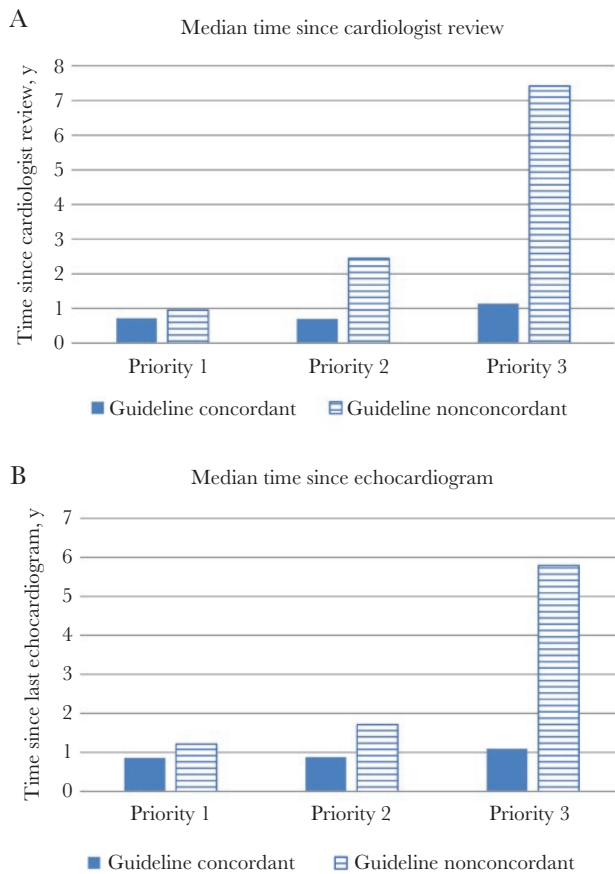


Figure 1. Time since most recent review according to guideline concordance and rheumatic heart disease severity. A, Median time since cardiologist review. B, Median time since echocardiogram.

or 40 years, or at the 10-year anniversary of their most recent ARF episode—to determine and document the safety of prophylaxis cessation at that point.

The process of identifying individuals who may be able to cease their secondary prophylaxis, and encouraging primary health centers to arrange for specialist review, has been underway for some time. This project has fed back findings to the local RHD control program to flag individual patients whose requirement for ongoing prophylaxis should be re-assessed. In particular, priority 2 and 3 clients should be reviewed with regards to their recommended penicillin stop date.

International guidelines differ, reflecting a lack of high-level evidence in the prevention of RHD. For instance, some international guidelines recommend lifelong secondary prophylaxis in those who have had cardiac valve surgery [14, 15] or those with severe valvular heart disease [15]. Guidelines also differ on the recommended duration of prophylaxis based on the presence and severity of carditis (refer to Table 5 for a summary of recommended secondary prophylaxis durations as per international guidelines) [16–18]. However, the intention of this study was to determine adherence to local Australian guidelines. Guidelines also rely largely on knowing when the most recent ARF episode has occurred to provide a recommended duration of prophylaxis. However, a substantial proportion of this cohort had RHD without a diagnosed prior event of ARF (138 of 307). This illustrates the diagnostic challenge of ARF, with diagnosis frequently being missed, and requires the clinician to opt for the recommendation to continue prophylaxis until 35 years of age for clients who are older than age 25 years at the time of RHD diagnosis (as shown in the Table 1 footnote).

Table 4. Factors Associated With Guideline Concordance Regarding Duration of Secondary Prophylaxis Against RHD Among Clients Age 35 Years and Older

Variable	Prophylaxis Concordant With Guidelines	Prophylaxis not Concordant With Guidelines	P Value
Overall, No.	234/343	109/343	
Age, median (IQR), y	42 (37–47)	42 (38–49)	.471
Region, by remoteness, No. (%)			
Urban	54/81 (67)	27/81 (33)	.731
Rural/remote	180/262 (68)	82/262 (31)	
Region, by site, No. (%)			
Central region	66/85 (78)	19/85 (22)	.031
Northern region	168/258 (65)	90/258 (35)	
Time since last ARF, median (IQR), y	5.9 (1.3–18.9)	24.0 (17.1–21.8)	<.001
Age at last ARF, mean (95% CI)	32.0 (30.2–33.8)	19.4 (17.1–21.8)	<.001
Years since last echocardiogram, median (IQR)			
Priority 1	0.86 (0.47–1.61)	1.21 (0.69–2.10)	
Priority 2	0.87 (0.40–1.31)	1.71 (0.66–4.85)	<.001
Priority 3	1.09 (0.57–2.36)	5.79 (2.99–12.18)	
Years since last cardiologist review, median (IQR)			
Priority 1	0.71 (0.34–1.39)	0.95 (0.47–2.31)	
Priority 2	0.70 (0.41–1.23)	2.45 (0.66–4.67)	<.001
Priority 3	1.14 (0.63–2.89)	7.42 (1.95–15.2)	
Days since last BPG, median (IQR)	21 (13–34)	42 (14–115)	.012

Abbreviations: ARF, acute rheumatic fever; BPG, benzathine penicillin G; CI, confidence interval; IQR, interquartile range; RHD, rheumatic heart disease.

Table 5. Recommended Durations of Secondary Prophylaxis According to Major International Guidelines

Guideline	Secondary Prophylaxis Duration Recommended
Australian (2012) [10]	<ul style="list-style-type: none"> • In all patients for at least 10 y after previous ARF • Severe RHD until age 40 y or indefinitely, per physician discretion • Moderate RHD or RHD without prior documented ARF date until age 35 y • Mild RHD or ARF without RHD diagnosis until age 21 y or for 10 y after last ARF (whichever is longer)
New Zealand (2014) [16]	<ul style="list-style-type: none"> • After definite/probable ARF, continue prophylaxis for at least 10 y, consider 5 y of prophylaxis after ARF in patients with mild or no carditis over 21 y or in patients with ARF classified as “possible” • Severe RHD generally until age 40 y, with review at age 30 y^a • Moderate RHD until age 30 y^a • Mild RHD or ARF without RHD diagnosis, until age 21 y or for 10 y after last ARF (whichever is longer)
American (AHA 2009) [17]	<ul style="list-style-type: none"> • ARF with carditis and residual heart disease until age 40 y or for 10 y after last ARF (whichever is longer); lifetime prophylaxis may be needed • ARF with carditis but no residual heart disease until age 21 y or for 10 y after last ARF (whichever is longer) • ARF without carditis until age 21 y or for 5 y after last ARF (whichever is longer)
Indian (2008) [18]	<ul style="list-style-type: none"> • Lifelong in severe disease or postintervention patients; may opt for secondary prophylaxis until age 40 y • ARF with healed, mild, or moderate carditis until age 25 y or for 10 y after last ARF (whichever is longer) • ARF without carditis until age 18 y or for 5 y after last ARF (whichever is longer)
WHO Expert Consultation Geneva (2001) [15]	<ul style="list-style-type: none"> • Lifelong if severe valvular disease or after valve surgery • For 10 y after last ARF or until age 25 y in patients with previous diagnosis of carditis • For 5 y after last ARF or until age 18 y in patients without proven carditis

Abbreviations: ARF, acute rheumatic fever; RHD, rheumatic heart disease.

^aFor severe RHD at age 40 years or moderate RHD at age 30 years, cessation of prophylaxis is still at the physician's discretion based on the individual patient risk.

A failure to cease prophylaxis in accordance with guidelines occurred more commonly when engagement between specialist services and clients was poor. Lack of attendance at follow-up cardiology appointments or echocardiography assessment meant missed opportunities for prophylaxis to be reviewed and potentially ceased. Decision-making in the management of individuals with ARF or RHD is often challenging for primary care staff, especially those unfamiliar with the conditions—a common problem due to high staff turnover [19]. They may lack confidence in recommending that prophylaxis be ceased, lest an ARF recurrence and RHD progression occur. We did not collect data on what efforts were made at either the client or health system level to foster engagement in health care. There are well-recognized gaps in health care service delivery in remote Indigenous Australian settings, due to systems factors, such as the staff turnover already alluded to and sociocultural factors (eg, differing languages and world views [20]).

A limitation of the study is that register data in some instances are incomplete [21]. We found that some clinical notes were missing from the register (eg, there was documentation that a clinical review had occurred, but no notes were entered), and we lacked access to primary data sources; therefore, this analysis may slightly underestimate the proportion of clients in whom prophylaxis continuation was concordant with specified clinician decisions. Another limitation is that we only audited clients still prescribed prophylaxis; the assessment of factors associated with guideline adherence was confined to this group and does not include people in this age group whose prophylaxis had been appropriately ceased. The register is continually updated; hence the data were accurate as of the day of extraction but may have been updated subsequently. We also note that the selected patient group is older than the general

RHD population and is more likely to have more severe RHD, so results do not apply to the entire population taking ARF prophylaxis.

In clinical practice in the NT, there have been anecdotal examples of individuals whose prophylaxis has been appropriately ceased according to guidelines yet who experience an ARF recurrence at a later stage. Given that the overwhelming challenge for primary care staff is to ensure adequate adherence for individuals needing prophylaxis, it is better that they err on the side of caution and continue administering penicillin rather than place individuals at risk. Nuanced decision-making is required, and the guidelines leave scope for individual decision-making by doctors; these discussions should take a participatory approach, allowing patients a lead role in chronic care self-management [22]. Work is underway to develop culturally appropriate RHD self-management support tools [23]. Nevertheless, the guidelines still provide a clear basis to guide decision-making. Case illustrations from this data set show that in some instances, the decision should be simple—such as a 55-year-old with no documented ARF episodes for 48 years and only mild RHD (trivial mitral regurgitation only) who clearly lacked any documented indication for prophylaxis continuation. From a patient perspective, the burden of ongoing onerous treatment would be immense. From a programmatic perspective, appropriate removal of such individuals from the database could affect the calculation of adherence, a key performance indicator of local health system performance. This would occur if adherence were systematically different in older individuals with mild disease. We were not able to investigate the determinants and outcomes of adherence in this study, but they are being examined in separate research.

Promotion of the guidelines is paramount, including in online electronic format and a recently available smart device application [13], in concert with increased reach and accessibility of specialist reviews. Upscaling the existing regional telemedicine services would be helpful in supporting decisions to cease prophylaxis, as in-person assessment of a client is not essential if a good history and recent echocardiogram are available.

Our results highlight the occurrence of ARF beyond the typical age range in this high-burden setting. Environmental conditions mean that GAS transmission is very common, and immunologically primed hosts are highly vulnerable to the immune complications of GAS infection. The estimated caseload of ARF occurrences in people age >40 years in the past has been approximately 1% [24]. In this data set, ascertainment bias is present as people with fewer total lifetime episodes of ARF (resulting in no RHD or mild RHD), who are presumably less likely to continue to have ARF recurrences beyond the age of 40 years, were mostly excluded because their prophylaxis would have been ceased earlier in life. The number of patients who had documentation of their last ARF episode was 205 (60%). Of these most recent ARF episodes, 32 (16%) occurred in people age ≥40 years, and 12 (6%) in people age ≥45 years. We included definite, probable, and possible ARF cases, and we acknowledge the difficulty in making this clinical diagnosis, but these findings of ongoing risk in some individuals in later life are supported by clinical experience in the NT and a previous report from the NT [1].

CONCLUSION

Streamlining of health systems is needed in the delivery of complex chronic care in challenging environments. We have identified an opportunity to strengthen register processes that could reduce the burden of care for primary care clinicians, improve the accuracy of reporting on adherence data, and improve patient quality of life by allowing discontinuation of regular BPG injections. Additional research is needed to assess the potential benefits of continuing prophylaxis in various patient groups, especially in RHD priority 1 patients older than age 40 years, many of whom are continued on secondary prophylaxis lifelong without adequate evidence to guide this practice.

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