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Improving primary prevention of acute rheumatic fever in Australia: consensus primary care priorities identified through an eDelphi process

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Abstract

Introduction

Rheumatic heart disease (RHD) causes a substantial and inequitable burden of disease for Aboriginal and Torres Strait Islander people in Australia. Acute rheumatic fever (ARF), which leads to RHD, can be largely prevented if preceding Group A streptococcal (Strep A) infections are treated with antibiotics. However, this primary prevention treatment is not reliably delivered in practice. This study seeks to elucidate from primary care practitioners what and where the solutions may lie.

Methods

First, an expert focus group was convened and literature review was conducted to identify potential strategies for improvement. These were classified as demand-side or supply-side using a conceptual framework on access to health care. Second, an electronic Delphi (eDelphi) technique was used with health care providers working in Aboriginal and Torres Strait Islander primary care to determine priorities for improving primary prevention of ARF. Participants ranked each option on a Likert scale and two web-based survey rounds were conducted. Qualitative data were also collected via free text entries to identify other potential strategies and these data were thematically analysed.

Results

Twenty-six participants from five jurisdictions participated, 16/26 (62%) completed both survey rounds. Seven strategies were endorsed as high priorities. Most were demand-side strategies with a focus on engaging communities and individuals in accessible, comprehensive, culturally appropriate primary health care. Eight strategies were not endorsed as high priority, all of which were supply-side approaches. Qualitative responses highlighted the importance of a comprehensive primary health care approach as standard of care rather than disease-specific strategies related to management of skin sores and sore throat.

Conclusion

Primary care staff priorities should inform Australia's commitments to reduce the burden of RHD. In particular, strategies to support comprehensive Aboriginal and Torres Strait Islander primary care services rather than an exclusive focus on discrete, disease-specific, initiatives are needed.

Strengths and limitations of this study

- This eDelphi study is the first structured approach to understanding what primary care staff think are the biggest priorities for improving primary prevention of acute rheumatic fever.
- Two rounds of Delphi responses are used to elucidate consensus priorities of primary care staff, with 62% of participants completing both survey rounds.
- In addition to quantitative Delphi survey results, a large amount of qualitative data strengthens the study and interpretation of results.
- Limitations of the study include a modest number of total participants (n=26) and the necessary limitation of purposive sampling to include experiential experts.

For peer review only

Introduction

Rheumatic heart disease (RHD) is a consequence of acute rheumatic fever (ARF), stemming from an abnormal immune reaction to untreated Group A streptococcal (Strep A) infection. RHD is rare in most high-income countries but persists in low- and middle-income countries and marginalised First Nations people in high income settings.¹ Aboriginal and Torres Strait Islander people in Australia have a high prevalence of RHD, leading to the greatest disparity in cardiovascular disease burden between Aboriginal and Torres Strait Islander people and non-Indigenous people.^{2,3} The highest rates of ARF and RHD occur in remote and very remote Aboriginal and Torres Strait Islander communities in Northern Australia.² These remote communities are socioeconomically deprived, with low household income, high rates of crowded living environments, and substantially lower life expectancy than urban and non-Indigenous people in Australia.^{4,5} Skin infections are endemic in remote communities with almost half of all children having skin infections at any time.⁶ The primary pathogen of these skin infections is *Streptococcus pyogenes* (Strep A).⁷ The incidence of throat infections is less well described, although there are indications that the rate of symptomatic pharyngitis is relatively low in ARF endemic Australian settings.^{8,9} The high burden of early life Strep A skin and throat infections are thought to lead to immune priming which increases the risk of developing ARF in childhood.¹⁰

There are a number of opportunities to intervene on the causal pathway from Strep A infection to ARF, RHD, and subsequent complications.¹¹ One of these opportunities is primary prevention. In the absence of a vaccine, primary prevention of ARF is exclusively antibiotic treatment of Strep A infections to reduce the risk of developing ARF.¹² The risk reduction for ARF following Strep A throat infection is well described. Treatment with oral penicillin can reduce the attack rate of ARF following Strep A throat infection by about 70%, increasing to 80% if a single intramuscular injection of benzathine benzylpenicillin is given within 9 days of symptom onset.¹³ The risk reduction of ARF following skin sores has not been empirically well documented but is biologically plausible and consistent with increasingly nuanced understanding of ARF pathogenesis.¹⁴ On this basis, if Strep A infections can be diagnosed and promptly treated with appropriate antibiotics, many episodes of ARF would be preventable.^{12,13}

Over the last decade Australia's efforts to reduce the burden of RHD have largely focused on delivering secondary prophylaxis for people who have already had ARF.^{15,16} An external review of Australia's Rheumatic Fever Strategy in 2017 identified improving primary prevention of ARF as a priority for ending RHD in Australia, however, there is no consensus on how this can be achieved.¹⁵ Research, anecdote, and opinions suggest that a wide range of strategies *could* be effective in improving treatment of sore throat and skin sores. However, potential approaches have not been collated, reviewed, or consulted with stakeholders. Clinics seeking to improve primary prevention have little indication of which strategies have a robust evidence base or stakeholder support for prioritisation. The END RHD Centre of Research Excellence (END RHD CRE) was funded in 2014 to help identify an 'endgame' for RHD in Australia, including recommendations to strengthen primary prevention of ARF.¹⁶

This study, embedded within the END RHD CRE, is intended to give voice to the operational priorities of primary health care staff working in Aboriginal and Torres Strait Islander health for improving primary prevention. The aim of the study is to identify which strategies primary health care workers believe would be most effective in improving assessment and treatment of sore throat and skin sores in remote Aboriginal and Torres Strait Island communities. Directly, these consensus findings help inform the RHD Endgame Strategy.¹⁶ Indirectly, this study adds to international literature about access to healthcare for Indigenous people by applying a disease-specific lens to an existing framework for analysing access. Finally, it seeks to provide avenues for future research to address knowledge gaps and implementation science to prevent RHD.

Methods

Focus group and theoretical framework

A focus group of END RHD CRE investigators and affiliates was initially convened to inform the scope of this research. The group was asked two questions: (1) 'What are the priority actions to improve primary prevention of ARF?' And (2) 'Which are the three highest priorities?' Responses were discussed and consensus recommendations were incorporated into a conceptual framework of access to healthcare proposed by Levesque et al. which has also been adapted for use in Indigenous primary health care settings (Figure 1).^{17,18}

Literature review

Informed by the focus group findings, a literature review was conducted to identify potential strategies for improving delivery of primary prevention and to sort these according to the Levesque et al. conceptual framework. A Medline search of peer-reviewed literature from Australia and New Zealand from January 2010 - December 2018 was conducted (search strategy, supplementary material 1). We focussed only on publications from Australia and New Zealand as both countries experience a large burden of ARF and RHD among Indigenous communities, have comparable health systems, and some shared challenges in improving access to healthcare. Citation tracking and recommendations from the investigator team were used to identify additional relevant publications. A supplemental grey literature search was conducted using similar search terms to identify operational reports and program evaluations. Documents were extracted into a Microsoft Excel file and duplicates removed; strategies for improving primary prevention were identified from these documents. Strategies were eligible for inclusion if they were an 'implementable action', specifically something which clinics or communities could do. Suggestions about research priorities and broad statements about general strategies not were included. Results were sorted into thematic areas of the Levesque et al. access framework and transformed into statements suitable for eDelphi review.

eDelphi study

The Delphi technique is used to identify consensus areas between experts, particularly 'in scenarios which cannot feasibly or ethically be subject to a randomised controlled trial'.¹⁹ The approach involves experts providing feedback on different options over repeated 'rounds,' with feedback between rounds to move the group towards consensus. Electronic Delphi (eDelphi) approaches mirror the process of an in-person Delphi, but maximise opportunities for people to participate from different places and at times most convenient to them. In this study, primary care staff with frontline expertise in service delivery participated in an eDelphi study to identify consensus priorities to improve assessment and treatment of skin sores and sore throat for primary prophylaxis of ARF.

Patient and Public Involvement

Patient and public stakeholders were not directly involved in this study of health professional preferences. However, patient perspectives were included in the literature review to solicit potential approaches to improving primary prevention.

Three levels of statements were developed from the literature synthesis: *concepts* (overarching ideas, 'what' should be done'), *strategies* (different approaches to implementing concepts), and *actions* ('how' concepts should be done'). Language in each statement was standardised to maximise applicability for both skin sores and sore throat and throughout Australia. A REDCap (Research Electronic Data Capture) database was built to electronically present concepts, strategies, and actions for ranking by participants.²⁰

Potential participants were identified through the professional networks of the investigator team. Participants were eligible if they had worked in any primary care role (including general practitioner, nurse, Aboriginal and Torres Strait Islander Health Practitioner, environmental health worker, school nurse, administrator, receptionist) within the last 5 years in one of the five states or territories with a high burden of ARF (New South Wales, Queensland, Northern Territory, South Australia, Western Australia). Invitation emails containing a link to Round 1 of the eDelphi were sent to participants followed by three reminder emails to participate over the following two weeks. In Round 1, participants rated each concept on 1 – 5 Likert scale ranging from low priority to high priority. If the concept was identified as low priority (1 – 3 / 5), the participant moved automatically to the next concept. If the concept was identified as high priority (4 -5 / 5), the participant was asked to rank associated strategies and actions on the 1- 5 scale. Following each concept, participants were also asked to add other strategies or comments about improving primary prevention as free text entries.

Round 1 responses were extracted and organised in a spreadsheet. Concepts rated as high priority (Likert 4 or 5) by more than 80% of participants were considered to be endorsed. Concepts rated as high priority by 60 – 80% of participants were considered equivocal and re-presented to participants in Round 2 alongside feedback from the group, allowing participants to adjust their ranking with a view to forming a consensus opinion. Round 1 concepts that were considered by fewer than 60% of participants to be high priority were excluded. New concepts, strategies, or actions identified from free text responses in Round 1 were also coded and presented to participants in Round 2. Participants who completed Round 1 were emailed four weeks later to complete Round 2. Concepts rated as high priority (Likert 4 or 5) by more than 80% of participants were considered to be endorsed. All other Round 2 concepts were excluded.

Qualitative data

Free text entries were also thematically analysed, identifying concept-specific feedback and overarching themes about primary prevention priorities.

Results

Scoping expert focus group

The expert focus group had nine participants: six researchers, two clinicians, and one 'employed in RHD' to generate a framework for literature review. Seven participants worked primarily in Australia, one in New Zealand, and one in another international setting. Twenty-seven distinct approaches for improving primary prevention were identified by the focus group (supplementary material 2). The group identified the three highest priorities as:

- **Health promotion, awareness, and education campaign** for skin sores and sore throats targeting health workers, education providers, community members, and families.
- Augmented approaches that look at **new ways to improve identification and management of sore throat**: exploring community workers, disruptive technologies, point of care tests and integration with other health issues, community knowledge, and preferences.
- **Research** to understand sore throat burden, how to improve control of skin infections in Aboriginal and Torres Strait Islander communities, and Strep A vaccine development.

Literature review

In total, 57 Australasian sources were identified containing suggested approaches to improving assessment and treatment of skin sores or sore throat. Twenty seven publications were identified from a Medline search with citation review; an additional 30 grey literature documents were identified from the internet Google search. Grey literature was drawn from a broad range of

sources, including six 'Rheumatic Fever Prevention Plans' developed by District Health Boards in New Zealand and consultative outcomes (including a RHDAustralia colloquium in 2015²¹ and evaluation of the Australian Rheumatic Fever Strategy in 2017¹⁵). From these sources, 15 concepts, comprising 29 strategies and 63 different actions for improving primary prevention of ARF were developed (supplementary material 3). The 15 concepts were mapped to the Levesque et al. access framework (Figure 2).

eDelphi

Investigators identified 53 potential participants through their professional networks. Recruitment, response, and retention rates are outlined in Figure 3; 43% of eligible participants successfully contacted by email participated in Round 1 and 16 (76%) of these people also participated in Round 2.

Overall, 26 people completed either Round 1 and/or Round 2 of the eDelphi process. Demographic details of participants are presented in Table 1. Two participants identified as an Aboriginal or Torres Strait Islander person.

	n (%)
Professional role	
General Practitioner	13 (50%)
Registered Nurse	3 (12%)
Aboriginal or Torres Strait Islander Health Professional	1 (4%)
Environmental Health Worker	1 (4%)
Not stated	8 (31%)
Jurisdiction	
Northern Territory	12 (46%)
South Australia	2 (8%)
Western Australia	2 (8%)
Queensland	1 (4%)
New South Wales	1 (4%)
Not stated	8 (31%)

Table 1: Characteristics of n=26 participants who completed either Round 1 or Round 2 of the eDelphi survey.

After the two rounds, 7 concepts (including 15 strategies and 21 actions) were endorsed as priorities by participants and eight concepts were not endorsed (Figure 4 and supplementary material 4).

Qualitative data findings

In total, 287 additional free text entries were provided by the participants across two survey rounds. Two passes of qualitative analysis were conducted. The first pass consolidated feedback specific to each concept; this occurred after Round 1 to inform development of Round 2 and again after Round 2 to explore the evolution of consensus. This concept-specific analysis is presented in supplementary Material 5. A second pass inductive analysis was conducted to identify repeated themes spanning across concepts to develop an understanding of deeper structural determinants of concept-specific responses. Three over-arching themes were identified; these themes were well illustrated with specific reference to skin sores (see Box).

Theme 1: Prevention and environmental health

Although eDelphi statements related to primary prevention of ARF through *treatment* of skin sores and sore throat, a large number of participants provided comments about how skin sores and sore

throat could be better *prevented*. Some of these comprised opportunities to embed preventative actions within primary care services: *“Linking primary care services with the ability to refer for services to address the social determinants of health in households with high rates of sore throats or skin sores, e.g. access to improved housing, reliable power and water, washing machines etc. – ID 9”*. However, the majority of qualitative comments implied that eDelphi statements about clinic-based activities to improve primary prevention were of limited value without separate and broader action on environmental determinants of health: *“Primary prevention ultimately can only be effective in reducing ARF alongside more effective primordial prevention measures - ID 20”*.

Theme 2: Aboriginal and Torres Strait Islander health workforce, culture, and community

Workforce issues were identified as relevant in almost all concepts. This included inadequate overall numbers of staffing in primary care (limiting access to approachable, timely care and guideline-based, technically acceptable services) and too few Aboriginal and Torres Strait Islander people delivering healthcare, contributing to care which people could not access or engage with: *“if a health service has a large number of Indigenous staff this will provide much better cultural oversight than giving 'formal' cultural training- ID13”* By extension the significance of Aboriginal and Torres Strait Islander ways of knowing, being, and doing were addressed in a number of domains. Operationally, this included strong support for the use of materials in Aboriginal and Torres Strait Islander languages for engagement, education, and health promotion. Some participants provided more detailed reflections about the importance of using Aboriginal and Torres Strait Islander languages: *“Most health inequity is due to ongoing colonisation, including loss of languages and culture. Including Aboriginal languages especially on a health topic sends a very strong message - ID 23”*. eDelphi statements about approachability and ability to engage in health services also elicited a number of reflections about services which are not culturally responsive nor welcoming for Aboriginal and Torres Strait Islander people attending with skin sores and sore throat: *“And how to manage culture shock and be aware of own prejudice when treating patients - can be very hard for patients to keep turning up when they feel misrepresented and misunderstood - ID19”*. Community control of health services, incorporation of traditional medicines, and community engagement were suggested by some participants as a means to improve culturally responsive care.

Theme 3: Permeability and navigability of primary health care services

Issues raised in Theme 2 manifest a number of tangible barriers to people accessing care, including long waiting times, limited after-hours services for non-urgent care, inadequate transport, and lack of outreach services. Participants identified a number of mitigating strategies, with strong support for increasing outreach care (particularly through schools) and extended clinic opening hours: *“Provide flexible access options to assessment and treatment. Perhaps option of streamlined skin check clinics, perhaps clinic for adults as well as their children collocated? at school for pickup drop off time walk-in - ID16”*.

Box: Skin sores an object lesson for qualitative themes

Skin sores provide a tangible example of how these themes affect access to health services. Participants identified in Theme 1 that the priority for skin sores was prevention rather than treatment: *“As per previous suggestions re skin sores having access to freely available hot water to wash clothes and bedding on a regular basis (not just when they have scabies) rather than having to buy a power card to wash with hot water. ID13”* In Theme 2, the importance of culturally responsive care, ideally by Aboriginal and Torres Strait Islander providers, was highlighted in order to work effectively within belief systems about skin sores which included both normalisation and stigmatisation: *“Need to reduce the shame factor and association with poor hygiene – ID23”* and *“Denormalising' skin sores is very important – ID17”*. Skin sore stigma was also described by healthcare workers, and some participants identified the risk that health promotion activities further contribute to this issue: *“health service led efforts are never going to*

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be as effective as community led initiatives to improve treatment uptake and may contribute to stigma associated with skin sores - ID13" Others reported that skin sores were considered a low clinical priority in some clinics, potentially contributing to the barriers to access expanded on in Theme 3 (*"Not being sent away from clinics ... told not an emergency.. come back tomorrow. - ID 21"*), though this was not universal.

Discussion

This study provides insights into primary care worker priorities to improve assessment and treatment of skin sores and sore throat amongst Aboriginal and Torres Strait Islander people as a core activity for prevention of ARF. It is the first time we are aware of that a primary care approach to inform priorities has been used for primary prevention of ARF, and aligns with the key characteristics of effective Indigenous led primary care.²² Four of seven endorsed priorities were demand-side domains (ability to perceive, ability to seek, and ability to engage in health care). These approaches reflect a provider focus on *how* services are delivered to drive greater demand for health services, including partnership with communities, empowerment, appropriate health promotion, and self-management support. Three of seven endorsed priorities were supply-side strategies (approachability, acceptability and appropriateness). These supply-side issues reflected a similar focus on providing accessible, culturally responsive, primary health care services. Conversely, all of the domains which were not endorsed were supply-side, including clinic level activities like health care worker training, quality improvement activities, and clinical guidelines. 'Improving treatment of scabies' was an endorsed supply side priority, somewhat incongruent with the broader focus on disease-agnostic priorities. This may reflect specific concern about scabies as a risk factor for skin sores or exposure to focused education on the impact of scabies.

Supply-side barriers to access (including navigability and permeability of services²³) were identified in qualitative feedback, including waiting times, limited after-hours services, and limited outreach capacity. A number of participants reflected on the root cause of these barriers, including an inadequate primary care workforce with too few Aboriginal and Torres Strait Islander people employed and too few employed to their full scope of practice. Navigability barriers have been reported in a number of other primary care studies and tackling these provides an ongoing opportunity to improve service access.^{18,22,24,25} Outreach services to provide care in schools, in homes, and to remote outstations were particularly emphasised in this study. Participants reflected on barriers and enablers to outreach, including the difficulty of delivering treatment outside clinical settings and the potential role of telehealth in supporting outreach workers to communicate with clinic-based staff. Despite these comments, eDelphi concepts including 'make it easier for people to access assessment and treatment of skin sores and sore throat' and 'make assessment and treatment of skin sores and sore throat available in more places' were not endorsed by the group. This may be because comments on care accessibility may have been perceived as an essential standard of care that did not need re-emphasis. They were dwarfed by feedback on the importance of community, cultural, and clinic context in which people seek and receive primary care, including who provides care, how it is governed, and how communities participate in decision making.

Few qualitative responses were specific to the issue of skin sores and sore throat. Rather, they reflected broader determinants of effective primary care for Aboriginal and Torres Strait Islander people. A 2018 systematic review of the characteristics of effective Indigenous primary care identified eight interdependent, elements: culture, accessible health services, community participation, continuous quality improvement, culturally appropriate and skilled workforce, flexible approach to care, holistic health care, and self-determination and empowerment.²² Each of these elements were clearly identifiable in qualitative responses to this eDelphi.

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3 The prioritisation by primary care staff of *how* – structurally and culturally – care is delivered for skin
4 sores and sore throat, is telling. Culturally and contextually appropriate ways of working in
5 Aboriginal and Torres Strait Islander health are already widely acknowledged to be a major
6 determinant of care quality and outcomes.^{22,26} However, it is not always clear how these ‘horizontal’
7 systems issues relate to vertical, disease-specific, initiatives. Efforts to improve care for specific
8 conditions more commonly focus on tangible supply-side interventions such as clinical guidelines,
9 decision support, and staff training. For example, in ten clinics participating in a stepped wedge
10 study to improve delivery of secondary prophylaxis for people with ARF, action plans developed by
11 clinic staff included far more actions addressing clinical information systems (29 items) than
12 community linkages (4 items) or self-management support (4 items).²⁷ Qualitative evaluation of that
13 study found that limited attention to community linkages and self-management, in addition to
14 contextual factors, contributed to limited gains in secondary prophylaxis adherence.²⁸ This eDelphi
15 parallels these findings, providing more evidence from clinical staff that the context in which
16 disease-specific initiatives are implemented is likely to be the determining factor of success. The
17 participating primary care providers in the current study indicated lack of support for approaches
18 which prioritise clinical supply-side issues over systematic approaches to strengths based,
19 comprehensive, community engaged, culturally responsive primary care. A number of participants
20 specifically identified the risks of vertical programs fragmenting care or services. Overall, supply-side
21 supports (such as clinical guidelines and staff training) are likely to be prerequisites to successful
22 disease management; but time, staffing and cultural constraints identified by primary health care
23 staff may make use of these resources prohibitively difficult. Participants identified broader
24 contextual factors as priorities in this study; presumably to potentiate use of existing and emerging
25 resources. Notably, priorities identified by primary care different from the scoping expert focus
26 group (comprised primarily of researchers and RHD content experts) which focused on health
27 promotion, improved clinical approaches to primary care and the need for further research. This
28 illustrates need for integrated approaches to address outstanding priorities across stakeholder
29 communities.
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35 This study was designed to identify clinic-level strategies in primary care for improving primary
36 prevention (by definition, once Strep A infections have already occurred) and therefore did not
37 include eDelphi statements related to community-level risk reduction strategies. However, this
38 appeared to be an arbitrary distinction for participants; many emphasised that clinical primary
39 prevention strategies alone would be insufficient. Risk factors for Strep A infections, ARF, and RHD
40 include household crowding, inadequate access to health hygiene infrastructure and socioeconomic
41 marginalisation.²⁹ In particular, housing and environmental health factors are the major driver of
42 Strep A skin sores in remote Aboriginal and Torres Strait Islander settings.³⁰ Approaches for
43 integrating environmental health into clinical care delivery were suggested by participants, including
44 the need for referral pathways for environmental assessments and services. Efforts to integrate
45 environmental health into comprehensive primary care are increasing in some parts of Australia and
46 warrant ongoing development.^{31,32} Other participants identified that broader actions addressing the
47 social and environmental drivers of Strep A infection outside the health service are needed,
48 including new housing and infrastructure. Some responses implied a frustration that the greatest
49 outstanding needs for addressing skin sores and sore throat were outside the influence of primary
50 care staff and services.
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54 Skin sores were an important object lesson, illustrating a broad range of clinical and non-clinical
55 issues which participants considered to be priorities. Primary health care staff identified complex
56 attitudes influencing community and clinic responses to skin sores, including stigma, normalisation,
57 and a strong association with poor hygiene. This resonates with a recently published study on
58 barriers and enablers to skin sore treatment in the Pilbara, which found that shyness, shame, fear of
59 judgement, normalisation and prejudice were significant factors in the decision to seek care.³³
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3 Primary health care staff in this eDelphi study, and in the Pilbara study, identified health promotion
4 as a priority to increase health seeking for skin sores.³³ However, a number of participants discussed
5 the risk of inadvertently increasing stigma if skin sores were associated with poor hygiene in health
6 promotion activities. A strong message from community is to prioritise a strengths based approach
7 to health promotion.³⁴ This risk is real; stigmatisation associated with health promotion campaigns
8 about sore throat and ARF for Māori and Pacific Islander peoples in New Zealand has been well
9 described.³⁵ Similarly, health promotion about handwashing and healthy living practices may be
10 alienating if people do not have access to functional household infrastructure such as taps and
11 soap.³⁶ Participants identified that culturally relevant, stigma-free, health information about skin
12 sores in Aboriginal and Torres Strait Islander languages was a priority. Other qualitative comments
13 made it clear that effective knowledge transfer was predicated on community engagement and
14 access to environmental health supports which would allow people to engage with and act on this
15 information.
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19 This study has a number of limitations. Participants were identified through the professional
20 networks of the investigator team. Therefore, they may not be representative of the primary care
21 workforce or may have been sensitised to issues around ARF and about cultural safety in healthcare.
22 Network based deliberative sampling is common in Delphi studies.³⁷ Identifying participants through
23 the networks of multiple investigators to approach colleagues in different jurisdictions, roles and
24 professional contacts helps to mitigate this risk. The overall number of study participants was
25 modest, though a 43% response rate higher than some comparable eDelphi projects involving
26 primary health care in Australia.³⁸ Further, participants were drawn from all five jurisdictions in
27 Australia with ARF/RHD registers and the number of participants is comparable with other eDelphi
28 studies in Aboriginal and Torres Strait Islander health.¹⁹ Only two Aboriginal and Torres Strait
29 Islander people participated in this study; consequently, results predominantly reflect perspectives
30 of non-Indigenous remote health staff. It is critically important that findings from this study are
31 considered in conjunction with the perspectives and priorities of Aboriginal and Torres Strait Islander
32 people living with skin sores, sore throat, and at risk of ARF. A number of publications address the
33 experiences of Aboriginal and Torres Strait Islander people with skin sores and address common
34 themes, including that information provided only in English is of limited value and that experiences
35 at the clinic have a major influence on care-seeking behaviour.^{33,39,40} Most Round 1 respondents
36 (76%) also completed Round 2, indicating reasonable engagement in the process and the quantity
37 and quality of free text comments indicate that participants were deeply committed and thoughtful
38 with regard to their responses. Detailed qualitative analysis is not a routine part of eDelphi
39 methodology, though qualitative adaptations have been described.^{37,41} The volume and detail of free
40 text responses to this eDelphi made it possible to use inductive thematic analysis to better
41 understand the rationale for participants endorsing and not endorsing different concepts.
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46 This study suggests that primary care providers perceive that improvements in primary prevention
47 of ARF need to come from broad systems strengthening to achieve excellence in culturally safe
48 primary health care. This aligns with what is already known about accessible primary care for
49 Indigenous people and the priorities of Aboriginal and Torres Strait Islander people, including those
50 living with skin sores, sore throat, ARF, and RHD.^{22,33,40} A number of initiatives are underway to map
51 a pathway to end RHD in Australia, including the RHD Roadmap and the RHD Endgame Strategy.^{42,43}
52 This eDelphi study suggests these efforts should call for culturally responsive, comprehensive
53 primary health care for Aboriginal and Torres Strait Islander people which involves whole
54 communities and is readily navigable for people seeking care. These systems approaches should be
55 augmented by a small number of disease-specific strategies for tackling Strep A infections.
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Conclusions

This eDelphi study demonstrates that primary care staff prioritise demand-side determinants of access to health care to improve primary prevention of ARF among Aboriginal and Torres Strait Islander people. In particular, partnership with communities, empowerment, self-management support, and approachable care were emphasised. These priorities reflect a focus on *how* care is delivered in context, rather than technical details of the care itself. Participants largely rejected the idea of vertical, disease-specific, strategies to improve primary prevention and consistently identified horizontal, access-strengthening approaches current priorities. Ultimately, these components are indivisible; guideline and training supports to improve the quality of supply-side primary prevention must be coupled with attention to demand-side drivers which enable people to seek and engage with care. The importance of environmental health strategies and strengthening the Aboriginal and Torres Strait Islander health workforce exemplify that a comprehensive approach to prevention and treatment is also needed for meaningful impact on skin sores and sore throat. Qualitative responses highlighted the importance of a comprehensive primary health care approach as standard of care rather than disease-specific strategies related to management of skin sores and sore throat.

Figure 1: Conceptual framework on access to healthcare, adapted from Levesque et al.¹³

*Figure 2: Concepts for improving primary prevention ARF mapped to the Levesque et al. framework for access to healthcare. *Strategies subsequently endorsed by the eDelphi process are indicated in orange text.*

Figure 3: Recruitment, response and retention rates in Round 1 and Round 2 of the eDelphi process

* Two participants completed more than one concept but did not complete full survey

** Invitations to participate in Round 2 of the eDelphi process were inadvertently shared with people who did not participate in Round 1. Five people responded to this invitation and participated in Round 2 who had not participated in Round 1 and these responses were not included in the analysis.

Figure 4: Outcomes of Round 1 and Round 2 eDelphi process

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Ethics statement

Ethics approval for the formative focus group was provided by Human Ethics Committee of University Western Australia (RA/4/20/4489). Ethics approval for the eDelphi survey was provided by the Human Research Ethics Committees of the University of New South Wales (HC180879) and the Aboriginal Health and Medical Research Council of New South Wales (HC180879).

Contributorship statement

RW, JC and DP conceived the study design. RW, GP and JC developed the formative focus group. RW and CW completed the literature review and extracted eDelphi statements based on the conceptual framework. All authors reviewed the eDelphi statements, contributed to identification of potential participants and interpretation of results. RW wrote the draft and all authors contributed to development of the manuscript text.

Competing interests

None declared

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Data availability statement

All data relevant to the study are included in the article or uploaded as supplementary information.

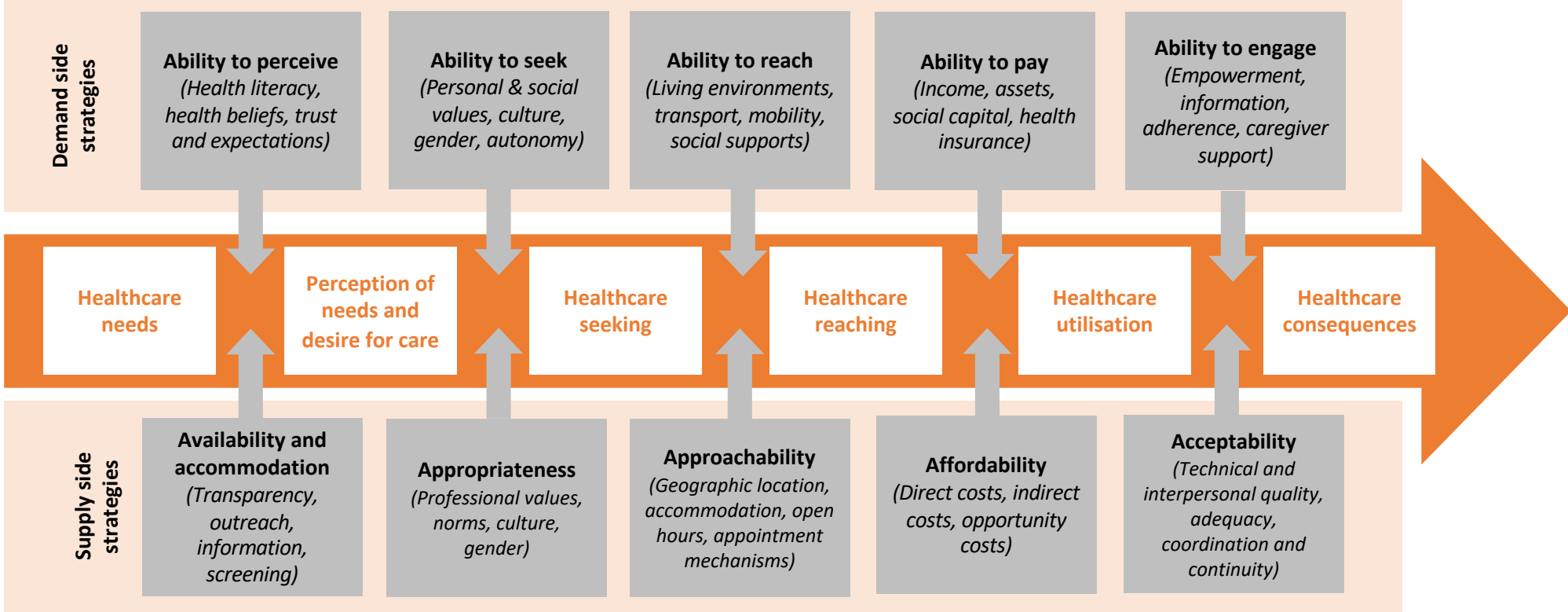
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Demand side strategies

Ability to perceive
1. Health promotion to increase assessment and treatment of skin sores and sore throats*

Ability to seek
2. Activate or empower people to seek health services for skin sores and sore throats*

Ability to reach
No concepts identified

Ability to pay
No concepts identified

Ability to engage
3. Engage communities at risk of ARF in preventing the disease*
4. Support people at risk of ARF/RHD to be engaged in their own health care and self management*

Healthcare needs

Perception of needs and desire for care

Healthcare seeking

Healthcare reaching

Healthcare utilisation

Healthcare consequences

Supply side strategies

Availability and accommodation
5. Actively work to identify people with skin sores

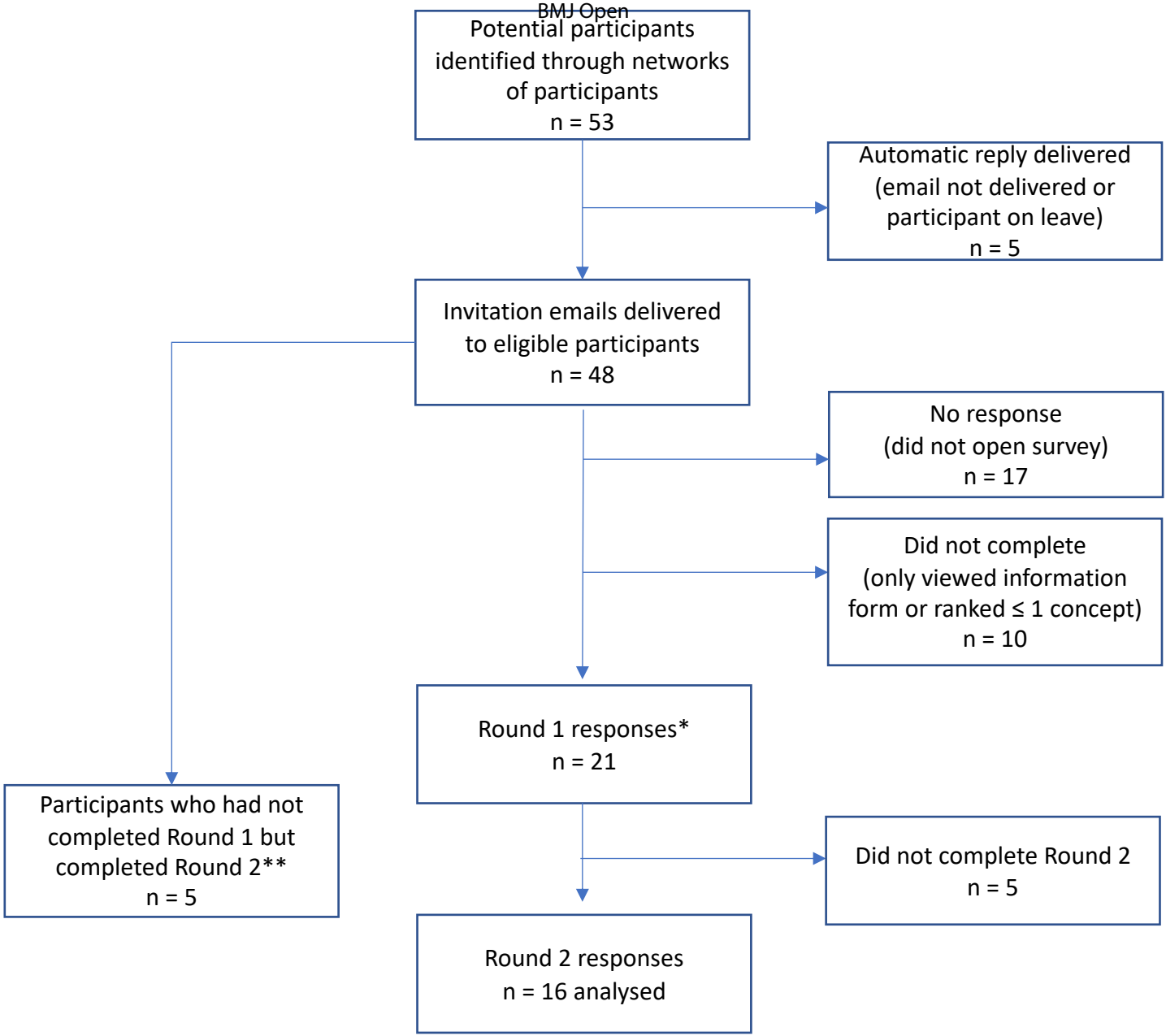
Appropriateness
6. Make health care more acceptable*

Approachability
7. Make it easier for people to access assessment and treatment of skin sores / sore throats
8. Make assessment and treatment of skin sores / sore throats available at more places
9. Provide practical or physical support to assist people to access health services*

Affordability
10. Reduce the costs for people seeking assessment & treatment of skin sores/sore throats
11. Improve service delivery by reducing costs to clinics

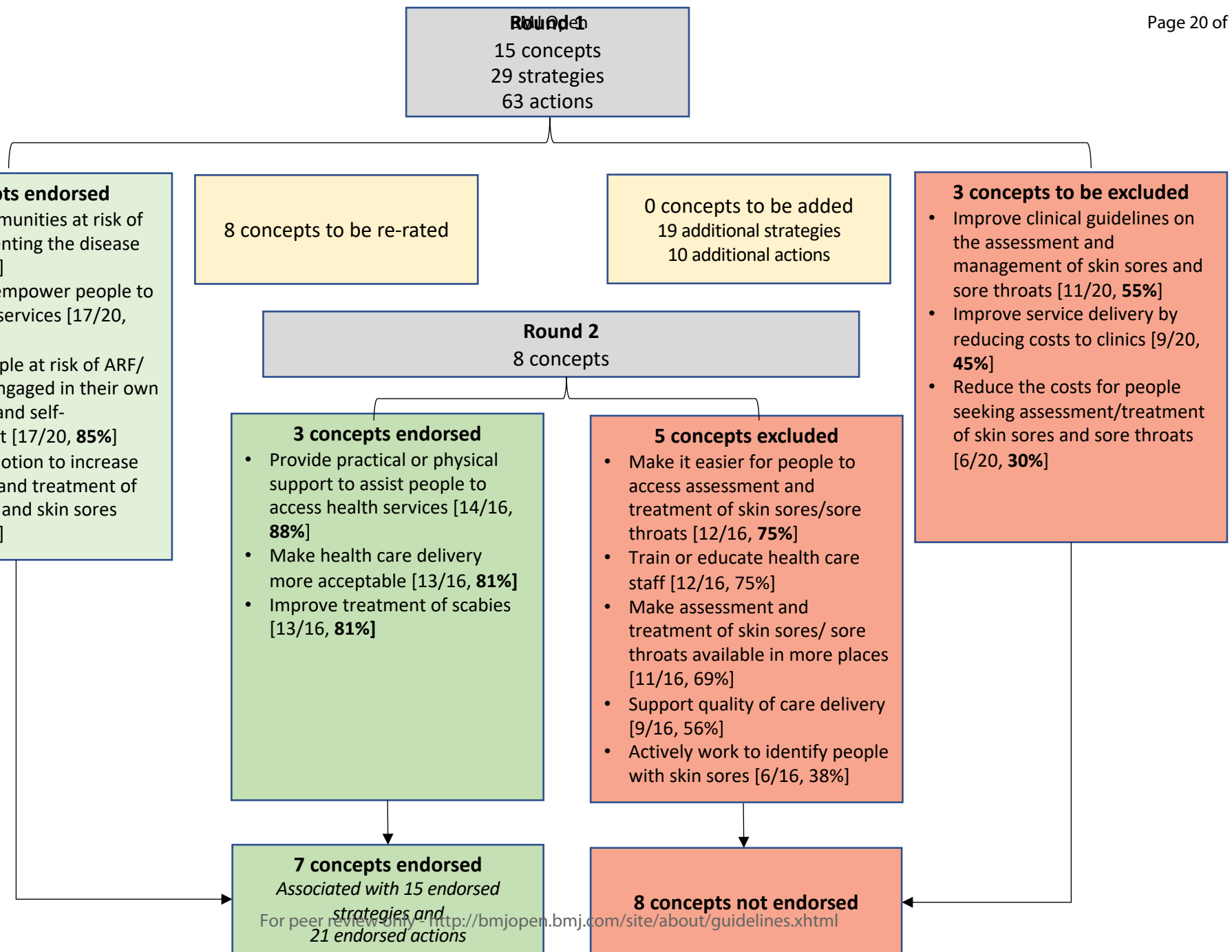
Acceptability
12. Improve clinical guidelines on the assessment and management of skin sores /sore throats
13. Train or educate healthcare staff
14. Improve treatment of scabies*
15. Support quality of care delivery

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*Two participants completed more than one concept but did not complete full survey. Their responses were included for completed survey items

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Supplementary material 1 – Search strategy

((rheumatic[All Fields] AND ("fever"[MeSH Terms] OR "fever"[All Fields])) AND ("prevention and control"[Subheading] OR ("prevention"[All Fields] AND "control"[All Fields]) OR "prevention and control"[All Fields] OR "prevention"[All Fields])) AND ("Australia"[MeSH Terms] OR "Australia"[All Fields])

((Rheumatic Fever [MeSH Terms] OR rheumatic fever.mp) AND (exp Primary prevention [MeSH Terms]) AND ((exp Australia [MeSH Terms]) OR (exp New Zealand (MeSH Terms))).

For peer review only

Supplementary material 2 – Scoping focus group outcomes

Supply side

Approachability (transparency, outreach, information, screening)

- School sore throat screening

Availability and accommodation (geographic location, accommodation, hours of opening, appointment mechanisms)

- Develop framework for external diagnosis done with photography of skin sores (for remote communities)
- Use telehealth for videoing diagnosis

Acceptability (professional values, norms, culture, gender)

- Develop sustainable training for AHWs
- Integrate AHWs into health system to better work alongside other health centre staff
- Address staff turnover at AMSs
- Deliver training + education of health care workers + school nurses for diagnosis + treatment of sore throat + skin sores
- Provide meaningful feedback to nurses re: clinic progress
- Provide systematic support and encouragement for clinic staff

Affordability (direct costs, indirect costs, opportunity costs)

- Provide affordable/free bandaids/bandages at school

Appropriateness (technical and interpersonal quality, adequacy, coordination and continuity)

- Include appropriate traditional remedies in health promotion campaigns, e.g. honey
- Develop clinical decision rules for sore throat
- Introduce affordable "point of care" testing for Strep A in skin sore and sore throat

Demand side

Ability to perceive (health literacy, health beliefs)

- Raise awareness of germ theory
- Raise awareness of transmission through bed sharing - provide better advice (top to tail)
- Improve baseline education - teach children about skin sores and sore throat
- Raise awareness in highest risk populations and target highest risk kids/families
- Raise awareness in school settings
- Raise awareness of hand washing and hand hygiene through school programs
- Raise awareness around prevention of transmission through open skin sores
- Run comprehensive health promotion campaign
- Raise awareness of need for skin sores to seal over
- Raise awareness of daily washing (parents and schools), particularly in first year of life
- Raise awareness re: reinfection rather than ineffective treatment
- Run comprehensive health promotion campaign
- Improve health seeking behaviour for skin sores and sore throat

Ability to seek (personal and social values, culture, gender, autonomy)

- Address stigma associated with sore throat, to improve acceptability of seeking health care

Supplementary 3: Delphi statements and structure

Concept	Strategy	Action
1. Health promotion to increase assessment and treatment of sore throat and skin sores	<p>↳ 1.1 General public education on germs causing disease</p> <p>↳ 1.2 General public education about skin sores, sore throat, ARF and RHD</p> <p>↳ 1.3 General public education to 'denormalise' skin sores</p> <p>↳ 1.4 Targeted public education on the specific risks of skin sores and sore throat</p>	<p>↳ 1.1a Develop mass media campaigns about germs causing disease</p> <p>↳ 1.1b Teach people about the cause and risks of skin sores through social media campaigns</p> <p>↳ 1.2a Raise awareness about skin sores, sore throat, ARF and RHD at community events and activities</p> <p>↳ 1.3a Develop positive media campaigns about normal healthy skin</p> <p>↳ 1.4a Teach children about the cause and risks of skin sores and sore throat at school</p> <p>↳ 1.4b Teach parents and families about the cause and risks of skin sores and sore throat through community events</p> <p>↳ 1.4c Train health care workers to educate children and families about the risk of skin sores and sore throat</p>
2. Engage communities at risk of ARF in preventing the disease	<p>↳ 2.1 Engage communities at risk of ARF and RHD in responding to the disease</p>	<p>↳ 2.1a Support community leaders to develop and facilitate key messages about sore throat and skin sores</p> <p>↳ 2.1b Share positive local stories about good news examples of treating skin sores / sore throat</p>
3. Empower people to seek health services	<p>↳ 3.1 Encourage people to actively seek assessment / treatment of skins sores and sore throat</p>	

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15 ↳ 4.1 Improve transport
16 for people to attend clinic
17 for skin sores and sore
18 throat

- ↳ 3.1a Train or support children on how to ask for their sore throat / skin sore to be assessed / treated
↳ 3.1b Train parents and caregivers to ask for recommended assessment of skin sores / sore throat
↳ 3.1c Develop the idea of a 'skin check' visit that people can ask for when they attend clinic

- ↳ 4.1a Fund primary care clinics to provide transport for people who need assessment and treatment
↳ 4.2b Provide education for temporary care providers (boarding schools, out-of-home carers) on the need for assessment and treatment of skin sores and sore throat.

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26 hours so that people can
27 attend for assessment /
28 treatment for more of the
29 day

30 5. Reduce the costs for
31 people seeking
32 assessment / treatment
33 of skin sores / sore
34 throat
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36 ↳ 5.1 Reduce out-of-
37 pocket costs for treating
38 skin sores and sore throat

- ↳ 5.1a Make antibiotics for skin sores and sore throat free for all high-risk people at point of care
↳ 5.1b Fund clinics to provide free dressings for keeping skin sores covered.
↳ 5.1c Promote availability of free or low cost treatment for skin sores and sore throat

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46 ↳ 5.2 Increase income for
47 people at risk of skin sores
48 and sore throat

- ↳ 5.2a Develop a system for families with sore throat and skin sores to be referred to service providers or Centrelink to review benefits and entitlements

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55 6. Support people at risk
56 of ARF / RHD to be
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59 management
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- ↳ 6.1 Ensure health staff support and encourage people engaging in their own health care
 - ↳ **6.1a** Train health staff to validate or congratulate people who present for care
 - ↳ **6.1b** Train clinic drivers, receptionists and other staff about the importance of skin sores and sore throat so these conditions are never minimised or dismissed
 - ↳ **6.1c** Train health staff to provide clear information about why skin sores / sore throat need treatment
 - ↳ 6.2 Support people seeking care to engage with assessment and treatment of skin sores and sore throat
 - ↳ **6.2a** Employ care navigators or support people to attend appointments
 - ↳ **6.2b** Provide training or support for people in communities with a high burden of ARF or RHD to be empowered health care consumers
 - ↳ 6.3 Support engagement by involving community in delivery of health care
 - ↳ **6.3a** Ensure community control of health care services in communities with a high burden of ARF or RHD
 - 7. Improve treatment of scabies which can cause skin damage which contributes to skin sores
 - ↳ 7.1 Improve treatment of scabies
 - ↳ **7.1a** Ensure everyone attending the clinic gets treatment for scabies and any skin sores present
 - ↳ **7.1b** Develop systems for household outreach for assessment and treatment when someone from the household is diagnosed with scabies
 - 8. Actively look for children with skin sores
 - ↳ 8.1 Identify people with skin sores outside the clinic
 - ↳ **8.1a** Develop programs for all children to have a healthy skin check at school or home
 - ↳ **8.1b** Develop a program so that children at highest risk (household contacts, siblings with ARF) have regular skin checks
 - ↳ 8.2 Identify people with skin sores inside the clinic

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9. Make assessment and treatment of skin sores / sore throat available in more places

↳ 9.1 Provide assessment / treatment for skin sores and sore throat in schools

↳ 8.2a Develop systems for children with skin sores to be referred for assessment / treatment a wider range of different services (dentists, schools)

↳ 8.2b Train health staff to opportunistically offer health skin checks for all children attending clinic for any reason

↳ 8.2c Train reception and other staff to invite / offer sore throat and skin checks

↳ 8.2d Include healthy skin checks as a mandated part of childhood health care (alongside child health checks or scheduled vaccination)

↳ 9.1a Provide staff trained to assess and treat skin sores / sore throat in schools

↳ 9.1b Ensure that guidelines on treating children at school (with and without parental consent) are clearer so health staff know what can be done

↳ 9.1c Employ care navigators who can help children in school access assessment / treatment of skin sores and sore throat

↳ 9.2 Provide assessment / treatment for skin sores and sore throat in other places

↳ 9.2a Change guidelines and regulations so that qualified staff can give assessment and treatment outside of the clinic

↳ 9.2b Facilitate assessment and / or treatment of skin sores / sore throat at pharmacies

↳ 9.2c Facilitate assessment and / or treatment of skin sores / sore throat at Centrelink offices

↳ 9.2d Facilitate assessment and / or treatment of skin sores / sore throat via dentists

↳ 9.2e Facilitate assessment and treatment of skin sores / sore throat via Emergency Departments and After Hours Services

10. Make health care delivery more acceptable

↳ 10.1 Provide culturally acceptable care

↳ 10.1a Provide health staff training on how to deliver culturally appropriate care

↳ 10.1b Routinely ask patients / consumers whether care experience is culturally appropriate

↳ 10.1c Teach health staff Indigenous languages

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11. Make it easier for people to access assessment and treatment of skin sores / sore throat

↳ 10.2 Increase the amount of care delivered by Aboriginal and Torres Strait Islander people

↳ **10.1d** Use or develop new terms for skin sores and sore throat in Indigenous languages

↳ **10.1a** Amend legislation to allow Aboriginal and Torres Strait Islander Health Practitioners to give medications for sore throat / skin sores in all jurisdictions

↳ **10.1b** Develop workforce strategies to recruit, train and retain Aboriginal and Torres Strait Islander people in primary health care

11.1 Provide more flexible clinical services

↳ **11.1a** Develop policy of 'no wrong door' so that people can access standardised sore throat and skin sore assessment / treatment at any facility they present to

↳ **11.1b** Offer assessment and treatment to all children who attend clinic with a family, not just those with a booked appointment

12. Improve service delivery by reducing costs to clinics

↳ 12.1 Reduce costs for primary care providers to assess and treat skin sores and sore throat

↳ **12.1a** Provide skin sore / sore throat treatment free at point of care in all settings

↳ **12.1b** Provide specific funding for waterproof dressings to be provided free of cost from the clinic to be used / replaced at home

13. Improve clinical guidelines on the assessment and management of skin sores and sore throat

↳ 13.1 Make clinical guidelines clearer and easier to use

↳ **13.1a** Develop easy-to-use algorithms for skin sore and sore throat management in high risk population

↳ **13.1b** Ensure sore throat and skin sore management is part of HealthPathways

↳ **13.1c** Review all clinical guidelines to ensure they align on management of skin sores and sore throat

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14. Train or educate health care staff

↳ 14.1 Provide local data about rates of ARF and RHD

↳ **13.1d** Use CARPA or other streamlined clinical guidelines throughout Australia in remote communities with a high population of Aboriginal and Torres Strait Islander people

↳ **13.1e** Develop more comprehensive guidelines which include a wider range of skin infections

↳ **13.1f** Develop clinical modules for assessment and treatment of sore throat / skin sores in medical software

↳ **14.1a** Provide all health staff with local data on the risk of ARF and RHD in the population they work with

↳ 14.2 Train health generally on skin sores and sore throat

↳ **14.2a** Provide general training for all staff about skin sores and sore throat

↳ 14.3 Train staff specifically on assessment and treatment of skin sores and sore throat

↳ **14.3a** Train health care staff specifically about how to use clinical guidelines for skin sores and sore throat

↳ 14.4 Provide specific training for specific types of health care staff

↳ **14.4a** Provide specific training for Emergency Department Staff

↳ **14.4b** Provide specific training for staff who start working in high risk regions

15. Support quality of care delivery

↳ 15.1 Undertake continuous quality care improvement

↳ **15.1a** Identify quality of care measures for sore throat and skin sores

↳ **15.1b** Undertake audits of sore throat / skin sore management based on clinical records

↳ **15.1c** Undertake case reviews of people diagnosed with acute rheumatic fever to identify any missed opportunities for primary prevention

Supplementary 4 – Detailed summary of eDelphi outcomes

eDelphi Priorities for improving primary prevention of ARF Summary of results Presented in order of % rated high priority by participants Endorsed concepts, endorsed strategies, endorsed actions and elements not endorsed *Indicates item added in Round 2 based on Round 1 feedback from participants ♦Indicates concept which was re-rated in Round 2 based on intermediate Round 1 feedback from participants (Items in brackets indicate strategies which were the same as concepts and were not presented to participants through the REDCap database to avoid duplication but retained for structural consistency)	Number of responses	Number rated as high priority (4 or 5)	%4 or 5
Concept Engage communities at risk of ARF in preventing the disease	21	20	95
(Strategy Engage communities at risk of ARF in preventing the disease)	21	20	95
Action Support community leaders to develop and facilitate key messages about sore throat and skin sores	19	15	79
Action Share positive local stories about good news examples of treating skin sores/sore throat	19	12	73
Strategy* Engage communities by addressing attitudes to skin sores and sore throat including reducing stigma and de-normalising sores	16	16	100
Strategy* Engage communities by improving access to local information about the rates of Strep A infection, ARF and RHD	16	11	69
Concept Activate or empower people to seek health services for skin sores and sore throat	20	17	85
Strategy Encourage people to actively seek assessment/treatment of skin sores	17	16	94
Action Train parents and caregivers to ask for recommended assessment of skin sores/sore throat	16	14	88
Action Train or support children on how to ask for their sore throat/skin sores to be assessed/treated	16	13	75
Action Develop the idea of a 'skin check' visit that people can ask for when they attend clinic	16	11	69
Strategy* Provide health services for skin sores and sore throat at schools	16	14	88
Strategy* Invite people to suggest strategies for reducing their own risk of skin sores/sore throat	16	11	69
Concept Support people at risk of ARF/RHD to be engaged in their own health care and self-management	20	17	85
Strategy Support engagement by involving community in delivery of health care	17	16	94
Action Ensure community control of health care services in communities with a high burden of ARF or RHD	16	14	88
Strategy Support people seeking care to engage with assessment and treatment of skin sores and sore throat	17	15	88
Action Provide training or support for people in communities with a high burden of ARF or RHD to be empowered health care consumers	15	13	87
Action Employ care navigators or support people to attend appointments	15	9	60
Strategy Ensure health staff support and encourage people engaging in their own healthcare	17	15	88
Action Train clinic drivers, receptionists and other staff about the importance of skin sores and sore throat so these conditions are never minimised or dismissed	15	13	87
Action Train health staff to validate or congratulate people who present for assessment and treatment of skin sores and sore throat	15	13	80
Action Train health staff to provide clear information and encouragement about why skin sores/sore throat need treatment	15	10	67
Strategy* Establish meaningful community governance mechanisms for skin sore and sore throat control strategies	17	14	82
Strategy* Develop peer support mechanisms for people at risk of ARF and RHD to learn more about Strep A infections and treatment	16	11	69
Strategy* Teach and empower people to do their own skin sore dressings	16	9	56
Strategy* Develop digital tools like apps or reminder texts to support self-management of skin sores and sore throat	16	6	38

Concept Health promotion to increase assessment and treatment of sore throat and skin sores	22	18	82
Strategy* Ensure health promotion occurs in local Aboriginal and Torres Strait Island languages	16	16	100
Strategy Targeted public education on the specific risks of skin sores and sore throat	17	16	94
Action Teach parents and families about the cause and risks of skin sores and sore throat through community events	16	16	100
Action Train health care workers to educate children and families about the risk of skin sore and sore throat	16	15	94
Action Teach children about the cause and risks of skin sores and sore throat at school	16	14	88
Strategy General public education to 'denormalise' skin sores	17	12	71
Strategy General public education about skin sores, sore throat, ARF and RHD	17	11	65
Strategy General public education on germs causing disease	17	9	53
Concept Provide practical or physical support to assist people to access health services*	16	14	88
Strategy Improve transport for people to attend clinic for skin sores and sore throat	14	12	86
Action Fund primary care clinics to provide transport for people who need assessment and treatment	12	11	92
Action provide education for temporary care providers (boarding schools, out of home carers) on the need for assessment and treatment of skin sores and sore throat	14	9	64
Strategy* Develop systems for people to send photos of skin sores or communicate with the clinic from outreach services	14	8	57
Strategy Extend clinic opening hours so that people can attend for assessment/treatment for more the day	16	9	56
Concept Make health care delivery more acceptable*	16	13	81
Strategy Provide culturally acceptable care	12	12	100
Action Routinely ask patients/consumers whether care experience culturally appropriate	12	11	92
Action Provide health staff training on how to deliver culturally appropriate care	12	10	83
Action Use or develop new terms for skin sores and sore throat in Aboriginal and Torres Strait Islander languages	12	10	83
Action Teach health staff Aboriginal or Torres Strait Islander languages	12	7	58
Strategy Increase the amount of care delivered by Aboriginal and Torres Strait Islander people	12	12	100
Action Develop workforce strategies to recruit, train and retain Aboriginal and Torres Strait Islander people in primary health care	12	12	100
Action Amend legislation to allow Aboriginal and Torres Strait Islander Health Practitioners to give medications for sore throat/skin sores in all jurisdictions	12	11	100
Action* Work with the community to recruit local Aboriginal and Torres Strait Islander staff	16	15	94
Action * Develop support roles for Aboriginal and Torres Strait Islander people without formal health worker training	16	15	94
Strategy* Provide formal, high quality, unconscious bias and cultural competence training for staff	16	9	56
Strategy* Facilitate use of traditional medications for skin sores and sore throat alongside guideline-based care	16	8	50
Concept Improve treatment of scabies, which can cause skin damage, which contributes to skin sores*	16	13	81
(Strategy Improve treatment of scabies, which can cause skin damage, which contributes to skin sores)	16	13	81
Action Develop systems for household outreach for assessment and treatment when someone from the household is diagnosed with scabies	15	15	100
Action Ensure everyone attending the clinic gets treatment for scabies and any skin sores present	15	14	93
Strategy* Provide or advocate for housing and environmental health services for people with scabies and skin sores	16	14	88
Action* Provide or advocate for facilities for people with scabies to wash clothes and bedding	16	12	75
Strategy* Develop specific resources about scabies and use of treatments in local language	16	13	81
Concept Make it easier for people to access assessment and treatment of skin sores/sore throat*	17	12	75

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Concept Train or educate health care staff [♦]	16	12	75
Concept Make assessment and treatment of skin sores/sore throat available in more places [♦]	16	11	69
Concept Support quality of care delivery [♦]	16	9	56
Concept Improve clinical guidelines on the assessment and management of skin sores and sore throat	20	11	55
Concept Improve service delivery by reducing costs to clinics	20	9	45
Concept Actively work to identify people with skin sores [♦]	16	6	38
Concept Reduce the costs for people seeking assessment/treatment of skin sores/sore throat	20	6	30

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Supplementary 5

Levesque et al. framework domain	Concept	Key themes	Illustrative quotes
Demand Ability to perceive	Health promotion to increase assessment and treatment of sore throat and skin sores	Responses focused on <i>how</i> to do health promotion (for example through songs, posters, events, radio), <i>who</i> should do health promotion (with strong support for school-based health promotion) and <i>where</i> to do health promotion (particularly outreach and home visits). Many participants identified the need for health promotion to be accessible to Aboriginal and Torres Strait Islander people through the use of local languages and with cultural and contextual relevance.	“Most health inequity is due to ongoing colonisation including loss of languages and culture. Including Aboriginal languages especially on a health topic sends a very strong message” ID 23, R2, I1 ”
Demand Ability to seek	Activate or empower people to seek health services for skin sores and sore throat	eDelphi strategies presented in this domain generated little qualitative engagement. Instead, qualitative feedback strongly supported the need for children to be able to seek healthcare at school.	“Provide flexible access options to assessment and treatment. Perhaps option of streamlined skin check clinics, perhaps clinic for adults as well as their children collocated at school for pickup drop off time walk-in” – ID 16, C3
Demand Ability to engage	Engage communities at risk of ARF in preventing the disease	There was strong support for the importance of ‘engagement’ and the need for community leaders to be involved in improving primary prevention. Specific engagement strategies included sharing local burden of disease data with the community and addressing community attitudes to skin sores. A number of participants identified the importance of reducing both the stigma, and the normalisation, of skin sores.	“ <u>Engage community leaders</u> to identify opportunities for prevention of ARF – e.g. a community forum on primary prevention” ID 5, C2 Strategies to effectively manage and destigmatise are important. Needs to be done with the elders and Tos (traditional owners) or community spokespeople. ID19, R2, I9
	Support people at risk of ARF/RHD to be engaged in their own healthcare and self-management	Qualitative responses had a very strong focus on community-level engagement with multiple participants identifying the need for ‘community governance’ or a ‘community reference group’. Two participants identified governance and representation within community-controlled health services as problematic. A small number of specific strategies for increasing individual engagement in care, including education for people to	“Obviously we already know what works with primary prevention of RHD so we just need to work on implementing it better and the people who can assist with guiding this are the communities themselves” – ID 5, FT16

		their own skin sore dressings, peer support groups or digital tools to support self-management.	
Supply Availability and accommodation	Actively work to identify people with skin sores	eDelphi statements in this concept included various strategies to actively deliver skin checks (through outreach, opportunistically to people attending clinic, through scheduled child health checks). There was a low level of support for these and few qualitative responses addressed any of these strategies directly. Some respondents highlighted the risks associated with active case finding of skin sores.	“Health service led efforts are never going to be as effective as community led initiatives to improve treatment uptake and <u>may contribute to stigma associated with skin sores.</u> ” ID13, R2, I8
Supply Appropriateness	Make health care delivery more acceptable	Acceptability (and thereby appropriateness) eDelphi statements were largely focused on ensuring culture was embedded in care delivery. This included strong support for the use of Aboriginal and Torres Strait Islander language in clinical care and increased recruitment, retention and role expansion for Aboriginal and Torres Strait Islander health staff. Responses supported cultural training to reduce racism of health care providers. There was equivocal support for incorporating elements of traditional medicines into management protocols for skin sores and sore throat.	“And how to manage <u>culture shock and be aware of Own prejudice</u> when treating patients – can be very hard for patients to keep turning up when they feel misrepresented and misunderstood”. ID19, R2, I14
Supply Approachability	Make it easier for people access assessment and treatment of skin sores / sore throat	Qualitative responses highlighted the need for flexibility in delivering clinic-based services. Specifically, this included a need to reduce waiting times, offer walk-in appointment and ensure a welcoming experience. Some participants supported an increase in after-hours service provision.	“Again, many of these strategies are still focused on somebody having access to the clinic. If they work or want their children to attend school, they may not want to miss large amounts of time <u>waiting at least an hour to be seen in the clinic.</u> Staff are generally quite aware of these things in remote health centres, but the <u>system isn’t designed to cope with the number of presentations and waiting times are often unacceptable</u> ” – ID 13, C6
	Make assessment and treatment available in more places	eDelphi statements in this concept included some of the approaches derived from the (urban) New Zealand experience of providing services in pharmacies, dental clinics and social services. These were generally not considered applicable to the	“Move <u>care outside of the clinic more</u> – e.g. a skin / sore throat mobile team to review and treat people in their homes” – ID 5, C4

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		remote Australian setting (“ <i>In aboriginal communities ... there are no dentists, pharmacies</i> ” – ID 21, C9) but qualitative responses reflected strong support for outreach service outside of the clinic, to schools or homes. The practicalities of outreach services were addressed by some participants, including scope for telehealth from outreach workers to clinics and the potential constrain of regulations about delivering treatment outside of clinical settings.	“Employ family-based support workers to perform household outreach for education, assessment, treatment, and prevention activities” – ID 29, C7
	Provide practical or physical support to assist people to access health services	Qualitative responses emphasised the importance of providing transport for people to attend the clinic and identified various strategies for this to be achieved (including taxi vouchers, regular bus routes and clinic transport). The costs of providing transport were identified as a barrier for clinics to improve services. A number of participants noted that outreach services or telehealth capacity could obviate some of these transport needs.	“Funding <u>transport</u> would not be as cost effective as Telehealth (emailing or texting photographs of sores and if relevant throats)” – ID 18, C4 “Must be tied with the <u>outreach service being able to provide treatment</u> rather than client then need to attend the health service(removes a barrier for timely treatment).” ID16, R2, I4
Supply Affordability	Reduce the costs for people seeking assessment and treatment of skin sores	eDelphi statements in this concept included cost reduction approaches used in New Zealand, including free medical visits and medications. Most participants identified these are not relevant to remote Aboriginal and Torres Strait Islander communities where clinic attendance and medication are generally free at point of care. The need to minimise costs in urban setting was noted.	“This <u>may be an issue in metropolitan services</u> but not one in community government funded clinics.” ID19, R2, I5 “in the context I work in <u>there isn’t any cost</u> . In areas where there is a <u>cost associated with accessing care then maybe this is a significant barrier</u> (I wouldn’t really know) however if care was available in schools etc this would also get around the cost issue.” ID13, R2, I5
	Improve service delivery by reducing costs to clinics	eDelphi statements in this concept included suggestions about funding clinics for consumable products (particularly dressings for skin sores). There was little support for this approach. Instead, qualitative responses identified the need for the Section 100 medication to be available in urban settings and for bulk billing of consults. A small number of participants	“Aboriginal medical services in cities such as Darwin, need to be provided free medications such as Benzathine penicillin (like under <u>S100</u>) to give immediate treatment for skin sores as well patients needing 2ndary prophylaxis” – ID 16, C12

		suggested new Medicare item numbers be created for skin checks.	"? An item number for Aboriginal and Torres Strait Islander skin presentations to signal how important this consultation is" – ID 23, C12
Supply Acceptability	Improve clinical guidelines on the assessment and management of skin sores / sore throat	There was limited support for improving or expanding clinical guidelines in eDelphi statements. Qualitative feedback suggested that existing guidelines were sufficient and that other issues (time, staff training, accessibility of guidelines) were more significant barriers to the delivery of guideline-based care. A small number of specific recommendations about guideline content were made (" <i>Clarify the distinction between 'scabies' and impetigo</i> " – ID 12, C13)	" <u>Guidelines</u> existing are reasonable." ID27, R2, I13 "My experience is often poor diagnosis including hospitals giving NSAIDS for painful knees and sending home. <u>Maybe not guidelines improvement</u> , maybe just following guidelines may help." ID1, R2, I13
	Train or educate health care staff	Although there was limited support for general staff training in eDelphi responses, qualitative feedback indicated that time sensitive training for new or locum staff prior to working in remote settings was important. A small number of participants provided feedback on existing training resources, specifically that there " <i>needs to be a punchier, short version of RHD online modules</i> " ID 16, C14	"I think the awareness in the remote NT of this issue is already very high and I don't think that further education is a high priority in this context but this may be an issue interstate??" ID13, R2, I14 "Ensure any locum staff (doctors or nurses) have ARF/RHD/skin sore training <u>PRIOR to starting at the clinic</u> – mandatory prior to starting placement" – ID 22, C14
	Improve treatment of scabies, which can cause skin damage, which contributes to skin sores	Qualitative feedback on improving scabies treatment elicited some specific opinions related to scabies management (including details of lyclear use) and broad support for action on the environmental health to mitigate scabies risk. This included support for washing, housing and bedding facilities. Many of these themes were re-emphasised in general qualitative feedback.	" <u>Embed health hardware home visits</u> as part of follow up of patients presenting with scabies, skin sores, ARD, RHD" – ID 16, C7
	Support quality of care delivery	Qualitative responses on improving quality of care delivery were mixed. Some participants identified the value of clinic audits or key performance indicators for quality improvement. Others felt these activities could be distracting or burdensome to clinics. A small number of participants identified specific process	"Bulk-bill, more Aboriginal health workers, subsidise the treatment, facilitate the access to the service, educate the community about what you are doing, audit and review really important.

		<p>indicators which may help identify progress towards improve primary prevention.</p>	<p><u>Everyone thinks they are doing a good job until they are audited</u> – ID 23, FT16 “I think this is a good idea but wonder if it will seem like a burden to clinics...” ID15, R2, I15”</p>
<p>General qualitative feedback</p>		<p>At the end of the eDelphi process participants were asked to ‘Please suggest any other ideas you have to improve delivery of primary prevention in primary care’. Overwhelmingly two issues were raised:</p> <ul style="list-style-type: none"> - the need for <u>prevention</u> of skin sores/sore throat rather than improving treatment - the need to increase the Aboriginal and Torres Strait Islander health workforce. <p>Implicit in some of these comments, and in qualitative feedback on other concepts, was the idea that disease-specific approaches which have a narrow focus are likely to be counterproductive in the absence of system-wide strategies.</p>	<p>“Primary prevention ultimately can only be effective in reducing ARF alongside more effective <u>primordial prevention measures</u>” - ID 20, FT16</p> <p>“There needs to be engagement of other government departments ie: housing to improve health hardware, expedited repair of housing issues especially health hardware, more housing with RHD clients given priority, more availability of emergency housing for families in communities” - ID 22, FT16</p> <p>“Many of the ideas here were related to educating staff however in the NT at least most staff are very proactive about treatment, however access to services, waiting times and <u>staff shortages</u> are the biggest barriers. Improving access to treatment for these conditions in easy to access places (such as school nurse/health workers, or in places that do have a private pharmacy etc) would do much more than telling overworked primary health care staff what they already know and are trying their best to achieve”- ID 13, FT16</p>

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Improving primary prevention of acute rheumatic fever in Australia: consensus primary care priorities identified through an eDelphi process

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Abstract

Objectives: To establish the priorities of primary care providers to improve assessment and treatment of skin sores and sore throats among Aboriginal and Torres Strait Islander people at risk of acute rheumatic fever (ARF) and rheumatic heart disease (RHD).

Design: Modified eDelphi survey, informed by an expert focus group and literature review

Setting: Primary care services in any one of the five Australian states or territories with a high burden of ARF.

Participants: People working in any primary care role within the last 5 years in jurisdiction with a high burden of ARF.

Results: Nine people participated in the scoping expert focus group which informed identification of an access framework for subsequent literature review. Fifteen broad concepts, comprised of 29 strategies and 63 different actions, were identified on this review. These concepts were presented to participants in a two round eDelphi survey. Twenty-six participants from five jurisdictions participated, 16/26 (62%) completed both survey rounds. Seven strategies were endorsed as high priorities. Most were demand-side strategies with a focus on engaging communities and individuals in accessible, comprehensive, culturally appropriate primary health care. Eight strategies were not endorsed as high priority, all of which were supply-side approaches. Qualitative responses highlighted the importance of a comprehensive primary health care approach as standard of care rather than disease-specific strategies related to management of skin sores and sore throat.

Results

Conclusion: Primary care staff priorities should inform Australia's commitments to reduce the burden of RHD. In particular, strategies to support comprehensive Aboriginal and Torres Strait Islander primary care services rather than an exclusive focus on discrete, disease-specific, initiatives are needed.

Strengths and limitations of this study

- This eDelphi study is the first structured approach to understanding what primary care staff think are the biggest priorities for improving primary prevention of acute rheumatic fever.
- Two rounds of Delphi responses are used to elucidate consensus priorities of primary care staff.
- In addition to quantitative Delphi survey results, a large amount of qualitative data strengthens the study and interpretation of results.
- Limitations of the study include a modest number of total participants and the necessary limitation of purposive sampling to include experiential experts.

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Introduction

Rheumatic heart disease (RHD) is a consequence of acute rheumatic fever (ARF), stemming from an abnormal immune reaction to untreated Group A streptococcal (Strep A) infection. RHD is rare in most high-income countries but persists in low- and middle-income countries and marginalised First Nations people in high income settings.¹ Aboriginal and Torres Strait Islander people in Australia have a high prevalence of RHD, leading to the greatest disparity in cardiovascular disease burden between Aboriginal and Torres Strait Islander people and non-Indigenous people.^{2,3} The highest rates of ARF and RHD occur in remote and very remote Aboriginal and Torres Strait Islander communities in Northern Australia.² These remote communities are socioeconomically deprived, with low household income, high rates of crowded living environments, and substantially lower life expectancy than urban and non-Indigenous people in Australia.^{4,5} These consequences of colonisation drive very high rates of ARF through indirect and direct risk factors.⁶ Skin infections are endemic in remote communities with almost half of all children having skin infections at any time.⁷ The primary pathogen of these skin infections is *Streptococcus pyogenes* (Strep A).⁸ The incidence of throat infections is less well described, although there are indications that the rate of symptomatic pharyngitis is relatively low in ARF endemic Australian settings.^{9,10} The high burden of early life Strep A skin and throat infections are thought to lead to immune priming which increases the risk of developing ARF in childhood.¹¹

There are a number of opportunities to intervene on the causal pathway from Strep A infection to ARF, RHD, and subsequent complications.¹² One of these opportunities is primary prevention. In the absence of a vaccine, primary prevention of ARF is exclusively antibiotic treatment of Strep A infections to reduce the risk of developing ARF.¹³ The risk reduction for ARF following Strep A throat infection is well described. Treatment with oral penicillin can reduce the attack rate of ARF following Strep A throat infection by about 70%, increasing to 80% if a single intramuscular injection of benzathine benzylpenicillin is given within 9 days of symptom onset.¹⁴ The risk reduction of ARF following skin sores has not been empirically well documented but is biologically plausible and consistent with increasingly nuanced understanding of ARF pathogenesis.¹⁵ On this basis, if Strep A infections can be diagnosed and promptly treated with appropriate antibiotics, many episodes of ARF would be preventable.^{13,14}

Over the last decade Australia's efforts to reduce the burden of RHD have largely focused on delivering secondary prophylaxis for people who have already had ARF.^{16,17} An external review of Australia's Rheumatic Fever Strategy in 2017 identified improving primary prevention of ARF as a priority for ending RHD in Australia, however, there is no consensus on how this can be achieved.¹⁶ Research, anecdote, and opinions suggest that a wide range of strategies *could* be effective in improving treatment of sore throat and skin sores. However, potential approaches have not been collated, reviewed, or consulted with stakeholders. Clinics seeking to improve primary prevention have little indication of which strategies have a robust evidence base or stakeholder support for prioritisation. The END RHD Centre of Research Excellence (END RHD CRE) was funded in 2014 to help identify an 'endgame' for RHD in Australia, including recommendations to strengthen primary prevention of ARF.¹⁷

This study, embedded within the END RHD CRE, is intended to give voice to the operational priorities of primary health care staff working in Aboriginal and Torres Strait Islander health for improving primary prevention. The aim of the study is to identify which strategies primary health care workers believe would be most effective in improving assessment and treatment of sore throat and skin sores in remote Aboriginal and Torres Strait Island communities. Directly, these consensus findings help inform the RHD Endgame Strategy.¹⁷ Indirectly, this study adds to international literature about access to healthcare for Indigenous people by applying a disease-specific lens to an existing

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3 framework for analysing access. Finally, it seeks to provide avenues for future research to address
4 knowledge gaps and implementation science to prevent RHD.
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7 8 9 **Methods**

10 **Focus group and theoretical framework**

11 A focus group of END RHD CRE investigators and affiliates was initially convened to inform the scope
12 of this research. The group was asked two questions: (1) 'What are the priority actions to improve
13 primary prevention of ARF?' And (2) 'Which are the three highest priorities?' Responses were
14 discussed and consensus recommendations were incorporated into a conceptual framework of
15 access to healthcare proposed by Levesque et al. which has also been adapted for use in Indigenous
16 primary health care settings (Figure 1).^{18,19}
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20 **Literature review**

21 Informed by the focus group findings, a literature review was conducted to identify potential
22 strategies for improving delivery of primary prevention and to sort these according to the Levesque
23 et al. conceptual framework. A Medline search of peer-reviewed literature from Australia and New
24 Zealand from January 2010 - December 2018 was conducted (search strategy, supplementary
25 material 1). We focussed only on publications from Australia and New Zealand as both countries
26 experience a large burden of ARF and RHD among Indigenous communities, have comparable health
27 systems, and some shared challenges in improving access to healthcare. Citation tracking and
28 recommendations from the investigator team were used to identify additional relevant publications.
29 A supplemental grey literature search using Google was conducted to identify operational reports
30 and program evaluations using adapted search terms [rheumatic fever + (prevention / plan /
31 program / strategy) + (Australia / New Zealand)]. All documents were reviewed for specific
32 strategies to improve assessment and treatment of skin sores and/or sore throats. Strategies were
33 eligible for inclusion if they were an 'implementable action', specifically something which clinics or
34 communities could do. Suggestions about research priorities and broad statements about general
35 strategies were not included. Strategies identified in each document were extracted to a Microsoft
36 Excel file by two authors and duplicates removed. Strategies were then sorted into thematic areas of
37 the Levesque et al. access framework, reviewed by the authorship team, and transformed into
38 statements suitable for eDelphi review.
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43 **eDelphi study**

44 The Delphi technique is used to identify consensus areas between experts, particularly 'in scenarios
45 which cannot feasibly or ethically be subject to a randomised controlled trial'.²⁰ The approach
46 involves experts providing feedback on different options over repeated 'rounds,' with feedback
47 between rounds to move the group towards consensus. Electronic Delphi (eDelphi) approaches
48 mirror the process of an in-person Delphi, but maximise opportunities for people to participate from
49 different places and at times most convenient to them. In this study, primary care staff with
50 frontline expertise in service delivery participated in an eDelphi study to identify consensus priorities
51 to improve assessment and treatment of skin sores and sore throat for primary prophylaxis of ARF.
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54 **Patient and Public Involvement**

55 Patient and public stakeholders were not directly involved in this study of health professional
56 preferences. However, patient perspectives were included in the literature review to solicit potential
57 approaches to improving primary prevention.
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3 Three levels of statements were developed from the literature synthesis: *concepts* (overarching
4 ideas, “what’ should be done’), *strategies* (different approaches to implementing concepts), and
5 *actions* (“how’ concepts should be done’). Language in each statement was standardised to
6 maximise applicability for both skin sores and sore throat and throughout Australia. A REDCap
7 (Research Electronic Data Capture) database was built to electronically present concepts, strategies,
8 and actions for ranking by participants.²¹
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11 Potential participants were identified through the professional networks of the investigator team.
12 Participants were eligible if they had worked in any primary care role (including general practitioner,
13 nurse, Aboriginal and Torres Strait Islander Health Practitioner, environmental health worker, school
14 nurse, administrator, receptionist) within the last 5 years in one of the five states or territories with
15 a high burden of ARF (New South Wales, Queensland, Northern Territory, South Australia, Western
16 Australia). Invitation emails containing a link to Round 1 of the eDelphi were sent to participants
17 followed by three reminder emails to participate over the following two weeks. In Round 1,
18 participants rated each concept on 1 – 5 Likert scale ranging from low priority to high priority. If the
19 concept was identified as low priority (1 – 3 / 5), the participant moved automatically to the next
20 concept. If the concept was identified as high priority (4 -5 / 5), the participant was asked to rank
21 associated strategies and actions on the 1- 5 scale. Following each concept, participants were also
22 asked to add other strategies or comments about improving primary prevention as free text entries.
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26 Round 1 responses were extracted and organised in a spreadsheet. Concepts rated as high priority
27 (Likert 4 or 5) by more than 80% of participants were considered to be endorsed. Concepts rated as
28 high priority by 60 – 80% of participants were considered equivocal and re-presented to participants
29 in Round 2 alongside feedback from the group, allowing participants to adjust their ranking with a
30 view to forming a consensus opinion. Round 1 concepts that were considered by fewer than 60% of
31 participants to be high priority were excluded. New concepts, strategies, or actions identified from
32 free text responses in Round 1 were also coded and presented to participants in Round 2.
33 Participants who completed Round 1 were emailed four weeks later to complete Round 2. Concepts
34 rated as high priority (Likert 4 or 5) by more than 80% of participants were considered to be
35 endorsed. All other Round 2 concepts were excluded.
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38 Qualitative data

39 Free text entries were also thematically analysed, identifying concept-specific feedback and
40 overarching themes about primary prevention priorities.
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43 All authors, two of whom are Aboriginal, contributed to interpretation of results.
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45 Results

46 Scoping expert focus group

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48 The expert focus group was convened in May 2018 and had nine participants: six researchers, two
49 clinicians, and one ‘employed in RHD’ to generate a framework for literature review. Seven
50 participants worked primarily in Australia, one in New Zealand, and one in another international
51 setting. There were no Aboriginal or Torres Strait Islander participants. Twenty-seven distinct
52 approaches for improving primary prevention were identified by the focus group (supplementary
53 material 2). The group identified the three highest priorities as:
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- 56 ○ **Health promotion, awareness, and education campaign** for skin sores and sore throats
57 targeting health workers, education providers, community members, and families.
- 58 ○ Augmented approaches that look at **new ways to improve identification and management of**
59 **sore throat**: exploring community worker roles, disruptive technologies such as clinical
60

photography and telehealth, point of care tests and integration with other health issues, community knowledge, and preferences.

- **Research** to understand sore throat burden, how to improve control of skin infections in Aboriginal and Torres Strait Islander communities, and Strep A vaccine development.

Literature review

In total, 57 Australasian sources were identified containing suggested approaches to improving assessment and treatment of skin sores or sore throat. Twenty seven publications were identified from a Medline search with citation review; an additional 30 grey literature documents were identified from the internet Google search. Grey literature was drawn from a broad range of sources, including six 'Rheumatic Fever Prevention Plans' developed by District Health Boards in New Zealand and consultative outcomes (including a RHD Australia colloquium in 2015²² and evaluation of the Australian Rheumatic Fever Strategy in 2017¹⁶). From these sources, 15 concepts, comprising 29 strategies and 63 different actions for improving primary prevention of ARF were developed (supplementary material 3). The 15 concepts were mapped to the Levesque et al. access framework (Figure 2).

eDelphi

Investigators identified 53 potential participants through their professional networks. Recruitment, response, and retention rates are outlined in Figure 3; 43% of eligible participants successfully contacted by email participated in Round 1 and 16 (76%) of these people also participated in Round 2.

Overall, 26 people completed either Round 1 and/or Round 2 of the eDelphi process between June – September 2019. Demographic details of participants are presented in Table 1. Two participants identified as an Aboriginal or Torres Strait Islander person.

	n (%)
Professional role	
General Practitioner	13 (50%)
Registered Nurse	3 (12%)
Aboriginal or Torres Strait Islander Health Professional	1 (4%)
Environmental Health Worker	1 (4%)
Not stated	8 (31%)
Jurisdiction	
Northern Territory	12 (46%)
South Australia	2 (8%)
Western Australia	2 (8%)
Queensland	1 (4%)
New South Wales	1 (4%)
Not stated	8 (31%)

Table 1: Characteristics of n=26 participants who completed either Round 1 or Round 2 of the eDelphi survey.

After the two rounds, 7 concepts (including 15 strategies and 21 actions) were endorsed as priorities by participants and eight concepts were not endorsed (Figure 4 and supplementary material 4).

Qualitative data findings

In total, 287 additional free text entries were provided by the participants across two survey rounds. Two passes of qualitative analysis were conducted. The first pass consolidated feedback specific to each concept; this occurred after Round 1 to inform development of Round 2 and again after Round 2 to explore the evolution of consensus. This concept-specific analysis is presented in supplementary Material 5. A second pass inductive analysis was conducted to identify repeated themes spanning across concepts to develop an understanding of deeper structural determinants of concept-specific responses. Three over-arching themes were identified; these themes were well illustrated with specific reference to skin sores (see Box).

Theme 1: Prevention and environmental health

Although eDelphi statements related to primary prevention of ARF through *treatment* of skin sores and sore throat, a large number of participants provided comments about how skin sores and sore throat could be better *prevented*. Some of these comprised opportunities to embed preventative actions within primary care services: *“Linking primary care services with the ability to refer for services to address the social determinants of health in households with high rates of sore throats or skin sores, e.g. access to improved housing, reliable power and water, washing machines etc. – ID 9”*. However, the majority of qualitative comments implied that eDelphi statements about clinic-based activities to improve primary prevention were of limited value without separate and broader action on environmental determinants of health: *“Primary prevention ultimately can only be effective in reducing ARF alongside more effective primordial prevention measures - ID 20”*.

Theme 2: Aboriginal and Torres Strait Islander health workforce, culture, and community

Workforce issues were identified as relevant in almost all concepts. This included inadequate overall numbers of staffing in primary care (limiting access to approachable, timely care and guideline-based, technically acceptable services) and too few Aboriginal and Torres Strait Islander people delivering healthcare, contributing to care which people could not access or engage with: *“if a health service has a large number of Indigenous staff this will provide much better cultural oversight than giving 'formal' cultural training- ID13”* By extension the significance of Aboriginal and Torres Strait Islander ways of knowing, being, and doing were addressed in a number of domains. Operationally, this included strong support for the use of materials in Aboriginal and Torres Strait Islander languages for engagement, education, and health promotion. Some participants provided more detailed reflections about the importance of using Aboriginal and Torres Strait Islander languages: *“Most health inequity is due to ongoing colonisation, including loss of languages and culture. Including Aboriginal languages especially on a health topic sends a very strong message - ID 23”*. eDelphi statements about approachability and ability to engage in health services also elicited a number of reflections about services which are not culturally responsive nor welcoming for Aboriginal and Torres Strait Islander people attending with skin sores and sore throat: *“And how to manage culture shock and be aware of own prejudice when treating patients - can be very hard for patients to keep turning up when they feel misrepresented and misunderstood - ID19”*. Community control of health services, incorporation of traditional medicines, and community engagement were suggested by some participants as a means to improve culturally responsive care.

Theme 3: Permeability and navigability of primary health care services

Issues raised in Theme 2 manifest a number of tangible barriers to people accessing care, including long waiting times, limited after-hours services for non-urgent care, inadequate transport, and lack of outreach services. Participants identified a number of mitigating strategies, with strong support for increasing outreach care (particularly through schools) and extended clinic opening hours: *“Provide flexible access options to assessment and treatment. Perhaps option of streamlined skin check clinics, perhaps clinic for adults as well as their children collocated? at school for pickup drop off time walk-in - ID16”*.

Box: Skin sores an object lesson for qualitative themes

Skin sores provide a tangible example of how these themes affect access to health services. Participants identified in Theme 1 that the priority for skin sores was prevention rather than treatment: *“As per previous suggestions re skin sores having access to freely available hot water to wash clothes and bedding on a regular basis (not just when they have scabies) rather than having to buy a power card to wash with hot water. ID13”* In Theme 2, the importance of culturally responsive care, ideally by Aboriginal and Torres Strait Islander providers, was highlighted in order to work effectively within belief systems about skin sores which included both normalisation and stigmatisation: *“Need to reduce the shame factor and association with poor hygiene – ID23”* and *“Denormalising’ skin sores is very important – ID17”*. Skin sore stigma was also described by healthcare workers, and some participants identified the risk that health promotion activities further contribute to this issue: *“health service led efforts are never going to be as effective as community led initiatives to improve treatment uptake and may contribute to stigma associated with skin sores - ID13”* Others reported that skin sores were considered a low clinical priority in some clinics, potentially contributing to the barriers to access expanded on in Theme 3 (*“Not being sent away from clinics ... told not an emergency.. come back tomorrow. - ID 21”*), though this was not universal.

Discussion

This study provides insights into primary care worker priorities to improve assessment and treatment of skin sores and sore throat amongst Aboriginal and Torres Strait Islander people as a core activity for prevention of ARF. It is the first time we are aware of that a primary care approach to inform priorities has been used for primary prevention of ARF, and aligns with the key characteristics of effective Indigenous led primary care.²³ Four of seven endorsed priorities were demand-side domains (ability to perceive, ability to seek, and ability to engage in health care). These were also the domains with high levels of agreement which were endorsed in Round 1, though agreement varied on specific associated actions. For example, ‘engage communities at risk of ARF in preventing the disease’ was ranked as high priority by 20/21 (95%) respondents to that question, with support for specific actions ranging from 100% (‘Engage communities by addressing attitudes to skin sores including reducing stigma and de-normalising skin sores) to 69% (Engage communities by improving access to local information about the rates of Strep A infection, ARF and RHD). Collectively, endorsed demand-side concepts reflect a provider focus on *how* services are delivered to drive greater demand for health services, including partnership with communities, empowerment, appropriate health promotion, and self-management support. Three of seven endorsed priorities were supply-side strategies (approachability, acceptability and appropriateness). These supply-side issues reflected a similar focus on providing accessible, culturally responsive, primary health care services. Conversely, all of the domains which were not endorsed were supply-side, including clinic level activities like health care worker training, quality improvement activities, and clinical guidelines. ‘Improving treatment of scabies’ was an endorsed supply side priority, somewhat incongruent with the broader focus on disease-agnostic priorities. This may reflect specific concern about scabies as a risk factor for skin sores or exposure to focused education on the impact of scabies.

Supply-side barriers to access (including navigability and permeability of services²⁴) were identified in qualitative feedback, including waiting times, limited after-hours services, and limited outreach capacity. A number of participants reflected on the root cause of these barriers, including an inadequate primary care workforce with too few Aboriginal and Torres Strait Islander people employed and too few employed to their full scope of practice. Navigability barriers have been reported in a number of other primary care studies and tackling these provides an ongoing

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3 opportunity to improve service access.^{19,23,25,26} Outreach services to provide care in schools, in
4 homes, and to remote outstations were particularly emphasised in this study. Participants reflected
5 on barriers and enablers to outreach, including the difficulty of delivering treatment outside clinical
6 settings and the potential role of telehealth in supporting outreach workers to communicate with
7 clinic-based staff. Despite these comments, eDelphi concepts including 'make it easier for people to
8 access assessment and treatment of skin sores and sore throat' and 'make assessment and
9 treatment of skin sores and sore throat available in more places' were not endorsed by the group.
10 This may be because comments on care accessibility may have been perceived as an essential
11 standard of care that did not need re-emphasis. They were dwarfed by feedback on the importance
12 of community, cultural, and clinic context in which people seek and receive primary care, including
13 who provides care, how it is governed, and how communities participate in decision making.
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16 Few qualitative responses were specific to the issue of skin sores and sore throat. Rather, they
17 reflected broader determinants of effective primary care for Aboriginal and Torres Strait Islander
18 people. A 2018 systematic review of the characteristics of effective Indigenous primary care
19 identified eight interdependent, elements: culture, accessible health services, community
20 participation, continuous quality improvement, culturally appropriate and skilled workforce, flexible
21 approach to care, holistic health care, and self-determination and empowerment.²³ Each of these
22 elements were clearly identifiable in qualitative responses to this eDelphi.
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25 The prioritisation by primary care staff of *how* – structurally and culturally – care is delivered for skin
26 sores and sore throat, is telling. Culturally and contextually appropriate ways of working in
27 Aboriginal and Torres Strait Islander health are already widely acknowledged to be a major
28 determinant of care quality and outcomes.^{23,27} However, it is not always clear how these 'horizontal'
29 systems issues relate to vertical, disease-specific, initiatives. Efforts to improve care for specific
30 conditions more commonly focus on tangible supply-side interventions such as clinical guidelines,
31 decision support, and staff training. For example, in ten clinics participating in a stepped wedge
32 study to improve delivery of secondary prophylaxis for people with ARF, action plans developed by
33 clinic staff included far more actions addressing clinical information systems (29 items) than
34 community linkages (4 items) or self-management support (4 items).²⁸ Qualitative evaluation of that
35 study found that limited attention to community linkages and self-management, in addition to
36 contextual factors, contributed to limited gains in secondary prophylaxis adherence.²⁹ This eDelphi
37 parallels these findings, providing more evidence from clinical staff that the context in which
38 disease-specific initiatives are implemented is likely to be the determining factor of success. The
39 participating primary care providers in the current study indicated lack of support for approaches
40 which prioritise clinical supply-side issues over systematic approaches to strengths based,
41 comprehensive, community engaged, culturally responsive primary care. A number of participants
42 specifically identified the risks of vertical programs fragmenting care or services. Overall, supply-side
43 supports (such as clinical guidelines and staff training) are likely to be prerequisites to successful
44 disease management; but time, staffing and cultural constraints identified by primary health care
45 staff may make use of these resources prohibitively difficult. Participants identified broader
46 contextual factors as priorities in this study; presumably to potentiate use of existing and emerging
47 resources. Notably, priorities identified by primary care differed from the scoping expert focus group
48 (comprised primarily of researchers and RHD content experts) which focused on health promotion,
49 improved clinical approaches to primary care and the need for further research. This highlights that
50 different stakeholders - including lived experience experts, service provision experts and subject
51 matter experts - have varying perspectives and priorities. Understanding and integrating these
52 perspectives into service design is likely to best support improved care delivery.
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58 This study was designed to identify clinic-level strategies in primary care for improving primary
59 prevention (by definition, once Strep A infections have already occurred) and therefore did not
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3 include eDelphi statements related to community-level risk reduction strategies. However, this
4 appeared to be an arbitrary distinction for participants; many emphasised that clinical primary
5 prevention strategies alone would be insufficient. Risk factors for Strep A infections, ARF, and RHD
6 include household crowding, inadequate access to health hygiene infrastructure and socioeconomic
7 marginalisation.³⁰ In particular, housing and environmental health factors are the major driver of
8 Strep A skin sores in remote Aboriginal and Torres Strait Islander settings.³¹ Approaches for
9 integrating environmental health into clinical care delivery were suggested by participants, including
10 the need for referral pathways for environmental assessments and services. Efforts to integrate
11 environmental health into comprehensive primary care are increasing in some parts of Australia and
12 warrant ongoing development.^{32,33} Other participants identified that broader actions addressing the
13 social and environmental drivers of Strep A infection outside the health service are needed,
14 including new housing and infrastructure. Some responses implied a frustration that the greatest
15 outstanding needs for addressing skin sores and sore throat were outside the influence of primary
16 care staff and services.
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20 Skin sores were an important object lesson, illustrating a broad range of clinical and non-clinical
21 issues which participants considered to be priorities. Primary health care staff identified complex
22 attitudes influencing community and clinic responses to skin sores, including stigma, normalisation,
23 and a strong association with poor hygiene. This resonates with a recently published study on
24 barriers and enablers to skin sore treatment in the Pilbara, which found that shyness, shame, fear of
25 judgement, normalisation and prejudice were significant factors in the decision to seek care.³⁴
26 Primary health care staff in this eDelphi study, and in the Pilbara study, identified health promotion
27 as a priority to increase health seeking for skin sores.³⁴ However, a number of participants discussed
28 the risk of inadvertently increasing stigma if skin sores were associated with poor hygiene in health
29 promotion activities. A strong message from community is to prioritise a strengths based approach
30 to health promotion.³⁵ This risk is real; stigmatisation associated with health promotion campaigns
31 about sore throat and ARF for Māori and Pacific Islander peoples in New Zealand has been well
32 described.³⁶ Similarly, health promotion about handwashing and healthy living practices may be
33 alienating if people do not have access to functional household infrastructure such as taps and
34 soap.³⁷ Participants identified that culturally relevant, stigma-free, health information about skin
35 sores in Aboriginal and Torres Strait Islander languages was a priority. Other qualitative comments
36 made it clear that effective knowledge transfer was predicated on community engagement and
37 access to environmental health supports which would allow people to engage with and act on this
38 information.
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42 This study has a number of limitations. Participants were identified through the professional
43 networks of the investigator team. Therefore, they may not be representative of the primary care
44 workforce or may have been sensitised to issues around ARF and about cultural safety in healthcare.
45 Network based deliberative sampling is common in Delphi studies.³⁸ Identifying participants through
46 the networks of multiple investigators to approach colleagues in different jurisdictions, roles and
47 professional contacts helps to mitigate this risk. The overall number of study participants was
48 modest, though a 43% response rate higher than some comparable eDelphi projects involving
49 primary health care in Australia.³⁹ Further, participants were drawn from all five jurisdictions in
50 Australia with ARF/RHD registers and the number of participants is comparable with other eDelphi
51 studies in Aboriginal and Torres Strait Islander health.²⁰ Only two Aboriginal and Torres Strait
52 Islander people participated in this study; consequently, results predominantly reflect perspectives
53 of non-Indigenous remote health staff. It is critically important that findings from this study are
54 considered in conjunction with the perspectives and priorities of Aboriginal and Torres Strait Islander
55 people with lived experience expertise of skin sores, sore throat, and at risk of ARF. A number of
56 publications address the experiences of Aboriginal and Torres Strait Islander people with skin sores
57 and address common themes, including that information provided only in English is of limited value
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and that experiences at the clinic have a major influence on care-seeking behaviour.^{34,40,41} Most Round 1 respondents (76%) also completed Round 2, indicating reasonable engagement in the process and the quantity and quality of free text comments indicate that participants were deeply committed and thoughtful with regard to their responses. Detailed qualitative analysis is not a routine part of eDelphi methodology, though qualitative adaptations have been described.^{38,42} The volume and detail of free text responses to this eDelphi made it possible to use inductive thematic analysis to better understand the rationale for participants endorsing and not endorsing different concepts.

This study suggests that primary care providers perceive that improvements in primary prevention of ARF need to come from broad systems strengthening to achieve excellence in culturally safe primary health care. This aligns with what is already known about accessible primary care for Indigenous people and the priorities of Aboriginal and Torres Strait Islander people, including those living with skin sores, sore throat, ARF, and RHD.^{23,34,41} A number of initiatives are underway to map a pathway to end RHD in Australia, including the RHD Roadmap and the RHD Endgame Strategy.^{43,44} This eDelphi study suggests these efforts should call for culturally responsive, comprehensive primary health care for Aboriginal and Torres Strait Islander people which involves whole communities and is readily navigable for people seeking care. These systems approaches should be augmented by a small number of disease-specific strategies for tackling Strep A infections.

Conclusions

This eDelphi study demonstrates that primary care staff prioritise demand-side determinants of access to health care to improve primary prevention of ARF among Aboriginal and Torres Strait Islander people. In particular, partnership with communities, empowerment, self-management support, and approachable care were emphasised. These priorities reflect a focus on *how* care is delivered in context, rather than technical details of the care itself. Participants largely rejected the idea of vertical, disease-specific, strategies to improve primary prevention and consistently identified horizontal, access-strengthening approaches current priorities. Ultimately, these components are indivisible; guideline and training supports to improve the quality of supply-side primary prevention must be coupled with attention to demand-side drivers which enable people to seek and engage with care. The importance of environmental health strategies and strengthening the Aboriginal and Torres Strait Islander health workforce exemplify that a comprehensive approach to prevention and treatment is also needed for meaningful impact on skin sores and sore throat. Qualitative responses highlighted the importance of a comprehensive primary health care approach as standard of care rather than disease-specific strategies related to management of skin sores and sore throat.

Figure 1: Conceptual framework on access to healthcare, adapted from Levesque et al.¹³

*Figure 2: Concepts for improving primary prevention ARF mapped to the Levesque et al. framework for access to healthcare. *Strategies subsequently endorsed by the eDelphi process are indicated in orange text.*

Figure 3: Recruitment, response and retention rates in Round 1 and Round 2 of the eDelphi process

* Two participants completed more than one concept but did not complete full survey

** Invitations to participate in Round 2 of the eDelphi process were inadvertently shared

with people who did not participate in Round 1. Five people responded to this invitation and participated in Round 2 who had not participated in Round 1 and these responses were not included in the analysis.

Figure 4: Outcomes of Round 1 and Round 2 eDelphi process

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Ethics statement

Ethics approval for the formative focus group was provided by Human Ethics Committee of University Western Australia (RA/4/20/4489). Ethics approval for the eDelphi survey was provided by the Human Research Ethics Committees of the University of New South Wales (HC180879) and the Aboriginal Health and Medical Research Council of New South Wales (HC180879).

Contributorship statement

RW, JC and DP conceived the study design. RW, GP and JC developed the formative focus group. RW and CL completed the literature review and extracted eDelphi statements based on the conceptual framework. All authors (RW, CL, VW, GP, JC, APR, ACB, DP) reviewed the eDelphi statements, contributed to identification of potential participants and interpretation of results. RW wrote the draft and all authors contributed to development of the manuscript text.

Competing interests

None declared

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Data availability statement

All data relevant to the study are included in the article or uploaded as supplementary information.

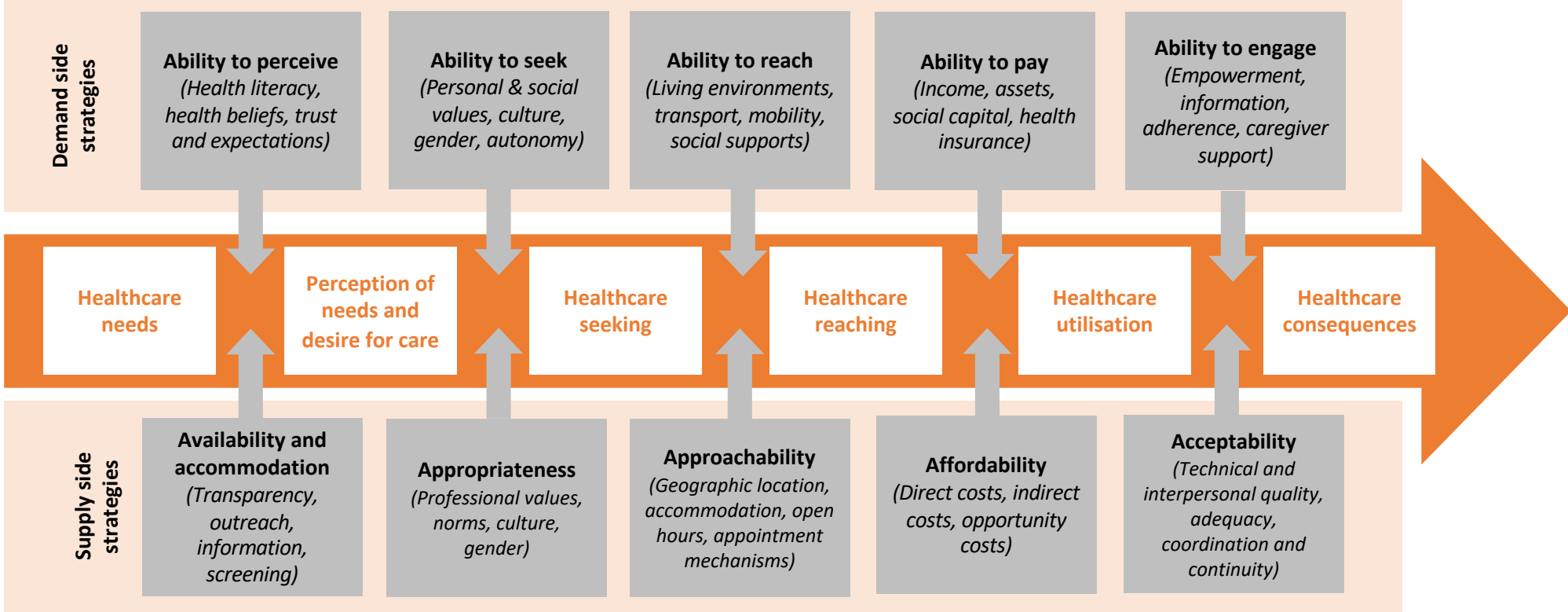
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Demand side strategies

Ability to perceive
1. Health promotion to increase assessment and treatment of skin sores and sore throats*

Ability to seek
2. Activate or empower people to seek health services for skin sores and sore throats*

Ability to reach
No concepts identified

Ability to pay
No concepts identified

Ability to engage
3. Engage communities at risk of ARF in preventing the disease*
4. Support people at risk of ARF/RHD to be engaged in their own health care and self management*

Healthcare needs

Perception of needs and desire for care

Healthcare seeking

Healthcare reaching

Healthcare utilisation

Healthcare consequences

Supply side strategies

Availability and accommodation
5. Actively work to identify people with skin sores

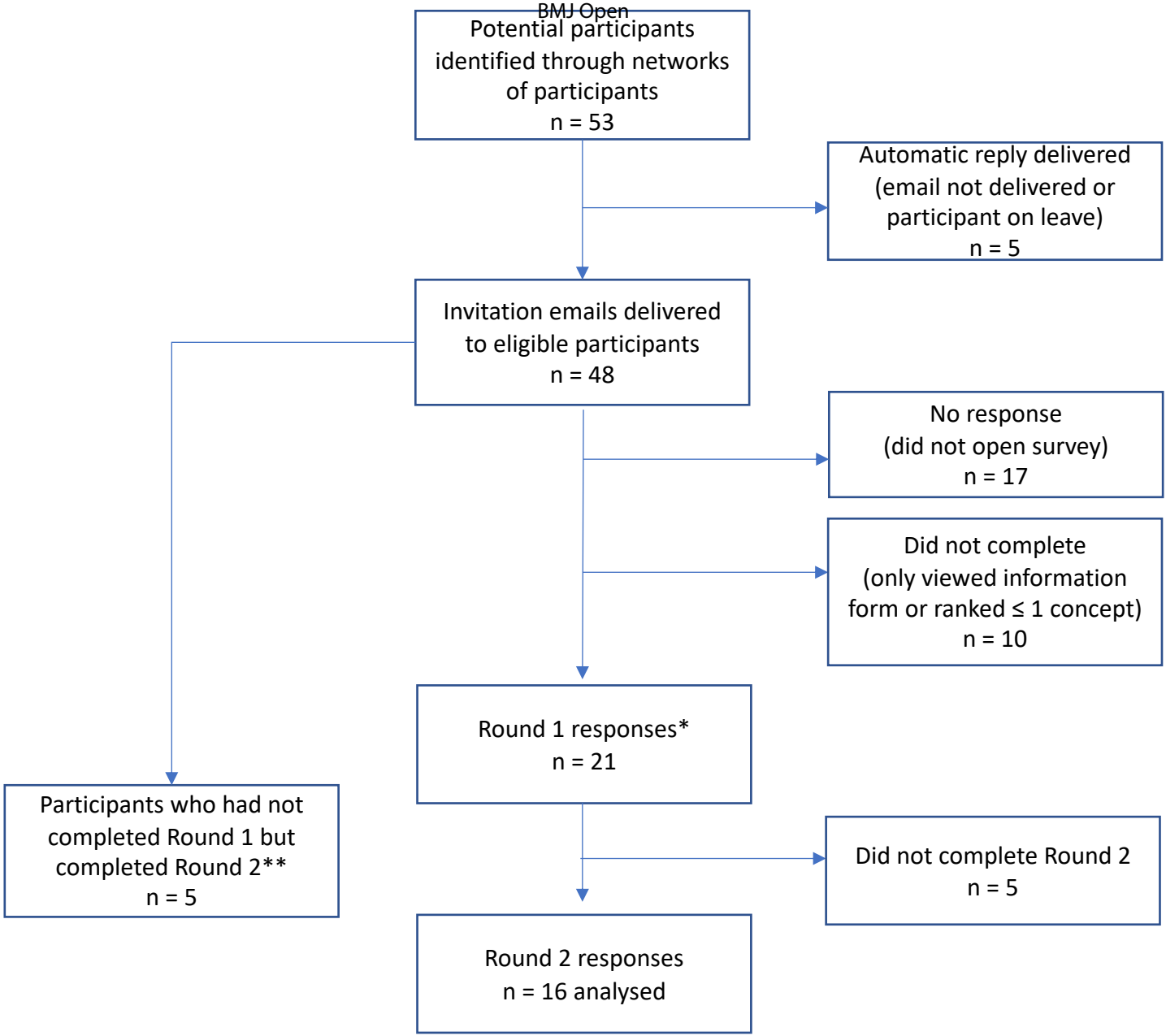
Appropriateness
6. Make health care more acceptable*

Approachability
7. Make it easier for people to access assessment and treatment of skin sores / sore throats
8. Make assessment and treatment of skin sores / sore throats available at more places
9. Provide practical or physical support to assist people to access health services*

Affordability
10. Reduce the costs for people seeking assessment & treatment of skin sores/sore throats
11. Improve service delivery by reducing costs to clinics

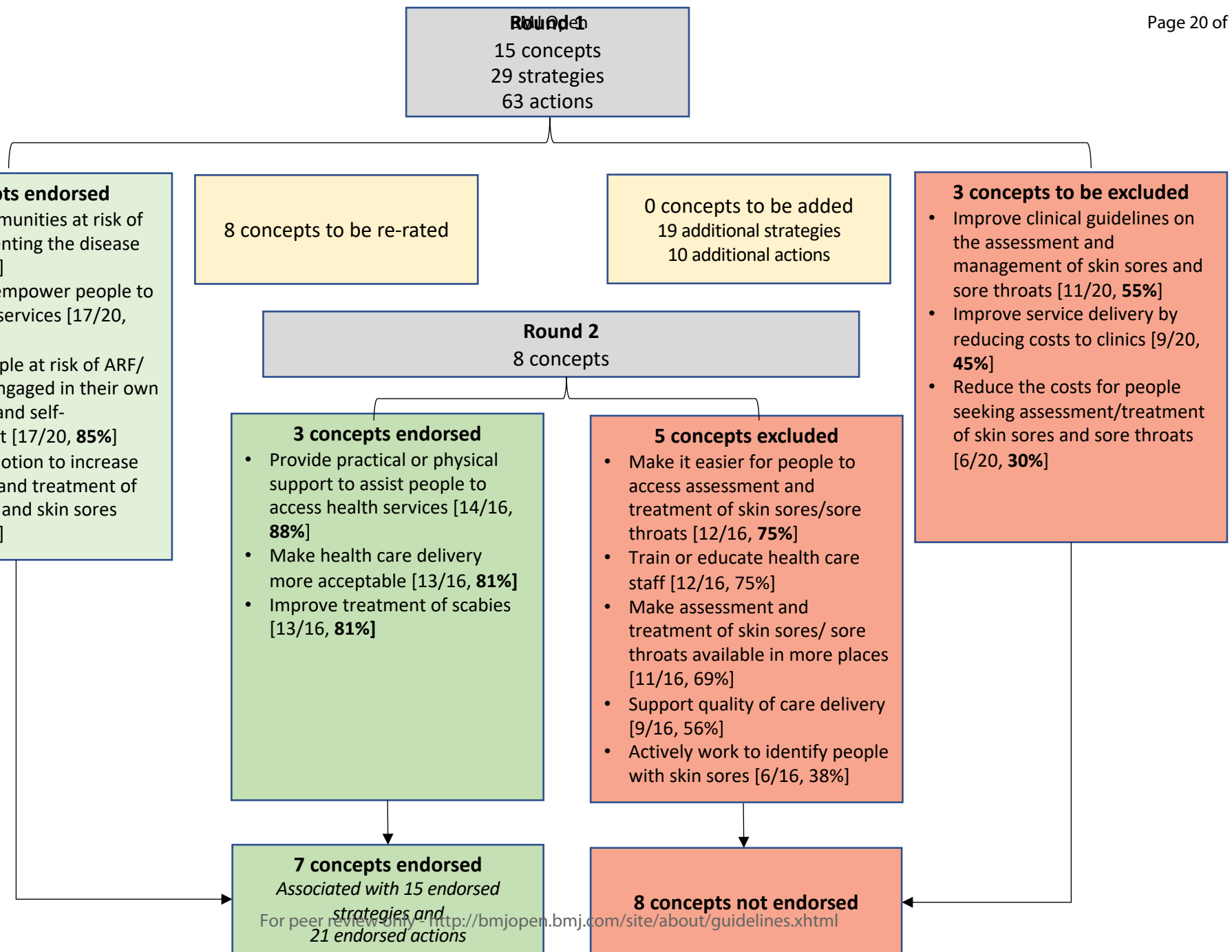
Acceptability
12. Improve clinical guidelines on the assessment and management of skin sores /sore throats
13. Train or educate healthcare staff
14. Improve treatment of scabies*
15. Support quality of care delivery

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*Two participants completed more than one concept but did not complete full survey. Their responses were included for completed survey items

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Supplementary material 1 – Search strategy

((rheumatic[All Fields] AND ("fever"[MeSH Terms] OR "fever"[All Fields])) AND ("prevention and control"[Subheading] OR ("prevention"[All Fields] AND "control"[All Fields]) OR "prevention and control"[All Fields] OR "prevention"[All Fields])) AND ("Australia"[MeSH Terms] OR "Australia"[All Fields])

((Rheumatic Fever [MeSH Terms] OR rheumatic fever.mp) AND (exp Primary prevention [MeSH Terms]) AND ((exp Australia [MeSH Terms]) OR (exp New Zealand (MeSH Terms))).

For peer review only

Supplementary material 2 – Scoping focus group outcomes

Supply side

Approachability (transparency, outreach, information, screening)

- School sore throat screening

Availability and accommodation (geographic location, accommodation, hours of opening, appointment mechanisms)

- Develop framework for external diagnosis done with photography of skin sores (for remote communities)
- Use telehealth for videoing diagnosis

Acceptability (professional values, norms, culture, gender)

- Develop sustainable training for AHWs
- Integrate AHWs into health system to better work alongside other health centre staff
- Address staff turnover at AMSs
- Deliver training + education of health care workers + school nurses for diagnosis + treatment of sore throat + skin sores
- Provide meaningful feedback to nurses re: clinic progress
- Provide systematic support and encouragement for clinic staff

Affordability (direct costs, indirect costs, opportunity costs)

- Provide affordable/free bandaids/bandages at school

Appropriateness (technical and interpersonal quality, adequacy, coordination and continuity)

- Include appropriate traditional remedies in health promotion campaigns, e.g. honey
- Develop clinical decision rules for sore throat
- Introduce affordable "point of care" testing for Strep A in skin sore and sore throat

Demand side

Ability to perceive (health literacy, health beliefs)

- Raise awareness of germ theory
- Raise awareness of transmission through bed sharing - provide better advice (top to tail)
- Improve baseline education - teach children about skin sores and sore throat
- Raise awareness in highest risk populations and target highest risk kids/families
- Raise awareness in school settings
- Raise awareness of hand washing and hand hygiene through school programs
- Raise awareness around prevention of transmission through open skin sores
- Run comprehensive health promotion campaign
- Raise awareness of need for skin sores to seal over
- Raise awareness of daily washing (parents and schools), particularly in first year of life
- Raise awareness re: reinfection rather than ineffective treatment
- Run comprehensive health promotion campaign
- Improve health seeking behaviour for skin sores and sore throat

Ability to seek (personal and social values, culture, gender, autonomy)

- Address stigma associated with sore throat, to improve acceptability of seeking health care

Supplementary 3: Delphi statements and structure

Concept	Strategy	Action
1. Health promotion to increase assessment and treatment of sore throat and skin sores	<p>↳ 1.1 General public education on germs causing disease</p> <p>↳ 1.2 General public education about skin sores, sore throat, ARF and RHD</p> <p>↳ 1.3 General public education to 'denormalise' skin sores</p> <p>↳ 1.4 Targeted public education on the specific risks of skin sores and sore throat</p>	<p>↳ 1.1a Develop mass media campaigns about germs causing disease</p> <p>↳ 1.1b Teach people about the cause and risks of skin sores through social media campaigns</p> <p>↳ 1.2a Raise awareness about skin sores, sore throat, ARF and RHD at community events and activities</p> <p>↳ 1.3a Develop positive media campaigns about normal healthy skin</p> <p>↳ 1.4a Teach children about the cause and risks of skin sores and sore throat at school</p> <p>↳ 1.4b Teach parents and families about the cause and risks of skin sores and sore throat through community events</p> <p>↳ 1.4c Train health care workers to educate children and families about the risk of skin sores and sore throat</p>
2. Engage communities at risk of ARF in preventing the disease	<p>↳ 2.1 Engage communities at risk of ARF and RHD in responding to the disease</p>	<p>↳ 2.1a Support community leaders to develop and facilitate key messages about sore throat and skin sores</p> <p>↳ 2.1b Share positive local stories about good news examples of treating skin sores / sore throat</p>
3. Empower people to seek health services	<p>↳ 3.1 Encourage people to actively seek assessment / treatment of skins sores and sore throat</p>	

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10 4. Provide practical or
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15 ↳ 4.1 Improve transport
16 for people to attend clinic
17 for skin sores and sore
18 throat

- ↳ 3.1a Train or support children on how to ask for their sore throat / skin sore to be assessed / treated
↳ 3.1b Train parents and caregivers to ask for recommended assessment of skin sores / sore throat
↳ 3.1c Develop the idea of a 'skin check' visit that people can ask for when they attend clinic

- ↳ 4.1a Fund primary care clinics to provide transport for people who need assessment and treatment
↳ 4.2b Provide education for temporary care providers (boarding schools, out-of-home carers) on the need for assessment and treatment of skin sores and sore throat.

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25 ↳ 4.2 Extend clinic opening
26 hours so that people can
27 attend for assessment /
28 treatment for more of the
29 day

30 5. Reduce the costs for
31 people seeking
32 assessment / treatment
33 of skin sores / sore
34 throat
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36 ↳ 5.1 Reduce out-of-
37 pocket costs for treating
38 skin sores and sore throat

- ↳ 5.1a Make antibiotics for skin sores and sore throat free for all high-risk people at point of care
↳ 5.1b Fund clinics to provide free dressings for keeping skin sores covered.
↳ 5.1c Promote availability of free or low cost treatment for skin sores and sore throat

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46 ↳ 5.2 Increase income for
47 people at risk of skin sores
48 and sore throat
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- ↳ 5.2a Develop a system for families with sore throat and skin sores to be referred to service providers or Centrelink to review benefits and entitlements

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55 6. Support people at risk
56 of ARF / RHD to be
57 engaged in their own
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- ↳ 6.1 Ensure health staff support and encourage people engaging in their own health care
 - ↳ **6.1a** Train health staff to validate or congratulate people who present for care
 - ↳ **6.1b** Train clinic drivers, receptionists and other staff about the importance of skin sores and sore throat so these conditions are never minimised or dismissed
 - ↳ **6.1c** Train health staff to provide clear information about why skin sores / sore throat need treatment
 - ↳ 6.2 Support people seeking care to engage with assessment and treatment of skin sores and sore throat
 - ↳ **6.2a** Employ care navigators or support people to attend appointments
 - ↳ **6.2b** Provide training or support for people in communities with a high burden of ARF or RHD to be empowered health care consumers
 - ↳ 6.3 Support engagement by involving community in delivery of health care
 - ↳ **6.3a** Ensure community control of health care services in communities with a high burden of ARF or RHD
 - 7. Improve treatment of scabies which can cause skin damage which contributes to skin sores
 - ↳ 7.1 Improve treatment of scabies
 - ↳ **7.1a** Ensure everyone attending the clinic gets treatment for scabies and any skin sores present
 - ↳ **7.1b** Develop systems for household outreach for assessment and treatment when someone from the household is diagnosed with scabies
 - 8. Actively look for children with skin sores
 - ↳ 8.1 Identify people with skin sores outside the clinic
 - ↳ **8.1a** Develop programs for all children to have a healthy skin check at school or home
 - ↳ **8.1b** Develop a program so that children at highest risk (household contacts, siblings with ARF) have regular skin checks
 - ↳ 8.2 Identify people with skin sores inside the clinic

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9. Make assessment and treatment of skin sores / sore throat available in more places

↳ 9.1 Provide assessment / treatment for skin sores and sore throat in schools

↳ 8.2a Develop systems for children with skin sores to be referred for assessment / treatment a wider range of different services (dentists, schools)

↳ 8.2b Train health staff to opportunistically offer health skin checks for all children attending clinic for any reason

↳ 8.2c Train reception and other staff to invite / offer sore throat and skin checks

↳ 8.2d Include healthy skin checks as a mandated part of childhood health care (alongside child health checks or scheduled vaccination)

↳ 9.1a Provide staff trained to assess and treat skin sores / sore throat in schools

↳ 9.1b Ensure that guidelines on treating children at school (with and without parental consent) are clearer so health staff know what can be done

↳ 9.1c Employ care navigators who can help children in school access assessment / treatment of skin sores and sore throat

↳ 9.2 Provide assessment / treatment for skin sores and sore throat in other places

↳ 9.2a Change guidelines and regulations so that qualified staff can give assessment and treatment outside of the clinic

↳ 9.2b Facilitate assessment and / or treatment of skin sores / sore throat at pharmacies

↳ 9.2c Facilitate assessment and / or treatment of skin sores / sore throat at Centrelink offices

↳ 9.2d Facilitate assessment and / or treatment of skin sores / sore throat via dentists

↳ 9.2e Facilitate assessment and treatment of skin sores / sore throat via Emergency Departments and After Hours Services

10. Make health care delivery more acceptable

↳ 10.1 Provide culturally acceptable care

↳ 10.1a Provide health staff training on how to deliver culturally appropriate care

↳ 10.1b Routinely ask patients / consumers whether care experience is culturally appropriate

↳ 10.1c Teach health staff Indigenous languages

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11. Make it easier for people to access assessment and treatment of skin sores / sore throat

↳ 10.2 Increase the amount of care delivered by Aboriginal and Torres Strait Islander people

↳ **10.1d** Use or develop new terms for skin sores and sore throat in Indigenous languages

↳ **10.1a** Amend legislation to allow Aboriginal and Torres Strait Islander Health Practitioners to give medications for sore throat / skin sores in all jurisdictions

↳ **10.1b** Develop workforce strategies to recruit, train and retain Aboriginal and Torres Strait Islander people in primary health care

11.1 Provide more flexible clinical services

↳ **11.1a** Develop policy of 'no wrong door' so that people can access standardised sore throat and skin sore assessment / treatment at any facility they present to

↳ **11.1b** Offer assessment and treatment to all children who attend clinic with a family, not just those with a booked appointment

12. Improve service delivery by reducing costs to clinics

↳ 12.1 Reduce costs for primary care providers to assess and treat skin sores and sore throat

↳ **12.1a** Provide skin sore / sore throat treatment free at point of care in all settings

↳ **12.1b** Provide specific funding for waterproof dressings to be provided free of cost from the clinic to be used / replaced at home

13. Improve clinical guidelines on the assessment and management of skin sores and sore throat

↳ 13.1 Make clinical guidelines clearer and easier to use

↳ **13.1a** Develop easy-to-use algorithms for skin sore and sore throat management in high risk population

↳ **13.1b** Ensure sore throat and skin sore management is part of HealthPathways

↳ **13.1c** Review all clinical guidelines to ensure they align on management of skin sores and sore throat

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14. Train or educate health care staff

↳ 14.1 Provide local data about rates of ARF and RHD

↳ **13.1d** Use CARPA or other streamlined clinical guidelines throughout Australia in remote communities with a high population of Aboriginal and Torres Strait Islander people

↳ **13.1e** Develop more comprehensive guidelines which include a wider range of skin infections

↳ **13.1f** Develop clinical modules for assessment and treatment of sore throat / skin sores in medical software

↳ **14.1a** Provide all health staff with local data on the risk of ARF and RHD in the population they work with

↳ 14.2 Train health generally on skin sores and sore throat

↳ **14.2a** Provide general training for all staff about skin sores and sore throat

↳ 14.3 Train staff specifically on assessment and treatment of skin sores and sore throat

↳ **14.3a** Train health care staff specifically about how to use clinical guidelines for skin sores and sore throat

↳ 14.4 Provide specific training for specific types of health care staff

↳ **14.4a** Provide specific training for Emergency Department Staff

↳ **14.4b** Provide specific training for staff who start working in high risk regions

15. Support quality of care delivery

↳ 15.1 Undertake continuous quality care improvement

↳ **15.1a** Identify quality of care measures for sore throat and skin sores

↳ **15.1b** Undertake audits of sore throat / skin sore management based on clinical records

↳ **15.1c** Undertake case reviews of people diagnosed with acute rheumatic fever to identify any missed opportunities for primary prevention

Supplementary 4 – Detailed summary of eDelphi outcomes

eDelphi Priorities for improving primary prevention of ARF Summary of results Presented in order of % rated high priority by participants Endorsed concepts, endorsed strategies, endorsed actions and elements not endorsed *Indicates item added in Round 2 based on Round 1 feedback from participants ♦Indicates concept which was re-rated in Round 2 based on intermediate Round 1 feedback from participants (Items in brackets indicate strategies which were the same as concepts and were not presented to participants through the REDCap database to avoid duplication but retained for structural consistency)	Number of responses	Number rated as high priority (4 or 5)	%4 or 5
Concept Engage communities at risk of ARF in preventing the disease	21	20	95
(Strategy Engage communities at risk of ARF in preventing the disease)	21	20	95
Action Support community leaders to develop and facilitate key messages about sore throat and skin sores	19	15	79
Action Share positive local stories about good news examples of treating skin sores/sore throat	19	12	73
Strategy* Engage communities by addressing attitudes to skin sores and sore throat including reducing stigma and de-normalising sores	16	16	100
Strategy* Engage communities by improving access to local information about the rates of Strep A infection, ARF and RHD	16	11	69
Concept Activate or empower people to seek health services for skin sores and sore throat	20	17	85
Strategy Encourage people to actively seek assessment/treatment of skin sores	17	16	94
Action Train parents and caregivers to ask for recommended assessment of skin sores/sore throat	16	14	88
Action Train or support children on how to ask for their sore throat/skin sores to be assessed/treated	16	13	75
Action Develop the idea of a 'skin check' visit that people can ask for when they attend clinic	16	11	69
Strategy* Provide health services for skin sores and sore throat at schools	16	14	88
Strategy* Invite people to suggest strategies for reducing their own risk of skin sores/sore throat	16	11	69
Concept Support people at risk of ARF/RHD to be engaged in their own health care and self-management	20	17	85
Strategy Support engagement by involving community in delivery of health care	17	16	94
Action Ensure community control of health care services in communities with a high burden of ARF or RHD	16	14	88
Strategy Support people seeking care to engage with assessment and treatment of skin sores and sore throat	17	15	88
Action Provide training or support for people in communities with a high burden of ARF or RHD to be empowered health care consumers	15	13	87
Action Employ care navigators or support people to attend appointments	15	9	60
Strategy Ensure health staff support and encourage people engaging in their own healthcare	17	15	88
Action Train clinic drivers, receptionists and other staff about the importance of skin sores and sore throat so these conditions are never minimised or dismissed	15	13	87
Action Train health staff to validate or congratulate people who present for assessment and treatment of skin sores and sore throat	15	13	80
Action Train health staff to provide clear information and encouragement about why skin sores/sore throat need treatment	15	10	67
Strategy* Establish meaningful community governance mechanisms for skin sore and sore throat control strategies	17	14	82
Strategy* Develop peer support mechanisms for people at risk of ARF and RHD to learn more about Strep A infections and treatment	16	11	69
Strategy* Teach and empower people to do their own skin sore dressings	16	9	56
Strategy* Develop digital tools like apps or reminder texts to support self-management of skin sores and sore throat	16	6	38

Concept Health promotion to increase assessment and treatment of sore throat and skin sores	22	18	82
Strategy* Ensure health promotion occurs in local Aboriginal and Torres Strait Island languages	16	16	100
Strategy Targeted public education on the specific risks of skin sores and sore throat	17	16	94
Action Teach parents and families about the cause and risks of skin sores and sore throat through community events	16	16	100
Action Train health care workers to educate children and families about the risk of skin sore and sore throat	16	15	94
Action Teach children about the cause and risks of skin sores and sore throat at school	16	14	88
Strategy General public education to 'denormalise' skin sores	17	12	71
Strategy General public education about skin sores, sore throat, ARF and RHD	17	11	65
Strategy General public education on germs causing disease	17	9	53
Concept Provide practical or physical support to assist people to access health services*	16	14	88
Strategy Improve transport for people to attend clinic for skin sores and sore throat	14	12	86
Action Fund primary care clinics to provide transport for people who need assessment and treatment	12	11	92
Action provide education for temporary care providers (boarding schools, out of home carers) on the need for assessment and treatment of skin sores and sore throat	14	9	64
Strategy* Develop systems for people to send photos of skin sores or communicate with the clinic from outreach services	14	8	57
Strategy Extend clinic opening hours so that people can attend for assessment/treatment for more the day	16	9	56
Concept Make health care delivery more acceptable*	16	13	81
Strategy Provide culturally acceptable care	12	12	100
Action Routinely ask patients/consumers whether care experience culturally appropriate	12	11	92
Action Provide health staff training on how to deliver culturally appropriate care	12	10	83
Action Use or develop new terms for skin sores and sore throat in Aboriginal and Torres Strait Islander languages	12	10	83
Action Teach health staff Aboriginal or Torres Strait Islander languages	12	7	58
Strategy Increase the amount of care delivered by Aboriginal and Torres Strait Islander people	12	12	100
Action Develop workforce strategies to recruit, train and retain Aboriginal and Torres Strait Islander people in primary health care	12	12	100
Action Amend legislation to allow Aboriginal and Torres Strait Islander Health Practitioners to give medications for sore throat/skin sores in all jurisdictions	12	11	100
Action* Work with the community to recruit local Aboriginal and Torres Strait Islander staff	16	15	94
Action * Develop support roles for Aboriginal and Torres Strait Islander people without formal health worker training	16	15	94
Strategy* Provide formal, high quality, unconscious bias and cultural competence training for staff	16	9	56
Strategy* Facilitate use of traditional medications for skin sores and sore throat alongside guideline-based care	16	8	50
Concept Improve treatment of scabies, which can cause skin damage, which contributes to skin sores*	16	13	81
(Strategy Improve treatment of scabies, which can cause skin damage, which contributes to skin sores)	16	13	81
Action Develop systems for household outreach for assessment and treatment when someone from the household is diagnosed with scabies	15	15	100
Action Ensure everyone attending the clinic gets treatment for scabies and any skin sores present	15	14	93
Strategy* Provide or advocate for housing and environmental health services for people with scabies and skin sores	16	14	88
Action* Provide or advocate for facilities for people with scabies to wash clothes and bedding	16	12	75
Strategy* Develop specific resources about scabies and use of treatments in local language	16	13	81
Concept Make it easier for people to access assessment and treatment of skin sores/sore throat*	17	12	75

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Concept Train or educate health care staff [♦]	16	12	75
Concept Make assessment and treatment of skin sores/sore throat available in more places [♦]	16	11	69
Concept Support quality of care delivery [♦]	16	9	56
Concept Improve clinical guidelines on the assessment and management of skin sores and sore throat	20	11	55
Concept Improve service delivery by reducing costs to clinics	20	9	45
Concept Actively work to identify people with skin sores [♦]	16	6	38
Concept Reduce the costs for people seeking assessment/treatment of skin sores/sore throat	20	6	30

For peer review only

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Supplementary 5

Levesque et al. framework domain	Concept	Key themes	Illustrative quotes
Demand Ability to perceive	Health promotion to increase assessment and treatment of sore throat and skin sores	Responses focused on <i>how</i> to do health promotion (for example through songs, posters, events, radio), <i>who</i> should do health promotion (with strong support for school-based health promotion) and <i>where</i> to do health promotion (particularly outreach and home visits). Many participants identified the need for health promotion to be accessible to Aboriginal and Torres Strait Islander people through the use of local languages and with cultural and contextual relevance.	“Most health inequity is due to ongoing colonisation including loss of languages and culture. Including Aboriginal languages especially on a health topic sends a very strong message” ID 23, R2, I1 ”
Demand Ability to seek	Activate or empower people to seek health services for skin sores and sore throat	eDelphi strategies presented in this domain generated little qualitative engagement. Instead, qualitative feedback strongly supported the need for children to be able to seek healthcare at school.	“Provide flexible access options to assessment and treatment. Perhaps option of streamlined skin check clinics, perhaps clinic for adults as well as their children collocated at school for pickup drop off time walk-in” – ID 16, C3
Demand Ability to engage	Engage communities at risk of ARF in preventing the disease	There was strong support for the importance of ‘engagement’ and the need for community leaders to be involved in improving primary prevention. Specific engagement strategies included sharing local burden of disease data with the community and addressing community attitudes to skin sores. A number of participants identified the importance of reducing both the stigma, and the normalisation, of skin sores.	“ <u>Engage community leaders</u> to identify opportunities for prevention of ARF – e.g. a community forum on primary prevention” ID 5, C2 Strategies to effectively manage and destigmatise are important. Needs to be done with the elders and Tos (traditional owners) or community spokespeople. ID19, R2, I9
	Support people at risk of ARF/RHD to be engaged in their own healthcare and self-management	Qualitative responses had a very strong focus on community-level engagement with multiple participants identifying the need for ‘community governance’ or a ‘community reference group’. Two participants identified governance and representation within community-controlled health services as problematic. A small number of specific strategies for increasing individual engagement in care, including education for people to	“Obviously we already know what works with primary prevention of RHD so we just need to work on implementing it better and the people who can assist with guiding this are the communities themselves” – ID 5, FT16

		their own skin sore dressings, peer support groups or digital tools to support self-management.	
Supply Availability and accommodation	Actively work to identify people with skin sores	eDelphi statements in this concept included various strategies to actively deliver skin checks (through outreach, opportunistically to people attending clinic, through scheduled child health checks). There was a low level of support for these and few qualitative responses addressed any of these strategies directly. Some respondents highlighted the risks associated with active case finding of skin sores.	“Health service led efforts are never going to be as effective as community led initiatives to improve treatment uptake and <u>may contribute to stigma associated with skin sores.</u> ” ID13, R2, I8
Supply Appropriateness	Make health care delivery more acceptable	Acceptability (and thereby appropriateness) eDelphi statements were largely focused on ensuring culture was embedded in care delivery. This included strong support for the use of Aboriginal and Torres Strait Islander language in clinical care and increased recruitment, retention and role expansion for Aboriginal and Torres Strait Islander health staff. Responses supported cultural training to reduce racism of health care providers. There was equivocal support for incorporating elements of traditional medicines into management protocols for skin sores and sore throat.	“And how to manage <u>culture shock and be aware of Own prejudice</u> when treating patients – can be very hard for patients to keep turning up when they feel misrepresented and misunderstood”. ID19, R2, I14
Supply Approachability	Make it easier for people access assessment and treatment of skin sores / sore throat	Qualitative responses highlighted the need for flexibility in delivering clinic-based services. Specifically, this included a need to reduce waiting times, offer walk-in appointment and ensure a welcoming experience. Some participants supported an increase in after-hours service provision.	“Again, many of these strategies are still focused on somebody having access to the clinic. If they work or want their children to attend school, they may not want to miss large amounts of time <u>waiting at least an hour to be seen in the clinic.</u> Staff are generally quite aware of these things in remote health centres, but the <u>system isn’t designed to cope with the number of presentations and waiting times are often unacceptable</u> ” – ID 13, C6
	Make assessment and treatment available in more places	eDelphi statements in this concept included some of the approaches derived from the (urban) New Zealand experience of providing services in pharmacies, dental clinics and social services. These were generally not considered applicable to the	“Move <u>care outside of the clinic more</u> – e.g. a skin / sore throat mobile team to review and treat people in their homes” – ID 5, C4

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		remote Australian setting (“ <i>In aboriginal communities ... there are no dentists, pharmacies</i> ” – ID 21, C9) but qualitative responses reflected strong support for outreach service outside of the clinic, to schools or homes. The practicalities of outreach services were addressed by some participants, including scope for telehealth from outreach workers to clinics and the potential constrain of regulations about delivering treatment outside of clinical settings.	“Employ family-based support workers to perform household outreach for education, assessment, treatment, and prevention activities” – ID 29, C7
	Provide practical or physical support to assist people to access health services	Qualitative responses emphasised the importance of providing transport for people to attend the clinic and identified various strategies for this to be achieved (including taxi vouchers, regular bus routes and clinic transport). The costs of providing transport were identified as a barrier for clinics to improve services. A number of participants noted that outreach services or telehealth capacity could obviate some of these transport needs.	“Funding <u>transport</u> would not be as cost effective as Telehealth (emailing or texting photographs of sores and if relevant throats)” – ID 18, C4 “Must be tied with the <u>outreach service being able to provide treatment</u> rather than client then need to attend the health service(removes a barrier for timely treatment).” ID16, R2, I4
Supply Affordability	Reduce the costs for people seeking assessment and treatment of skin sores	eDelphi statements in this concept included cost reduction approaches used in New Zealand, including free medical visits and medications. Most participants identified these are not relevant to remote Aboriginal and Torres Strait Islander communities where clinic attendance and medication are generally free at point of care. The need to minimise costs in urban setting was noted.	“This <u>may be an issue in metropolitan services</u> but not one in community government funded clinics.” ID19, R2, I5 “in the context I work in <u>there isn’t any cost</u> . In areas where there is a <u>cost associated with accessing care then maybe this is a significant barrier</u> (I wouldn’t really know) however if care was available in schools etc this would also get around the cost issue.” ID13, R2, I5
	Improve service delivery by reducing costs to clinics	eDelphi statements in this concept included suggestions about funding clinics for consumable products (particularly dressings for skin sores). There was little support for this approach. Instead, qualitative responses identified the need for the Section 100 medication to be available in urban settings and for bulk billing of consults. A small number of participants	“Aboriginal medical services in cities such as Darwin, need to be provided free medications such as Benzathine penicillin (like under <u>S100</u>) to give immediate treatment for skin sores as well patients needing 2ndary prophylaxis” – ID 16, C12

		suggested new Medicare item numbers be created for skin checks.	"? An item number for Aboriginal and Torres Strait Islander skin presentations to signal how important this consultation is" – ID 23, C12
Supply Acceptability	Improve clinical guidelines on the assessment and management of skin sores / sore throat	There was limited support for improving or expanding clinical guidelines in eDelphi statements. Qualitative feedback suggested that existing guidelines were sufficient and that other issues (time, staff training, accessibility of guidelines) were more significant barriers to the delivery of guideline-based care. A small number of specific recommendations about guideline content were made (" <i>Clarify the distinction between 'scabies' and impetigo</i> " – ID 12, C13)	" <u>Guidelines</u> existing are reasonable." ID27, R2, I13 "My experience is often poor diagnosis including hospitals giving NSAIDS for painful knees and sending home. <u>Maybe not guidelines improvement</u> , maybe just following guidelines may help." ID1, R2, I13
	Train or educate health care staff	Although there was limited support for general staff training in eDelphi responses, qualitative feedback indicated that time sensitive training for new or locum staff prior to working in remote settings was important. A small number of participants provided feedback on existing training resources, specifically that there " <i>needs to be a punchier, short version of RHD online modules</i> " ID 16, C14	"I think the awareness in the remote NT of this issue is already very high and I don't think that further education is a high priority in this context but this may be an issue interstate??" ID13, R2, I14 "Ensure any locum staff (doctors or nurses) have ARF/RHD/skin sore training <u>PRIOR to starting at the clinic</u> – mandatory prior to starting placement" – ID 22, C14
	Improve treatment of scabies, which can cause skin damage, which contributes to skin sores	Qualitative feedback on improving scabies treatment elicited some specific opinions related to scabies management (including details of lyclear use) and broad support for action on the environmental health to mitigate scabies risk. This included support for washing, housing and bedding facilities. Many of these themes were re-emphasised in general qualitative feedback.	" <u>Embed health hardware home visits</u> as part of follow up of patients presenting with scabies, skin sores, ARD, RHD" – ID 16, C7
	Support quality of care delivery	Qualitative responses on improving quality of care delivery were mixed. Some participants identified the value of clinic audits or key performance indicators for quality improvement. Others felt these activities could be distracting or burdensome to clinics. A small number of participants identified specific process	"Bulk-bill, more Aboriginal health workers, subsidise the treatment, facilitate the access to the service, educate the community about what you are doing, audit and review really important.

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		<p>indicators which may help identify progress towards improve primary prevention.</p>	<p><u>Everyone thinks they are doing a good job until they are audited” – ID 23, FT16</u> “I think this is a good idea but wonder if it will seem like a burden to clinics...” ID15, R2, I15”</p>
<p>General qualitative feedback</p>		<p>At the end of the eDelphi process participants were asked to ‘Please suggest any other ideas you have to improve delivery of primary prevention in primary care’. Overwhelmingly two issues were raised:</p> <ul style="list-style-type: none"> - the need for <u>prevention</u> of skin sores/sore throat rather than improving treatment - the need to increase the Aboriginal and Torres Strait Islander health workforce. <p>Implicit in some of these comments, and in qualitative feedback on other concepts, was the idea that disease-specific approaches which have a narrow focus are likely to be counterproductive in the absence of system-wide strategies.</p>	<p>“Primary prevention ultimately can only be effective in reducing ARF alongside more effective <u>primordial prevention measures” - ID 20, FT16</u></p> <p>“There needs to be engagement of other government departments ie: housing to improve health hardware, expedited repair of housing issues especially health hardware, more housing with RHD clients given priority, more availability of emergency housing for families in communities” - ID 22, FT16</p> <p>“Many of the ideas here were related to educating staff however in the NT at least most staff are very proactive about treatment, however access to services, waiting times and <u>staff shortages</u> are the biggest barriers. Improving access to treatment for these conditions in easy to access places (such as school nurse/health workers, or in places that do have a private pharmacy etc) would do much more than telling overworked primary health care staff what they already know and are trying their best to achieve”- ID 13, FT16</p>