

**Revealing the public health significance of
skin infections among Aboriginal children
living in the Pilbara: A call to action in
Western Australia**

by

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This thesis is presented for the degree of Doctor of Philosophy
of The University of Western Australia,
School of Paediatric and Child Health

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AUTHOR'S DECLARATION

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The research involving human data reported in this thesis was assessed and approved by The University of Western Australia Human Research Ethics Committee. Approval #: RA/4/1/6454, RA/4/1/6563 and RA/4/1/6199

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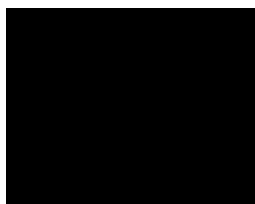
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ABSTRACT

The aim of the work presented in this manuscript was to document for the first time the extent to which skin infections are a public health issue in Western Australia (WA) and to provide qualitative insights that will inform comprehensive, culturally secure and sustainable ways of improving the prevention and control of skin infections in remote Aboriginal communities. The need for this work followed from an earlier regional study that set out to assess the early child development status of children living in four remote Aboriginal communities in the Pilbara region of WA. The study, which reported high levels of developmental vulnerability among Aboriginal children aged 4-5 years, reported on concerns voiced by community people and stakeholders that suggested that skin infections were among the major issues impacting on child health in these communities.

Epidemiological and intervention studies over the past two decades have established the importance of skin infections and their sequelae among Australian Indigenous children living in remote communities of the Northern Territory (NT). Childhood scabies and impetigo prevalences as high as 50 and 70% respectively have emphasized the need for more effective skin infection prevention and control strategies in the region. However, limited data on the burden of skin infections are currently available for Western Australia. Its impact on children living in remote Aboriginal communities therefore remains largely undocumented, precluding the funding, development and implementation of comprehensive 'healthy skin' programs in the state.

Much of the work described here stems from the close collaborative relationships we have established with Aboriginal controlled health services and community organizations in the Pilbara. These collaborations have facilitated the implementation of a retrospective audit of early childhood clinic presentations to estimate the burden of skin infections in

four remote Aboriginal communities, as well as a qualitative study that set out to document parent/carer, healthcare practitioner and other service provider attitudes and practices regarding skin infections and their treatment. In addition, we performed an extensive analysis of state-wide child hospitalization data to determine the occurrence of severe skin infections across WA and identify at risk groups. Finally, we undertook a systematic review to assess the possible health and wellbeing benefits that have been associated with swimming pools in remote Aboriginal communities, including possible reductions in the prevalence and severity of skin infections.

The findings presented in this thesis go some way in addressing the current gap in knowledge. Our principal findings are:

- 1) Skin infections are the most common infectious cause for children to present to primary care clinics in remote Aboriginal communities located in the Pilbara region of WA (16% of all early childhood clinic presentations).
- 2) Aboriginal children are 15 times more likely to be hospitalized with a skin infection compared to non-Aboriginal children, with Aboriginal infants living in remote areas being at a particularly high risk.
- 3) Health service utilization for skin infections in Pilbara communities is affected by a range of barriers. These include the need for more culturally secure and patient-centred healthcare provider practices, the normalization of skin infections, and the limitations of current skin infection treatment options.
- 4) As well as providing a safe social and cultural space for Aboriginal children and their families, swimming pools have been shown to improve skin health in remote Aboriginal communities.

Our findings confirm the high burden of skin infections among children living in remote Aboriginal communities in WA and provide direction in defining what is needed to improve the prevention and control of skin infections in remote Aboriginal communities. The outcomes of this work are being shared with Aboriginal controlled health services and community organizations in the Pilbara. Work is currently underway to trial alternative treatment strategies, address the normalization of skin infections through community-driven health promotion activities, and train healthcare practitioners in the identification and culturally secure management of skin infections.

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AUTHORSHIP DECLARATION:

CO-AUTHORED PUBLICATIONS

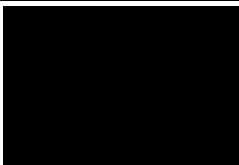
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Details of the work: <i>Primary care clinic attendance among young Aboriginal children living in four remote communities in Western Australia</i>	
Location in thesis: Chapter 2	
Student contribution to work: <i>Contributed to the study design, performed the audit of patient records, contributed to the analysis and interpretation of results, wrote the chapter.</i>	

Details of the work: <i>High burden of severe skin infections in Aboriginal children: A population-based, record-linkage cohort study of hospitalisations in Western Australian children, 1996 - 2012</i>	
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Student contribution to work: <i>Contributed to the study design, contributed to the analysis and interpretation of results, co-wrote the chapter. The paper was published in PLOS ONE on 30/11/2017. The student was listed as joint first author and as corresponding author.</i>	

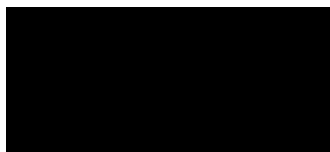
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I, A/Prof. Roz Walker, certify that the student statements regarding his contribution to each of the works listed above are correct.

Coordinating supervisor signature:



Date: 04/05/2017

LIST OF ABBREVIATIONS

AHW	Aboriginal Health Workers
AMS	Aboriginal Medical Service
APSGN	Acute Post-Streptococcal Glomerulonephritis
ARF	Acute Rheumatic Fever
BPG	Benzathine Penicillin G
CARPA	Central Australian Rural Practitioners Association
CREAHW	Centre for Research Excellence in Aboriginal Health and Wellbeing
DCPFS	Department for Child Protection and Family Support
FGD	Focus Group Discussions
GAS	Group A Streptococcus
GOSR	Getting Our Story Right
GP	General Practitioner
HMDC	Hospital Morbidity Data Collection
HREC	Western Australian Aboriginal Health Ethics Committee
IQR	Interquartile Range
LRTIs	Lower Respiratory Tract Infections
NT	Northern Territory
OM	Otitis Media
PBS	Pharmaceutical Benefits Scheme
RCT	Randomized Controlled Trial
RFDS	Royal Flying Doctor Service
RHD	Rheumatic heart disease
URTIs	Upper Respiratory Tract Infections

WA	Western Australia
WAACHS	Western Australian Aboriginal Child Health Survey
WADLS	WA Data Linkage System
YMCA	Young Men's Christian Association

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PUBLICATIONS DURING CANDIDATURE

Peer-reviewed publications

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Other

Hendrickx D, Carapetis J & Walker R. Swimming pools in remote Aboriginal communities: A report on the current evidence for the effectiveness of swimming pools on the reduction of skin and ear infections. Report to the Minister for Health. Telethon Institute for Child Health Research, Centre for Child Health Research, UWA. Perth; 2012.

PRESENTATIONS ARISING FROM THIS PROJECT

International Conferences

Hendrickx D, Walker R, Carapetis JC, Boelaert M. The human factor in the clinical management of infectious diseases of poverty in remote, low-resource settings. A discussion of four qualitative studies on healthcare provider attitudes and practices. 9th European Congress on Tropical Medicine and International Health, Basel, September 2015. (oral)

Hendrickx D, Peeters K. *Public health research in marginalised populations. Turning challenges into opportunities*. 56th Annual International Colloquium of the Institute of Tropical Medicine, Antwerp, November 2014. (invited speaker)

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National Conferences

Walker R, **Hendrickx D**, Carapetis JC, Bowen A, Abdalla T, Moore H & Duff I. *Skin infections in remote Aboriginal communities of Western Australia. From research to action*, 3rd Population Health Congress 2015 - One Vision Many Voices. Hobart, September 2015. (oral)

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Oral Presentations at Local Meetings and Symposia

Abdalla T, **Hendrickx D**, Bowen A, Walker R, Moore H. Epidemiology of skin infection hospitalisations in Aboriginal and Non-Aboriginal children in Western Australia: A retrospective data linkage study. Scientific Retreat, University of Western Australia Perth, November 2016.

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CHAPTER 1 INTRODUCTION

1.1 Rationale

The research presented and discussed in this manuscript is framed within a larger program of work on Aboriginal maternal health and child development in Western Australia's Pilbara region. For over a decade, this program of work has employed community-based participatory action research methods to engage with remote Aboriginal communities and the various services and organisations that operate in that setting. It was through the establishment of these collaborations and the application of participatory methods that the burden of skin infections among children living in remote Aboriginal communities and their effect on early childhood development in the Pilbara first became apparent. This informed the urgent need for the work that is presented in this manuscript: to quantify the burden of skin infections in the remote Aboriginal communities of the Pilbara, and to document barriers to their prevention and control. The PhD work was performed in close collaboration with the Puntukurnu Aboriginal Medical Service, community schools and other key organisations that engage with local Aboriginal children and their families, such as World Vision Australia and the YMCA (Young Men's Christian Association). The outcomes of this thesis will be shared and discussed with all partners and community representatives to identify culturally appropriate and sustainable ways of improving the prevention and control of skin infections in the region.

1.2 The Researcher

The researcher is a non-Aboriginal, Belgian researcher with a master's degree in sociology who was working as a qualitative researcher on the control of neglected tropical diseases prior to commencing his PhD research. Having moved to Australia from Belgium to undertake the study described in this thesis, this work constituted the researcher's first experience in the context of Aboriginal health. The researcher was embedded in a team of Aboriginal health researchers (both Aboriginal and non-Aboriginal) that ground their research activities in the broad framework of *participatory action research*, which reinforces the concept of research as an equal partnership between researchers and Aboriginal organisations, families and communities [1]. This facilitated a culturally reflexive research environment that continually stimulated the researcher to be critically reflective of his role as a white, male, European researcher and how that might affect his assumptions and interpretations in research practice. This process, and the regular exchange and feedback that occurred with senior Aboriginal researchers associated with the Centre for Research Excellence in Aboriginal Health and Wellbeing (CREAHW), experts in transformative and decolonising methodologies, ensured that commitment to Aboriginal voices and aspirations were central to his work.

This chapter will provide an overview of the context for this thesis. It will introduce the broad geographical, demographic, cultural and socio-economic background of our study setting (Western Australia), as well as the specific remote Aboriginal community setting to which most of the work presented here appertains. Finally, the issue of skin infections will be introduced by describing its global burden, illustrating its public health relevance to Aboriginal health and by providing a succinct overview of current community control strategies for skin infections.

This will set the scene for the first two chapters of this thesis, which will describe the burden of skin infections in WA. Chapter 2 reports on the results of a retrospective clinical audit study that was performed in four remote communities in the Pilbara region, thereby providing some much needed data on the reportedly high burden of skin infections amongst children living there. Chapter 3 will present the findings of a retrospective cohort study of WA-wide hospitalisation data that documents paediatric skin infection associated hospital admissions over a period of 16 years, to provide context for the state-wide burden of skin infections in children. Key findings of this chapter are that Aboriginal children have the highest rate of skin infections in the state, with the more remote sectors and youngest children having the highest burden. The Pilbara demonstrated the highest rate of skin infection associated hospitalisation rates, closely followed by the Kimberley.

Adopting a qualitative methodology, chapter 4 maintains focus on these four remote communities and report on a series of semi-structured interviews, “yarning sessions”¹ and focus group discussions that were performed with Aboriginal community members,

¹ This refers to *yarning*, a narrative-driven, informal and culturally safe approach to research interviews with Indigenous people [145].

health workers, teachers and other service providers on topics concerning the prevention and control of skin infections. The chapter describes the barriers and enablers of health service utilisation for skin infections in these communities.

Chapter 5 consists of a systematic review of the potential health benefits that have been associated with the provision of swimming pools in remote Aboriginal communities, including reducing the burden of skin infections. In context, previous studies to evaluate the role of swimming pools were conducted in one of the four communities where the retrospective audit and qualitative study reported in Chapters 2 and 4 occurred. Finally, Chapter 6 provides a summary of the main findings of this thesis and reflects on their implications for the prevention and control of skin infections and their sequelae in remote Aboriginal communities of Australia.

1.4 Introduction to Western Australia, Pilbara and the Martu People

Western Australia (WA) is Australia's largest state, extending over approximately 2.6 million square kilometres (almost four times the size of Texas, USA, see Figure 1.1). It is sparsely populated, with most of its 2.4 million inhabitants living in and around its capital, Perth (1.7 million people live in the Greater Perth area) [2].

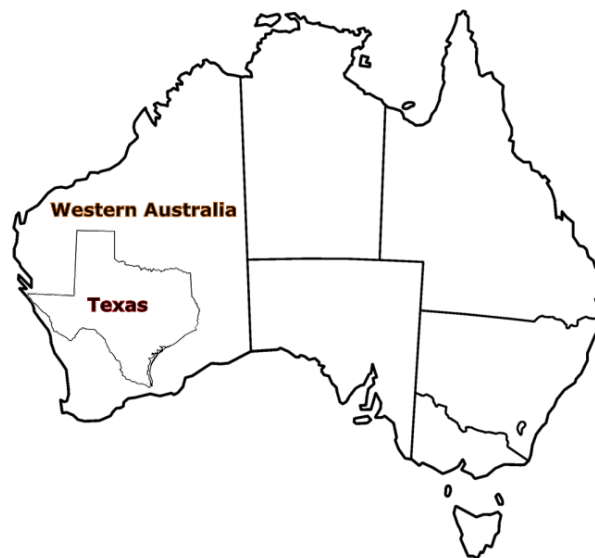


Figure 1.1 Map of Australia with the state of Texas, USA overlaid for size comparison

The state is classified into eight health administrative regions (see Figure 1.2), which are categorised in metropolitan (Perth and its surrounds), rural (Midwest, Wheatbelt, Great Southern, South West) and remote regions (Pilbara, Kimberley, Goldfields) [3,4]. Given the vastness of the state, there is wide ecological and climatic diversity, varying from tropical conditions in WA's most northern parts, to desert land in its inland areas, and more temperate conditions in the state's southwestern corner (see the Australian climate



Figure 1.2 The health administrative regions of WA.

classification map provided in Appendix A1 for a detailed visual representation of climatic variation in WA) [5].

The Australian Bureau of Statistics document that 3.1% (69,664) of the WA population is Aboriginal² [6], 65.2% of whom live in regional, remote and very remote areas compared to only 28.7% of non-Aboriginal people [7,8]. Table 1.1 provides an overview of demographic and socio-economic characteristics of WA's Aboriginal and non-Aboriginal populations. A significant health gap exists between Australia's Aboriginal people and the general population. This is illustrated by a lower life expectancy, a higher infant mortality rate, higher hospitalisation rates and a higher burden of both chronic and infectious diseases [9–12]. Furthermore, the poor environmental and living conditions found in many remote Aboriginal communities are associated with the high burden of ear, skin and respiratory infections that has been reported in these settings, especially in children [13–18]. Overcrowding, which affects over half of all Aboriginal people living in remote communities, is considered to be a particularly important factor in this regard [18–20].

The studies that are reported on in chapters 2 and 4 all took place in four remote Aboriginal communities in the eastern part of the Pilbara region. The communities are located in the Western Desert, which extends from WA's Pilbara region into the adjacent jurisdictions of the Northern Territory and South Australia (see the map of the Pilbara and its relative remoteness provided in Appendix A2). This is the traditional country of the Martu, an Aboriginal people that lived a highly autonomous nomadic existence until societal dynamics fuelled by European colonization, pastoral exploitation and missionary work led to a way of life that was organised around several remote communities and

² Indigenous Australians consist of the Aboriginal and Torres Strait Islander people that are descendants of the groups of people that populated Australia for more than forty thousand years prior to European colonisation. For the purpose of brevity and consistent with the WA Health policy, we will refer to this population as Aboriginal people throughout this manuscript.

outstations that were established from the early 20th century onwards [21]. The Martu are a distinct group of Aboriginal people that share a common *Tjukurrpa* or ‘Law’ that lays the foundation for social organisation and defines the interactions between the Martu people, their extended family members and their spiritual connection to the lands [22]. This Martu ‘domain’ [23] forms the core of cultural identity and Indigenous strength, existing separate from that of the White world and its norms and values [22]. The ‘contested domain’ then refers to the inherent conflict that arises from the interaction between these two worldviews [22]. This is the space within which government and non-government services engage with the Martu. Consequently, it also forms the conceptual setting for health service provision and the interaction between health workers and community members that is explored in chapter 4.

Table 1.1 Summary of demographic characteristics of the Aboriginal and non-Aboriginal populations in Western Australia.

	WA population in 2011	
	Aboriginal	non-Aboriginal
<i>median age, in years</i>	22	37
<i>median household income per week</i>	\$1.043	\$1.425
<i>average number of people per household</i>	3,5	2,6
<i>average number of people per bedroom</i>	1,3	1,1
<i>unemployment rate</i>	17,8%	4,5%
<i>% resident in remote and very remote areas</i>	21,4%	1,7%
<i>life expectancy at birth, in years*</i>	male: 65.0 female: 70.2	male: 80.1 female: 83.7

source: Australian Bureau of statistics, Australian Census 2011

* Australian Institute of Health and Welfare 2014. Mortality and life expectancy of Indigenous Australians: 2008 to 2012. Cat. No. IHW 140. Canberra: AIHW.

According to the 2011 Australian census data, the population of the four Western Desert communities that form the focus of the work presented in chapters 3 through 5 varied from approximately 70 people in the smallest community to 350 in the largest [2], although these are likely to be underestimations of the true population size [24]. Moreover, this number fluctuates throughout the year, as the Martu are highly mobile and

travel extensively throughout the region for routine, social and cultural business, including funerals. Each of the four communities has a local clinic that is managed by the same community-controlled Aboriginal Medical Service (AMS)³. The clinics range from one-nurse posts in the smaller communities to a facility with a resident GP and two to four nurses in the largest community. The WA Health Department's Country Health Service also provides specialist health services to all communities in the area, including 6-weekly visits by a paediatrician and regular visits by occupational therapists. Each community also has a school (up to year 12) and a small shop that stocks basic supplies and food items. The communities can be accessed by a network of unsealed roads. The driving distance to the nearest regional town varies from 150 to 700 km and can require up to a full day's drive to reach. Each community also has a gravel airstrip that is used by health and other services to access the communities. This includes the Royal Flying Doctor Service (RFDS), chartered planes that transport medical personnel and patients and a 'mail plane' service that does the rounds of the various remote communities in the region once a week and which is used to transport small goods and individual passengers to and from the communities. Road and air access can be limited during the peak of the "wet season" from January to March, when excessive rainfall and cyclones can occur.

A 2014 evaluation report on the effectiveness of state-funded Aboriginal Health programs found that the Pilbara was relatively underfunded in this respect [25]. Yet, various studies and reports have highlighted the important burden of health and wellbeing issues that persist among Aboriginal children and remote communities in the Pilbara, including significantly higher notification rates for notifiable infectious diseases compared to state averages [26]. The Pilbara population experiences a significantly higher mortality rate than the state average and is also the WA region with the greatest mortality rate disparity

³ The Aboriginal Medical Service is a model of Aboriginal community controlled health care that is employed throughout Australia in an effort to provide high quality and culturally appropriate medical services to Aboriginal communities.

between Aboriginal and non-Aboriginal people; the mortality rate was reported in 2001 to be five times higher for Aboriginal people compared to the non-Aboriginal population [27]. The impact of environmental factors such as poor housing quality, household overcrowding and excessive dust levels contribute to the health and wellbeing outcomes in WA remote communities [18,28,29]. This is also the case in the remote communities located in the Pilbara, which experience extensive overcrowding [30]. Furthermore, results of the 2012 Australian Early Development Census showed that children living in remote areas of the Pilbara have comparably high rates of developmental vulnerability [26], which has been linked to higher hospital admission rates for infection [31]. These data confirm the urgent need to address the health status of children living in remote Aboriginal communities of the Western Desert.

1.5 The Public Health Relevance of Skin Infections

Skin infections have an important public health impact globally [32–34]. Although rarely fatal, skin conditions such as impetigo and scabies are among the most prevalent diseases in the world and contribute substantially to the global burden of disease [32]. Over 162 million children living in low and low-middle income countries are thought to be affected by impetigo at any one time [33], while the global prevalence of scabies has been estimated at 100 million cases, with the highest burden found in children living in tropical climates [35]. In high income countries, skin infections are most common in disadvantaged populations [33,35,36], although outbreaks of scabies infestations also regularly occur in institutional settings such as hospitals, nursing homes, prisons, schools or childcare facilities [36–40].

Impetigo, commonly referred to as ‘skin sores’⁴, is an infection of the superficial layers of the epidermis caused by the bacteria *Staphylococcus aureus* or *Streptococcus pyogenes* (also often referred to as Group A Streptococcus or GAS) [33,41]. While *S. pyogenes* is the most common cause of impetigo in tropical areas, *S. aureus* is the major pathogen in temperate climates [37]. In low-resource settings in particular, impetigo is associated with various severe complications. *S. pyogenes* skin infection can lead to the development of acute post-streptococcal glomerulonephritis (APSGN) and an increased risk of chronic kidney disease later in life [42–44]. A possible link between *S. pyogenes* skin infections and the development of acute rheumatic fever (ARF) and rheumatic heart disease (RHD) has also been postulated [45]. Furthermore, *S. pyogenes* and *S. aureus*

⁴ The terms ‘impetigo’ and ‘skin sores’ are used interchangeably throughout this manuscript. While ‘impetigo’ is more commonly used in the scientific literature due to its precise clinical definition, the term ‘skin sores’ is used more predominantly in the context of day-to-day clinical practice in remote communities. It is also the term that service providers and other community actors are more familiar with.

infections can both become invasive, leading to acute life-threatening bacteraemia, sepsis and skeletal infections [46–48].

Scabies is a parasitic infection caused by *Sarcoptes scabiei* var *hominis*, a mite that tunnels into the epidermis of the skin, thereby initiating an immune response that leads to the characteristic intense itching sensation associated with scabies [49]. The ensuing scratching can result in complications, as the skin damage increases the risk of secondary bacterial infection by *S. aureus* and *S. pyogenes*. Scabies infections are therefore considered to be a driver of impetigo and its complications in low-resource settings [14,35,37,50]. Crusted scabies is a particularly severe form of the disease where the host's immune system is unable to control the infection. While a case with simple scabies usually has no more than 10 to 15 mites on their body at any given time, the mite load in a case of crusted scabies can be over a million mites [51]. This hyper-infestation of scabies mites causes severe crusted lesions requiring intensive treatment and is highly infectious, thereby putting contacts at a high risk of cross-infection [51,52].

Both impetigo and scabies are highly transmissible. While direct skin contact between persons is the primary mode of transmission, fomites also play a role in both infections (although this is thought to be minimal for simple scabies) [41,53]. Household overcrowding therefore is an important facilitating factor for the transmission of both impetigo and scabies. A tropical climate and poor access to water are also considered to be associated with higher impetigo prevalence. However, while hygiene factors have been shown to be an important factor in bacterial skin infections, no such association has been established for scabies infestation [32,35,37,53,54].

1.6 Skin Infections in Remote Aboriginal Communities of Australia

In Australia, high rates of impetigo and scabies have been documented in remote Aboriginal communities of the Northern Territory (NT) [33,37]. A series of studies showed that scabies and skin sores were among the most important infectious causes of infant and childhood primary care presentations in remote Aboriginal communities located in NT's East Arnhem Land [14–16]. Furthermore, these studies also underlined the early occurrence of skin infections in Aboriginal children living in remote communities; up to 68% and 82% of children had presented with scabies and impetigo respectively by the age of 12 months [14,15]. These findings also further illustrated how impetigo infections were being driven by preceding scabies infestations, as co-infections were common and scabies presentations occurred earlier in life than impetigo presentations [14–16]. Skin infection prevalence data in the NT showed a similarly high burden of childhood impetigo and scabies, with prevalence rates as high as 50% for scabies and 70% for impetigo having been documented in the past [42]. While rare in children, crusted scabies rates in remote communities of the NT are the highest in the world [51,52]. This ubiquity of skin infections is thought to be the main driver of the disproportionately high rates of APSGN, ARF and RHD reported amongst Aboriginal people living in remote areas in the NT [45,54].

The burden of skin infections in the Aboriginal populations of other Australian states and territories has not been described as thoroughly as in the NT. While relatively recent hospital admission data in Queensland, New South Wales and WA show that Aboriginal children are at a much higher risk of being admitted for skin infections and associated complications compared to non-Aboriginal children [48,55,56], current primary care level data are sparse, especially in regards to the remote Aboriginal community setting [13]. This is also the case for WA, where the only published community prevalence data

on skin infections come from a study conducted in 2000 [57]. The study documented a declining prevalence of skin sores in children in two remote WA communities after swimming pools had been opened there. The baseline prevalence of skin sores in those two communities (prior to the opening of swimming pools) was 62% and 70%, suggesting that the prevalence of skin infections in other remote communities in WA might have been comparably high. In chapters 2 and 3 we will present current data that show that the burden of skin infections remains unequivocally high among Aboriginal children in WA.

1.7 Community Prevention and Control of Skin Infections: Current Strategies and Challenges

While effective treatment options are currently available for the clinical management of skin infections in remote Aboriginal communities, they do come with limitations that undermine their real-world effectiveness. The CARPA (Central Australian Rural Practitioners Association) Standard Treatment Manual is the gold-standard reference that supports good clinical practice for health care providers working in remote Aboriginal communities [58]. Table 1.2 summarises the current treatment recommendations for bacterial skin infections, scabies and tinea.

Table 1.2 Skin infection characteristics, treatment options and risks

	causative agents	signs and symptoms	first line treatment*	other
impetigo (skin sores)	bacterial <i>Staphylococcus aureus</i> <i>Streptococcus pyogenes</i>	crusted sores, redness, pus	single dose of intramuscular benzathine penicillin, or oral trimethoprim-sulfamethoxazole, bd, 5 days	risk of APSGN, ARF, RHD, invasive infections
boils	bacterial <i>Staphylococcus aureus</i> <i>Streptococcus pyogenes</i>	swelling, tenderness, red lump, pus	oral dicloxacillin, qid, 5 days, or oral flucloxacillin, qid, 5 days	risk of APSGN, ARF, RHD, invasive infections
scabies	parasitic (mite) <i>Sarcoptes scabiei</i>	itching, scratching, visible burrows, possible secondary infections	apply permethrin 5% cream to whole body, repeat treatment after 1 week	crusted scabies, secondary bacterial infections
tinea	fungal <i>tinea capitis</i> , <i>tinea corporis</i> , <i>tinea pedis</i> , <i>tinea cruris</i>	ring-like rash, itchy, scaly, possible secondary infection	apply miconazole 2% cream, bd, 4 to 6 weeks, or oral terbinafine, daily, 2 weeks	risk of secondary bacterial infection

* as recommended in the 6th edition of the CARPA Standard Treatment Manual (2014, CARPA Inc., Flinders University)

The first line treatment option for scabies is the application of 5% permethrin cream. The cream is to be applied to the entire body and left on overnight with a repeat treatment seven days later to ensure that the infestation is cleared [59]. While this has been shown to be an effective method of treating patients with scabies [60], compliance can be problematic as it relies on self-application and can be regarded as an unpleasant experience [60,61]. Topical scabies treatment adherence has been shown to be challenging in the remote Aboriginal community context, particularly when it comes to

treating household contacts of the index case, which is important to avoid re-infestation [61]. Permethrin is not advised for the treatment of scabies in infants under the age of two months, in which case 10% crotamiton cream is recommended [58]. However, this topical treatment requires more repeat applications than permethrin and has been shown to be less effective compared to permethrin [60]. Ivermectin, an oral scabicide requiring two doses 8 to 15 days apart, has been shown to be an effective treatment for scabies [60,62]. However, it cannot be used to treat young children ($\leq 15\text{kg}$) and pregnant woman [59] and is currently not licenced for the indication of simple scabies in Australia [63]. The development of antimicrobial resistance to permethrin and ivermectin also remains a concern in communities with endemic scabies [59,61,64,65]. Thoughtful consideration and caution are needed when it comes to the widespread use of these drugs, particularly in the context of mass-drug administration control strategies [62,66,67].

The CARPA manual recommends a single dose of intramuscular benzathine penicillin G as the treatment of choice for impetigo in remote Aboriginal communities [58]. There are however concerns that this particularly painful injection might affect treatment uptake for impetigo and associated conditions [68,69]. The rationale to recommend benzathine penicillin G over oral antibiotic options stems from a wariness of incomplete adherence to oral therapy [54] and until recently, a lack of evidence for effective treatment of severe impetigo in communities with high prevalence [70]. Recently either of two short courses of oral trimethoprim-sulphamethoxazole have been shown to be non-inferior to the injection of benzathine penicillin G for treatment of impetigo [70]. This provides an oral antibiotic that is short course, palatable and with fewer adverse events and has been incorporated into the CARPA manual and other national guidelines.

Given the high burden of skin infections in remote Aboriginal communities in the NT and sequelae of these, various initiatives and intervention studies have been implemented in the region over the past 20 years in an attempt to reduce the prevalence of impetigo and

scabies. Initial studies in individual communities trialled mass treatment models for the reduction of scabies prevalence through the use of topical agents (permethrin and crotamiton) combined with the opportunistic treatment of -or clinic referral for- skin sores. This approach resulted in reductions in scabies and skin sore prevalence in two studies [71,72], but only a reduction in skin sores in a third [68]. Low treatment uptake for topical agents might help explain why scabies rates remained unchanged in this latter study [68]. Applying the cream and leaving it on overnight can be messy and uncomfortable, which might also affect the willingness of household contacts to apply the cream if they believe they do not have scabies [61]. Furthermore, while intervention-based studies have shown promise, ensuring the long-term impact of skin infection control interventions is challenging and requires sustainable, community-driven strategies [72–74].

In the search for a more acceptable form of treatment to be used for the community control of scabies, and bolstered by the promising results of international studies [62,67,75], skin infection control interventions in the NT have shifted their focus to the use of ivermectin. While a study published in 2015 found that mass drug administration with ivermectin on two separate occasions led to a significant reduction of scabies in a remote NT community, the study also showed that long term sustainability of that success was undermined by living conditions, population mobility and the presence of ‘hyper-transmitting’ cases of crusted scabies [74]. Given that crusted scabies is highly infectious and has the potential to infect many other persons, recent skin infection control strategies have started to include a focus on active case finding and intensive treatment of community members affected by this debilitating disease [52]. Ivermectin is pivotal to the treatment of crusted scabies cases and is therefore registered with the Australian Therapeutics Goods Administration for this use. However, ivermectin currently remains

unlicensed as a first-line option for the treatment or community control of simple scabies in Australia [63].

While these interventions have demonstrated a potential to reduce the burden of skin infections in remote Aboriginal communities in the short term, questions remain around sustainability, the optimal implementation of community-based strategies and a need to also strengthen routine health services and their capacity to address skin infections [71–73].

Inadequate housing, overcrowding, hygiene practices, high population mobility, a lack of access to culturally secure health services and underdiagnosis have all been identified as factors that contribute to the high burden of skin infections in low-resource settings, including remote Aboriginal communities [14,19,53,76–78]. This suggests that until the living conditions in remote Aboriginal communities are adequately addressed, the long-term and sustained reduction of skin (and other) infections is going to continue to be a challenge. Moreover, control strategies described up to now have been very labour intensive, often requiring substantial input and resources from services and organisations outside the community. In order to be sustainable and transferable, new strategies are needed that can be incorporated into routine service delivery. Nevertheless, new treatment strategies with increased acceptability [62,70,74], the promise of a GAS vaccine [79] and an increasing recognition of the need for community-driven prevention and control strategies [13] have the potential to have an important impact on the burden of skin infections in remote Aboriginal communities.

1.8 Revealing Skin Infection Burden in Western Australia

Although a comprehensive body of work on skin disease control over more than two decades exists for the NT [14–16,19,42,46,48,52,61,68,70–72,74,80], limited similar work has been published for WA. Given that many of the factors that drive the presence of skin infections in the NT are also present in the remote communities of WA (overcrowding, environmental and living conditions), it is likely that the burden of skin infections is similarly high. However, the lack of a coordinated focus on skin infections in WA demonstrates that local data are needed in order to inform a policy and practice response.

The scant available data for WA indeed suggests a high prevalence of skin infections amongst Aboriginal children. Community-level data on skin sores recorded a prevalence of 70% in children in one WA community in the year 2000 and suggested that skin infections were a common reason for presenting to the local community clinic [17,57]. Previously published hospitalisation data also points towards a high burden in Aboriginal children compared to the general population in WA [56]. More recently, a community-based participatory action research program around maternal health and early child development (led by the Telethon Kids Institute in Perth) provided indications that issues around skin health, scabies and skin sores affected school attendance and contributed to the high levels of vulnerability that were recorded amongst Aboriginal children living in the Western Desert in the 2007-2008 Australian Early Development Index surveys [30,81].

This thesis will build on these initial studies and provide a more current and comprehensive insight into the burden of skin infections in WA, with a particular focus on the remote Aboriginal community setting in the Pilbara. Furthermore, by including a substantial qualitative data collection component in our work, we aim to address a gap in

the literature: to describe the issue of skin infections in remote Aboriginal communities from the perspective of the Aboriginal people impacted by this burden as well as the health and service providers that live and work there, and to identify the various barriers and facilitators that might affect the prevention and control of skin infections in remote settings. We believe that the outcomes of the work presented here will be of great value to Aboriginal community controlled health services, government health services and non-governmental organisations and researchers operating in the field of Aboriginal health. It provides the foundations of an evidence base that will facilitate the planning of future programs of work to address skin infections in WA.

1.9	Ethics Approval
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Ethics approval for this work was obtained from the Western Australian Aboriginal Health Ethics Committee (reference numbers 477 and 510) and the University of Western Australia Human Research Ethics Office (references RA/4/1/6563 and RA/4/1/6199). Access to the linked data presented was approved separately by the University of Western Australia Human Research Ethics Committee (reference RA/4/1/6454), Western Australian Department of Health Human Research Ethics Committee (reference #2012/56) and the Western Australian Aboriginal Health Ethics Committee (reference number 437).

The PhD candidate was supported in his research by senior Aboriginal and non-Aboriginal researchers of the Centre for Research Excellence in Aboriginal Health and Wellbeing (CREAHW). They provided him with feedback on a regular basis to ensure that the methods and implementation of the studies were culturally secure and methodologically sound. This occurred through three-to-six monthly ‘update presentations’ to the CREAHW and its investigators. This supportive environment was crucial to the process of this PhD.

1.10 Summary of Introduction

Skin infections (scabies and impetigo) are common in Aboriginal children living in remote communities in Australia, with almost one in two children affected with impetigo at any one time [33]. Aboriginal children suffer the highest prevalence of impetigo world-wide [82] and this burden has remained unchanged over more than 20 years [33]. The vast majority of information currently available on skin infection burden and control in remote Aboriginal settings comes from two decades worth of research and intervention studies performed in the NT. No such body of work presently exists in WA. The aim of this thesis is to address this gap and significantly contribute to the state-wide and community level evidence on the high burden of skin infections that currently exists in WA, and to provide insights into the issues affecting their prevention and control in the context of remote communities in the Pilbara. While it is critical to address the underlying social determinants such as poverty, housing, employment and education that contribute to increased risk of skin infection, more short-term measures for the prevention, early detection and treatment of skin infections should be considered a public health priority. Addressing skin infections in Aboriginal children will not only provide an immediate benefit to their overall health and development, but is also likely to reduce the incidence of severe acute and chronic sequelae that disproportionately affect the Aboriginal population.

CHAPTER 2 PRIMARY CARE CLINIC ATTENDANCE AMONG YOUNG ABORIGINAL CHILDREN LIVING IN FOUR REMOTE COMMUNITIES IN WESTERN AUSTRALIA

2.1 Preamble

This first results chapter reports on the outcomes of a retrospective clinical audit study that was performed in four remote Aboriginal communities in the Pilbara region of Western Australia. The aim of the study was to substantiate anecdotal reports from community members that suggested a high burden of skin infections amongst children living in these communities. We documented all clinic presentations occurring between January 2007 and December 2012 for children up to the age of 5. The study outcomes describe a high burden of skin and other infections amongst children in Pilbara remote communities and provides some insight into skin infection treatment practices.

2.2 Introduction

The health disparities affecting Indigenous populations around the world are well documented. A recent international population study showed that Indigenous people experience poorer health and social circumstances, which is reflected in a range of key health and wellbeing indicators when compared to non-indigenous or total population benchmarks, including life expectancy at birth, infant mortality, birth weight, child malnutrition and educational attainment [9]. In Australia, the health status of Aboriginal and Torres Strait Islander people¹ is marked by a 10 year life expectancy gap [83] and significantly higher rates of chronic [11] and communicable diseases [12] when compared to the non-Aboriginal population. Furthermore, 21.4% of Aboriginal people live in remote and very remote areas of Australia (compared to 1.7% of non-Aboriginal Australians) [84], where life expectancy is lowered further, access to health services is less consistent and the burden of many chronic and communicable diseases is higher compared to Aboriginal people living in urban areas [56,85–88]. Many socioeconomic, environmental and cultural factors contribute to the ill health that has been documented in rural and remote Australia [89,90], including inadequate housing and overcrowding [18–20], excessive exposure to dust [28] and lacking access to health services [91].

In Western Australia (WA), where 40% of the Aboriginal population live in remote or very remote areas [6], the Western Australian Aboriginal Child Health Survey (WAACHS) documented high parent/carer-reported rates of recurring respiratory, ear, skin and gastrointestinal infections in their children between 2000 and 2001, with the highest rates reported among young children living in very remote communities [92]. Self-reported rates of recurring skin infections in children were particularly high in a vast,

¹ The term ‘Aboriginal and Torres Strait Islander people’ is used to refer to the descendants of the Indigenous population that existed in Australia long prior to European colonization. It underlines the diversity of the Indigenous peoples living in Australia. However, for the purpose of brevity, we will use the term ‘Aboriginal people’ throughout this paper in reference to this heterogeneous group of people.

remote area in the north of the State known as the ‘Western Desert’ (17% compared to 9% for the state average [92]). This high burden of skin infections among children living in the Western Desert was also noted in anecdotal reports from teachers, child health nurses and other stakeholders in the Western Desert, who described high rates of observable infections and illness among children, singling out skin infections (‘scabies’, ‘boils’, ‘sores’) as a major concern [30]. The report concluded that the burden of childhood infections was likely to constitute an important barrier to early childhood development, school readiness and engagement and on the subsequent health, economic and social wellbeing of Aboriginal communities in the region [30]. Notwithstanding such reports, few recent prevalence or clinic presentation data on skin and other common childhood infections in remote Aboriginal communities are available, in particular for WA [13].

Here we address this gap and report on the outcomes of a retrospective review of community clinic presentations in the Western Desert. This study was undertaken to ascertain the burden of infectious diseases in the first five years of life of children living in the Western Desert region and to assess the level of health-care seeking behaviour in this context. The emphasis of our study was on scabies and skin sores in particular, given the high level of concern from community members that had been previously reported.

2.3	Methods
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2.3.1 Study setting

The study was conducted in four remote Aboriginal communities located in the Western Desert region of Western Australia, 1,000 to 1,400 km north east of Perth. These communities have an estimated total population of 792, of whom 650 (82%) are Aboriginal people [2]. The communities are located between 150 and 700 km from the nearest regional town and are only accessible by unsealed roads or by air (each community has a gravel air strip). In the wet season (from November to April) flooding can make the communities inaccessible. These four communities are culturally linked, all being home to the Martu, a distinct group of Aboriginal people that share a common cultural tradition. However, dislocation from ancestral lands and cultural practices and displacement into towns has had an adverse effect on their cultural continuity and collective sense of health and wellbeing [21,22].

Each of the four communities has a local clinic, all managed by the same regional Aboriginal Medical Service (AMS). The clinic in the largest community (total population of 427) is usually staffed by two to four nurses and a general practitioner (GP), while the clinics in the three smaller communities (with populations ranging between 81 and 156 people [2]) are generally staffed by a single nurse. All clinic staff are full-time and resident. At the time of data collection, no full-time Aboriginal health workers were based in any of the communities. The GP from the largest community visits the three smaller communities every few weeks over the course of three consecutive days. Similarly, an external specialist paediatrician visits the communities once every six weeks.

2.3.2 Data collection and analysis

We performed a retrospective review of medical records for all children aged 0-5 years that presented to any of the four clinics between 1 January 2007 and 31 December 2012, which includes the timeframe of the study that anecdotally reported on the importance of skin infections and its possible effect on childhood development in the region [30]. Patient consultation records prior to 2010 were only available in hard copy patient files located in each of the clinics, while all patient consultation data from 2010 onwards was accessed through MMEX (ISA Health Care, Perth, WA), a web-based e-health platform. We reviewed MMEX consultation records in their entirety, including progress notes and specific diagnosis and treatment fields. We mirrored the data collection process first established by Clucas *et al* [14] and later repeated in two other similar studies implemented in remote Aboriginal communities in the Northern Territory (NT) of Australia [15,16].

Eligible children were those registered at clinics in any of the four communities. Frequency of presentations per disease category and per child were summarised by diagnosis either for age group (<1, 1 to <2, 2 to <3, 3 to <4, 4 to <5, 5 to <6 years) or by calendar year (1 January to 31 December for each year, 2007-2012). Continuous asymmetric data were expressed as medians with interquartile range (IQR) and dichotomous data as counts and percentages. Individual person-years (time contributed to the study during which the child was in the 0-5 year age range) were calculated as the time from birth or 1 January 2007, whichever was later, until the child's sixth birthday or 31 December 2012, whichever was sooner, or part thereof for age-specific person-years. Children were therefore followed for variable lengths of time. It was assumed that all children registered at one of the four remote community clinics were born in the community and remained in the community until their sixth birthday, therefore, the person-years (rate denominators) are potentially over-estimated since the frequencies of

presentations (rate nominator) are potentially under-estimated due to birth elsewhere or movement to other locations. Because these are relatively stable communities with limited population movement, the age- and year-specific rates were thought to be reasonable approximations. Age- and year-specific rates were also calculated using 2011 Australian census data for these communities [2], which may under-represent the total Aboriginal population in Australia [24]. All 95% confidence intervals were calculated using Poisson exact methods. Data were analysed in R version 12.1 (R Project for Statistical Computing, City, State <http://www.R-project.org>). Treatment prescription data are reported for new skin sore presentations only and exclude any possible follow up visits. This avoids overestimation of the prescription of oral antibiotics (which may require multiple visits to complete a full course of antibiotics) compared to benzathine penicillin G injections (requiring only one visit).

Date of birth, gender and community of residence were recorded. For each episode we recorded: date of presentation, the child's height and weight when documented, the reason(s) for presentation, prescribed treatment and whether the child was referred to hospital. The reasons for presentation were categorised *a priori* and according to the classification described in Clucas *et al* [14]. Our data collection form recorded the following reasons for presentation (multiple reasons per presentation possible): scabies, skin sores, acropustulosis (this was an addition compared to Clucas *et al* [14], informed by discussions with community healthcare providers), dermatophytes, eye infections (with a separate indicator for trachoma), ear infections (any of acute otitis media, otitis externa, chronic suppurative otitis media), throat infections, glomerulonephritis, acute rheumatic fever, lower respiratory tract infection, upper respiratory tract infection, asthma, diarrhoea and other fever illness (fever recorded and no other reason for presentation documented). Repeat presentations for the same disease category within a 2-week period were considered as the same episode of disease, unless clinic consultation

notes stated otherwise. We also documented hospital referrals, which included urgent evacuations (including retrievals by the Royal Flying Doctor Service), and referrals to a regional hospital for tests. The patient record review and data-entry was performed by DH between October 2013 and November 2015.

Ethics approval was obtained from the Western Australian Aboriginal Health Ethics Committee and the University of Western Australia Human Research Ethics Office (references 477 and RA/4/1/6563). Waiver of individual consent was provided. The study was discussed with the regional AMS and their input was sought in preparation of the study. Previous community consultations with the AMS, school staff and other community members had identified skin infections as a priority health issue.

2.4 Results

There were a total of 304 children under the age of six years with available data. This total decreased to 231 (76.0%) children (61% male) after removing records for children whose patient files indicated a place of residence other than the four communities that were the focus of our study. There were 7,504 individual clinic presentations for the 231 children, equating to on average 32.5 visits / child or 10.4 /person-year (7,504 presentations/724.1 person-years). Data were collected from birth for 116 children. Approximately 100 children contributed an entire calendar-year in each age group and about 120 person-years were contributed to each age group and calendar year rate estimate (see Table 2.1).

Approximately half of all recorded clinic presentations were for infectious disease diagnoses (Table 2.2 and Figure 2.1), a proportion that was maintained across all ages. Ear infections, upper respiratory tract infections (URTIs) and skin sores were the most frequently diagnosed infections, accounting for 15%, 13% and 12% respectively. These infection types were all experienced by the majority of children at least once in the time frame of our study (66%, 75% and 72% of all included children, respectively).

The number of clinic presentations per child per age category (Table 2.1) was highest in the first two years of life, with a median of around 13 presentations per year, and steadily declined to a median of six presentations per year by school age, although there was considerable variability in the individual rates. Overall, 33.8% of clinic presentations involved one infection, 9.3% two infections and 2.4% involved three or more infections. These proportions were constant across all age groups (Figure 2.2).

Skin sore presentations affected all age groups with the highest presentation rate in 5–6 year olds (162/100 person years; 95% confidence interval [CI] 140-186).

Table 2.1 Study participants: children under 6 years registered at Pilbara community health clinics, January 2007 to December 2012.

age in years	population estimate (census 2011)	# children registered at the clinics	# children with data for entire year	% of children with at least 1 presentation	person-years	median (IQR) number of presentations	
						all children*	presenting children**
< 1	90	136	100 (73.5%)	87.0%	117.8	13.5 (4.8,22.0)	17.0 (10.0,23.5)
1 to <2	96	139	104 (74.8%)	82.7%	119	13.0 (3.0,21.0)	16.0 (8.3,22.8)
2 to <3	54	143	98 (68.5%)	79.6%	120.7	10.0 (1.3,16.0)	12.0 (7.0,17.0)
3 to <4	156	141	102 (72.3%)	82.4%	120.7	6.0 (2.0,11.8)	9.0 (4.8,12.0)
4 to <5	66	145	100 (87.0%)	85.0%	123.8	6.0 (2.0,12.0)	7.0 (4.0,13.0)
5 to <6	72	147	95 (64.6%)	89.5%	122.1	6.0 (3.0,11.0)	7.0 (4.0,11.0)

* Presentations among all eligible children for whom data is available for entire year (includes children with no presentations).

** Presentations among children who have presented at least once for the age group (excludes children with no presentations).

Table 2.2 Reasons for presentation of children under 6 years of age at four Pilbara community health clinics, January 2007 to December 2012

Reason for presentation	Number (%) of presentations* N=7504		Number (%) of children presenting* N = 231	
non-infectious disease diagnosis	4088	(54%)	225	(97%)
respiratory infections				
upper RTI	966	(13%)	173	(75%)
lower RTI	414	(6%)	118	(51%)
skin infections				
skin sores	935	(12%)	167	(72%)
fungal	148	(2%)	60	(26%)
scabies	137	(2%)	60	(26%)
crusted scabies	6	(<0.1%)	4	(2%)
acropustulosis	11	(0.1%)	4	(2%)
other infections				
ear infections	1138	(15%)	152	(66%)
throat infections	214	(3%)	104	(45%)
other febrile illness	127	(2%)	77	(33%)
complications associated with GAS				
APSGN	8	(0.1%)	2	(1%)
acute rheumatic fever	1	(<0.1%)	1	(<1%)
rheumatic heart disease	1	(<0.1%)	1	(<1%)
other				
diarrhoea	534	(7%)	135	(58%)
asthma	6	(<0.1%)	6	(3%)
hospital referrals	61	(1%)	45	(19%)

* More than one reason can be recorded at each presentation.

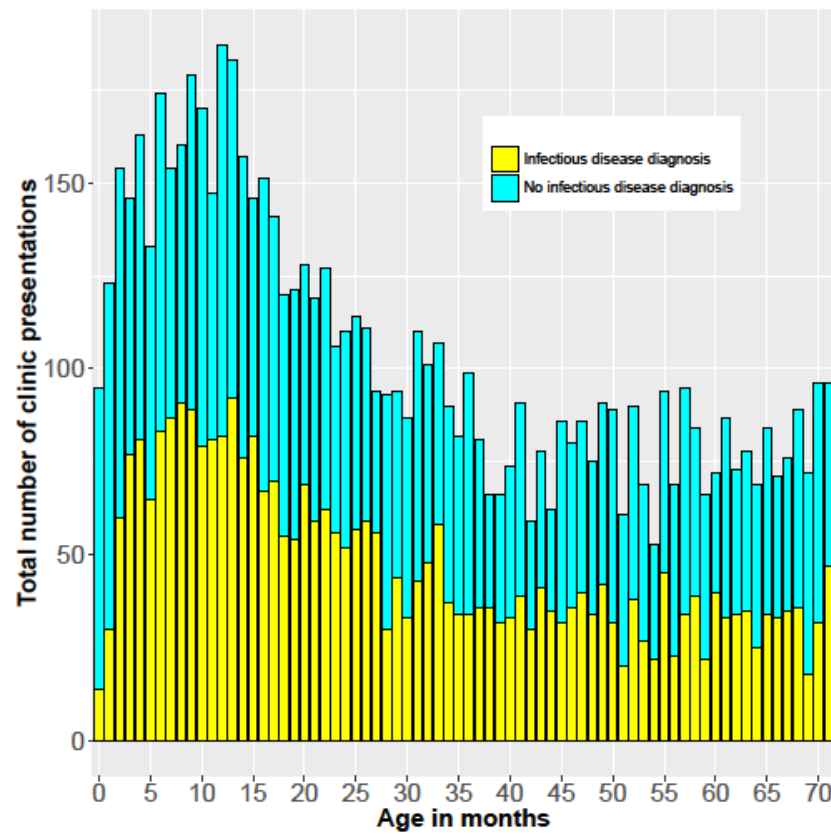


Figure 2.1 Age-specific frequency of clinic presentations for children under 6 years by infectious disease diagnosis

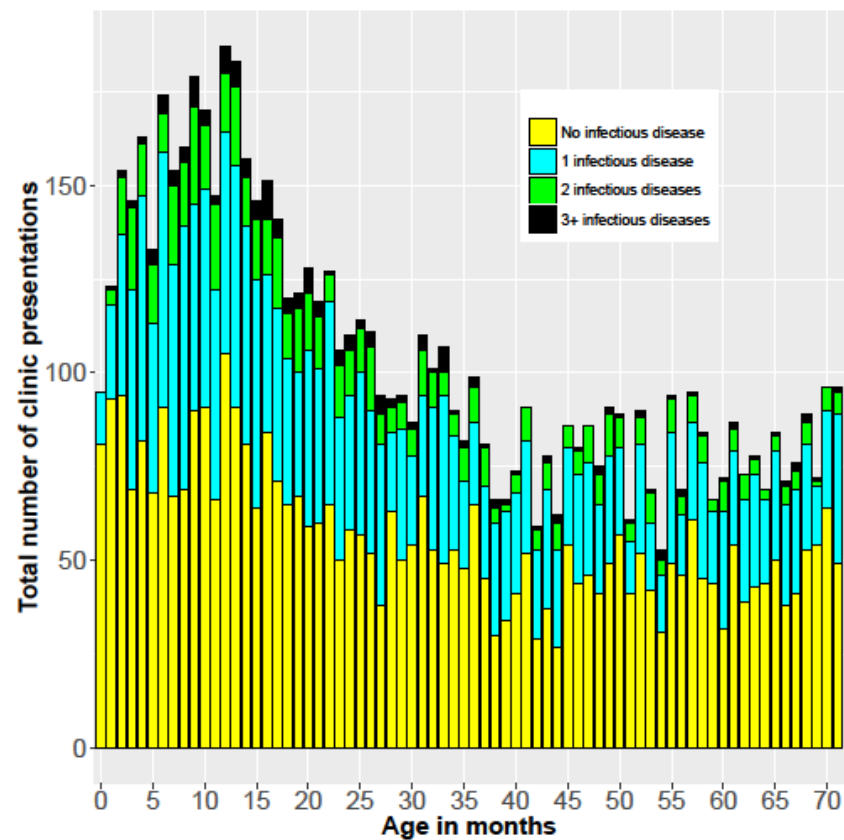


Figure 2.2 Age-specific frequency of clinic presentations for children under 6 years by number of infectious disease diagnoses at presentation

An intramuscular dose of benzathine penicillin G alone was administered in 30 (5%) of a total of 563 presentations for skin sores, while oral antibiotics alone and topical antibiotics alone were prescribed in 34% and 14% of skin sore presentations respectively. Combined oral and topical antibiotics was prescribed in 16% of skin sore presentations. No antibiotics were prescribed in 28% of presentations. Out of a total of 137 presentations for scabies, 51 (37.2%) also included a diagnosis of skin sores. Overall, 2% (n=137) of all presentations were for children presenting with scabies. 26% of children presented at least once for a scabies infestation. The rate of scabies presentations was highest in infants (57/100 person years; 95% CI 44-72). One quarter of all scabies presentations occurred before the age of 6 months (see Table 2.3 and Figure 2.3).

Infectious disease associated clinic presentation rates were relatively constant between 2007 and 2012 (Figure 2.4), with the exception of presentations for URTIs and ear infections, which showed some evidence of a reduction over time, especially for the latter. However, there was large variability in the disease-specific presentation rates across the age groups (Figure 2.3). Presentation rates for ear infections, URTIs, lower respiratory tract infections (LRTIs) and gastrointestinal infections were higher in children up to the age of three years when compared to older children.

Table 2.3 Median age at first clinic presentation for scabies, skin sores, ear infections, URTIs and LRTIs, January to December 2012.

Reason for presentation	n	Median age in years at first presentation (IQR)
Scabies	137	1.11 (0.46,3.08)
Skin sores	935	3.23 (1.79,4.82)
Ear infections	1138	2.17 (1.19,3.88)
LRTI	966	1.68 (0.80,3.23)
URTI	414	1.18 (0.58,2.54)

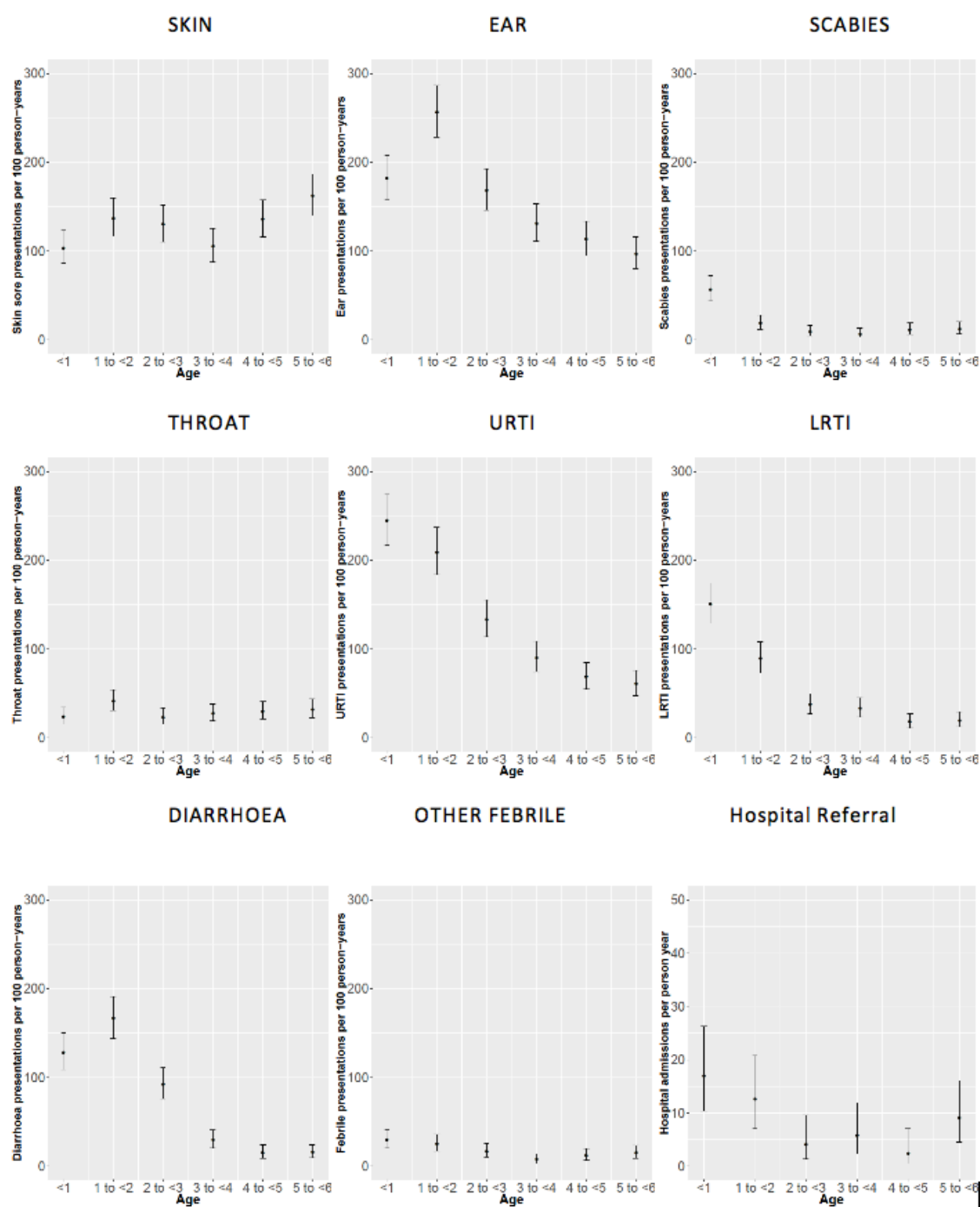


Figure 2.3 Rates of disease-specific presentations, by age, for children under 6 years of age at four Pilbara community health clinics, January 2007 to December 2012

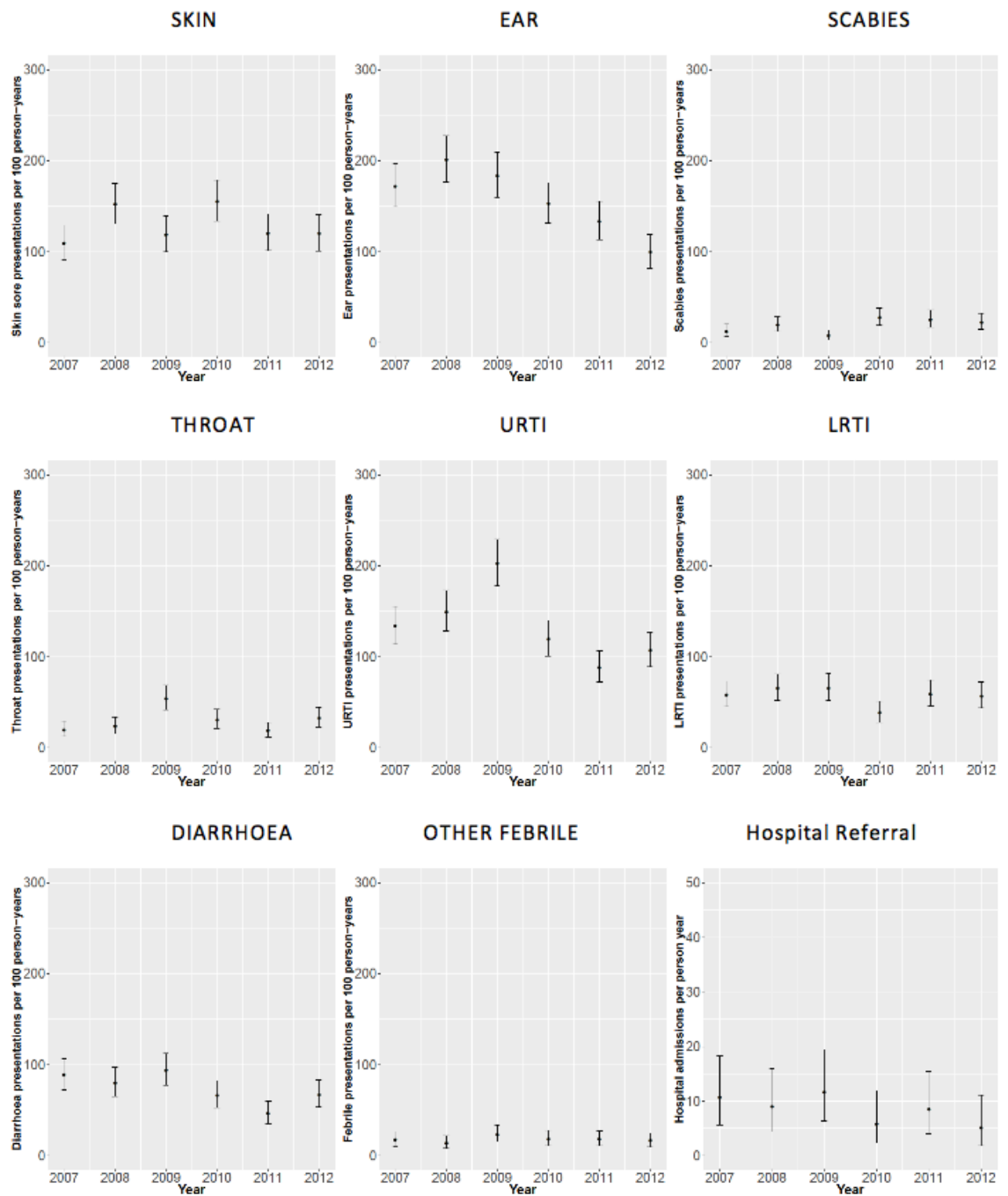


Figure 2.4 Rates of disease-specific presentations, by year, for children under 6 years of age at four Pilbara community health clinics, January 2007 to December 2012

2.5 Discussion

We report a high burden of primary health care presentations amongst Aboriginal children living in remote communities in the Western Desert of Western Australia. Primary care presentation rates are particularly high in the first three years of life. While some of these would be for routine child health checks and immunisations, the high presentation rates for infections in this age group represent a substantial infectious disease burden. Overall, almost half of all child presentations were for infectious causes, amongst which ear infections (15%), upper respiratory tract infections (13%), and skin sores (12%) were the three most common diagnoses made between 2007 and 2012. However, while presentations for ear infections and URTIs seemed to decline with age, skin sore presentations remained similarly high throughout all age groups, with a slight peak in the older age group (5 year olds). Our findings confirm and further substantiate the anecdotal and self-reported data that suggested a high burden of infectious diseases in the Western Desert area [30,92]. The high presentation rates for skin sores across all age groups were particularly striking and are in line with previous reports of the importance of skin infections in the western desert region [17,30,57,92]. Notwithstanding an observed decline in ear infection presentations over time, the data summarised here show that presentations for all infectious causes remain high in the Western Desert communities, suggesting an urgent need to re-evaluate current prevention and control strategies for common childhood infections in the region.

An additional reason for public health action on common infections in the Western Desert follows from their association with Aboriginal childhood development. Recurring infections affect the school readiness, school attendance and physical development of Aboriginal children in remote communities [20,30,93–95]. A recent study also showed that severe childhood infection requiring hospital admission is associated with

developmental vulnerabilities [31], which suggests that the developmental deficits previously documented among Aboriginal children living in the Western Desert [26,30] are likely to be at least in part due to the high burden of childhood infections found in these communities. Our findings therefore further underscore the importance of addressing this high burden of skin infections in remote Aboriginal communities; reducing the burden of infectious diseases is likely to benefit overall child development.

The consistently high rate of skin sores we reported is particularly concerning considering the acute and chronic sequelae that are associated with bacterial skin infections. Prolonged exposure to the causative bacteria of these infections (*Staphylococcus aureus* and *Streptococcus pyogenes*) can lead to a range of complications, including invasive disease [37]. Indeed, the high prevalence of group A streptococci in Australia's remote communities is the key determinant of the excessive burden of glomerulonephritis, ARF and RHD in Australia's Indigenous population [34,96,97]. Early and effective treatment of skin infections is therefore crucial. While a single intramuscular dose of benzathine penicillin is recommended as the first line of treatment for skin sores [58], we found this was only administered in 5% of skin sore presentations. Oral antibiotic courses were prescribed in most cases, notwithstanding concerns about treatment adherence [54,70]. Furthermore, we found that a topical antibiotic alone (mupirocin) was prescribed in one out of every seven skin sore presentations, when guidelines advise against its use out of concern of increasing drug resistance [58]. These findings suggest that health care practitioners do not necessarily follow current skin infection treatment guidelines and that other factors affect their clinical management practices, as has also been documented previously for other maternal and child health issues in remote Aboriginal communities [98].

The methodology we used for this study was based on that of three similar retrospective clinic audit studies that were implemented in remote communities located in the Northern

Territory [14–16]. While those studies reported similarly high proportions of presentations for skin sores, ear and throat infections, substantially higher proportions of primary care presentations were reported in the NT communities for upper and lower respiratory tract infections (13% vs 31.8% for URTI and 6% vs 10.7 % for LRTI), scabies (2% vs 7.8%) and diarrhoea (7% vs 14%) [14]. Given that scabies is considered an important contributor to bacterial skin sores in remote Aboriginal community settings [15,16,37], it is of note that we nevertheless reported similarly high numbers of skin sore presentations in the Western Desert. This suggests that even in settings with relatively low rates of scabies, structural factors such as overcrowding, housing conditions and poor environmental health can still drive the incidence of skin sores in children living in remote Aboriginal communities to extreme levels [18–20,28]. Alternatively, this might also be a reflection of the long history of research and public health campaigns on scabies in the NT, which possibly leads to an increased awareness and ability to diagnose scabies amongst health services operating there. Scabies might be underdiagnosed in rural and remote WA, as has been shown to occur in a recent study [78]. Finally, we also report fewer primary care presentations per child overall compared to the NT, which could be due to an actual lower burden of disease, but could also reflect variability in health service utilisation practices in both settings.

Our study was based on a retrospective review of community clinic records, both in the form of hand-written notes (for consultations from 2007 to 2010) and a digital format (for consultations from 2010 onwards). This type of study is largely dependent on the quality of these consultation notes. Since diagnosis in these kind of settings is typically based on clinical signs and symptoms, it relies greatly on the experience and knowledge of the healthcare provider (in addition to the use of standardised clinical guidelines, such as the CARPA manual [58]). Laboratory confirmation for the infections discussed here is rare. Misdiagnosis might therefore occur, and at times variability between health providers in

diagnosing cases was apparent in the notes. Under-diagnosis of skin infections might also occur [78]. Given the study design, its time frame and the age range we focussed on (0-5 years), children were followed for variable lengths of time. One additional limitation of this study is that due to logistical limitations, we were unable to perform a systematic validation of the quality of the entered data beyond logic data checks. However, we used a standardised data collection protocol [14] to minimise the chance of systematic data entry error. Furthermore, the rates reported in this article are based on Australian census data, which may under-represent our study population [24]. The primary care presentation rates by age and year we reported here may therefore be overestimates.

We conclude that infectious diseases are an important reason for Aboriginal children to present to community clinics in the Western Desert. The burden of ear, respiratory and skin infections are particularly high. Notwithstanding a reduction of presentation rates for some infections over time (URTI, ear infections), skin sore presentation rates remained high over time and across all ages. The high rates of primary care presentations for infections in remote Aboriginal communities documented in this and other studies [13] indicates a crucial need for improved prevention and control strategies. The high burden of skin infections, the severe sequelae that can arise, and the availability of practical, community-based control strategies to reduce this burden justify an increased focus on this public health issue in remote WA. There is an urgent need for greater awareness among health and early child development practitioners, as well as for culturally relevant education and health promotion materials for families and communities to address normalisation and encourage early clinic presentations.

CHAPTER 3 HIGH BURDEN OF SEVERE SKIN INFECTIONS IN ABORIGINAL CHILDREN: A POPULATION-BASED, RECORD-LINKAGE COHORT STUDY OF HOSPITALISATIONS IN WESTERN AUSTRALIAN CHILDREN 1996 - 2012

3.1 Preamble

This chapter provides an insight in the burden of skin infections among children living across all regions of WA and puts the findings of chapter 2 in a broader perspective. The study consisted of a retrospective cohort analysis of state-wide hospitalisation data on paediatric skin infection associated hospital admissions over a period of 16 years (1996 to 2012). The analysis confirms the high burden of skin infections amongst Aboriginal children living in the Pilbara, where the highest hospitalisation rates for skin infections were reported. These findings provide further impetus for the urgent need to address skin infections amongst Aboriginal children.

3.2 Introduction

Skin and soft tissue infections have an important public health impact globally [32–34]. Although rarely fatal, skin conditions such as impetigo, scabies and fungal infections are among the most prevalent diseases in the world and contribute substantially to the global burden of disease [32]. Over 162 million children living in low and low-middle income countries are affected by impetigo at any one time (most frequently caused by *Staphylococcus aureus* or *Streptococcus pyogenes*) [33], while the global prevalence of scabies (caused by the mite *Sarcoptes scabiei*) has been estimated at 100 million cases, with the highest burden found in children living in tropical climates [35]. In Australia, high rates of skin infections have been documented in children of Aboriginal and/or Torres Strait Islander descent (herein referred to as Aboriginal) living in remote Indigenous communities [13,33], where prevalence rates as high as 50% for scabies and 90% for impetigo have been documented in some areas [33,42]. Most published studies are from remote, tropical communities of the Northern Territory (NT) [13]. The few studies available for Western Australia (WA) are consistent with the NT findings [9-11]. Published data on the burden of skin infections in children elsewhere in Australia are minimal, and hospitalisation data are limited [55,56,99]. Skin infections are generally considered a primary health issue [33] and their potential impact on hospital admissions has not previously been documented comprehensively. We aimed to describe the hospital admission profile for skin infections in a cohort of children born in WA between 1996 and 2012.

3.3 Methods

3.3.1 Population and setting

Western Australia (WA) extends over approximately 2.6 million square kilometres, spanning the entire western third of Australia. In 2011, WA had a population of 2.4 million people, 3.7% of whom identify as Indigenous, predominantly Aboriginal [6]. The state is divided into health administrative regions, comprising Perth metropolitan (North and South), rural (Midwest-Murchison, Wheatbelt, Great Southern, South West) and remote regions (Pilbara, Kimberley, Goldfields). Most Western Australians (73.5%) live in the Perth metropolitan area, with the remainder living in regional and remote regions [7]. Relatively higher proportions of Aboriginal people reside in regional, remote and very remote regions (65.2%) in comparison to non-Aboriginal people (28.7%) [8]. In 2012, children and young people aged 0-17 years comprised 22.9% of the state's population, 73% of which were living in metropolitan areas, 17% in regional areas and 10% in remote regions [100]. The median age of Aboriginal people in Western Australia is 22 years, compared to 37 years in its non-Aboriginal population [2]. The climate in WA varies throughout the state: a warm temperate climate in metropolitan Perth, the south-west and Great Southern areas; dry climate in the Goldfields, Midwest-Murchison and Wheatbelt; and warm, humid conditions in the sub-tropical and tropical northern regions of the Pilbara and the Kimberley [101].

3.3.2 Study design and data sources

We conducted a retrospective population-based cohort study of all live births in WA between 1996 and 2012, using de-identified probabilistically linked population-based data derived from the WA Data Linkage System (WADLS) [102–104]. Data were

extracted from Birth and Death registrations, Midwives Notification System, and the Hospital Morbidity Data Collection (HMDC). The HMDC contains all inpatient separations in public and private hospitals in WA. All admission records contain clinically coded principal and additional diagnoses and procedures. Skin infection diagnosis codes were identified using the Australian version of the International Classification of Diseases 9th revision, Clinical Modification (ICD-9-CM) and 10th revision, Australian Modification (ICD-10-AM). The diagnosis codes were selected and categorised into scabies, impetigo and pyoderma, cellulitis, abscess, fungal infection, lice and other skin infections [105] (Appendix Table App B.1). Inter-hospital transfers were combined into a single hospital admission. Readmissions within 14 days of discharge were combined into one episode of infection.

3.3.3 Data analysis

Age specific skin infection admission rates per 1000 child-years and their 95% confidence intervals (CI) were calculated. Child-years at risk denominators were calculated using the date of birth and -if deceased- date of death. Skin infection cases were defined using the principal and additional diagnoses fields of hospital records, unless otherwise stated. Admissions rates grouped by age groups were presented separately for Aboriginal and non-Aboriginal children, by geographical location and socio-economic status. Aboriginal children were identified using the 'Getting Our Story Right' flag (GOSR) [106]. GOSR is a validated flag proven to reduce missing data, to ensure consistent, reliable recording of Aboriginal status [106]. The mother's postcode at the time of her child's birth was used to define the geographical location and socio-economic status. We used the Index of Relative Socio-economic Advantage and Disadvantage defined by the Australian Bureau of Statistics to stratify the population into socio-economic quantiles ranging from most-

disadvantaged to least-disadvantaged [107]. Median differences in admission age were compared using the non-parametric equality of medians tests, and proportional difference in length of stay was compared using the Mann-Whitney test. Year to year percentage changes in admission rates from 1996 to 2012, were calculated using log-linear modelling with negative-binomial regression. Deviation from uniform distribution of admissions across seasons was analysed by stratifying admissions by month, and testing for statistical significance using the Chi-square test of seasonality. A $p < 0.05$ was considered significant. Seasonal differences in principal skin infections admissions were investigated in the Kimberley and Perth metropolitan areas due to their distinct seasonal patterns. Perth metropolitan is part of the Southern hemisphere with seasons being: summer (December – February), autumn (March – May), winter (June – August) and spring (September - November). In the Kimberley, the seasons are bimodal, with a wet season from November – April and a dry season from May – October.

3.3.4 Ethical approval

This study was part of a larger program of work to assess the pathogen-specific burden of acute lower respiratory infections in children using skin infections as a non-vaccine preventable infection control group in order to understand temporal trends in hospital admissions in light of targeted vaccination programs. The study was approved by the Western Australian Department of Health Human Research Ethics Committee, the Western Australian Aboriginal Health Ethics Committee and the University of Western Australia Human Research Ethics Committee.

3.4 Results

3.4.1 Study population

Our birth cohort consisted of 469,589 children born between 1996 and 2012. Of these, 31,348 (6.7%) were Aboriginal and 240,237 (51.2%) were boys. Singleton births accounted for 97.0% of the cohort and 2538 children (0.5%) were deceased by 2012. There were 15,377 hospital admissions for skin infection in children aged <16 years, accounting for 2.8% of 541,297 hospital admissions between 1996 -2012. Aboriginal children had a 15.0 (95% CI 14.5-15.5) times higher admission rate for skin infection (31.7/1000 child-years) than non-Aboriginal children (2.1/1000 child-years). The proportion of children hospitalised for skin infection was significantly higher in Aboriginal children compared to non-Aboriginal children (14.8% vs. 1.5%; odds ratio [OR] 11.3; 95%CI 10.9–11.7). Multiple admissions per child for skin infections were more common in Aboriginal children (OR 3.8; 95% CI: 3.4–4.1). Admissions across all age groups were 1.1 (95% CI 1.1-1.2) times higher in males than females. The median age at admission was younger in Aboriginal children (26.0 months (interquartile range [IQR]: 10.0–64.0 months) vs. 35.0 months (IQR: 14.0–75.0 months)) in non-Aboriginal children. The mean length of stay was longer for Aboriginal children compared to non-Aboriginal children (7.3 days v 4.8 days; $p<0.001$). Children from the most socio-economically disadvantaged areas had higher admission rates compared to children from the least socio-economically disadvantaged areas (IRR 2.3; 95% CI 1.4-3.8 for Aboriginal children and IRR 2.1; 95% CI 1.8-2.3 for non-Aboriginal children) (Table 3.1).

Table 3.1 Admission rates for skin infection in Western Australian Aboriginal and non-Aboriginal children, by socioeconomic status, 1996-2012

IRSAD‡	Aboriginal		Non-Aboriginal	
	Rate/1000	IRR‡ (95% CI)	Rate/1000	IRR‡ (95% CI)
91-100%	14.9	Ref	1.5	Ref
76-90%	19.2	1.3 (0.8 -2.2)	1.7	1.1 (1.0-1.3)
26-75%	25.4	1.7 (1.0-2.8)	2.3	1.5 (1.4-1.7)
11-25%	23.8	1.6 (1.0-2.6)	2.5	1.7 (1.5-1.9)
0-10%	34.7	2.3 (1.4-3.8)	3.1	2.1 (1.8-2.3)

*Rate of admission/1000 child-years.

‡Index of Relative Socioeconomic Advantage and Disadvantage; 90-100%, least disadvantaged; 0-10%, most disadvantaged.

CI, Confidence interval.

3.4.2 Principal diagnosis of skin infection

Admissions with a skin infection associated principal diagnosis accounted for 59.4% of the total skin infection admissions. In Aboriginal children, abscess was the most common principal diagnosis (42.2%) followed by cellulitis (26.0%), scabies (15.8%), impetigo and pyoderma (14.3%), fungal infection (1.1%) and head lice (0.7%). In non-Aboriginal children, cellulitis was the most common principal diagnosis (52.8%), followed by abscess (33.3%), impetigo and pyoderma (12.5%), scabies (0.8%), fungal infection (0.4%) and head lice (0.2%). In children aged <16 years the hospitalisation rate of skin infection by principal diagnosis was 17.5/1000 (95% CI 17.0-18.0) in Aboriginal children and 1.4/1000 (95% CI 1.3-1.4) in non-Aboriginal children. 87.6% of admissions for any skin infection as principal diagnosis were emergency admissions. Where skin infections were coded as an additional diagnosis, the principal reason for hospital admission was most commonly due to respiratory and gastrointestinal infections (27.3%).

3.4.3 Temporal trends in neonates and infants

Hospital admissions for skin infections were significantly higher in infants aged <1 year throughout the study period, with the rate 22.5 times higher in Aboriginal infants (78.9/1000; 95% CI 75.8-82.1) than non-Aboriginal infants (3.5/1000; 95% CI 3.4-3.7; Table 3.2). Among Aboriginal infants, hospital admission rates were highest in those aged 6-11 months (83.8/1000; 95% CI 78.8-88.9) whereas for non-Aboriginal infants the rates were highest among those aged <1 month (10.9/1000; 95% CI 9.9-12.1) (Figure 3.1 A & B). The rate in Aboriginal infants significantly declined by 6.2%/year over the study period in those aged 1-5 months and by 6.2%/year in those aged 6-11 months (both $P < 0.001$; Figure 3.1 C & D). The declines were predominately observed in admissions for cellulitis (4.9 %/year; $p < 0.004$), and scabies (8.9 %/year; $p < 0.001$). The highest disparity in admission rates between Aboriginal and non-Aboriginal was in scabies admissions among infants (IRR 417.0; 95% CI 308.8-576.7). Cellulitis and abscess accounted for the lowest disparity between Aboriginal and non-Aboriginal (Table 3.2).

3.4.4 Temporal trends in older children

In children aged 1-4 years, the rate of skin infection admissions was 34.1/1000 in Aboriginal children and 2.5/1000 in non-Aboriginal children (Table 3.2). The overall rate of admissions declined significantly by 3.8%/year in Aboriginal and 1.6%/year in non-Aboriginal children aged 1-4 years (both $p < 0.001$; Figure 3.1 B & D). In Aboriginal children aged 1-4 years significant declines were mainly seen in admissions for scabies (4.2%), impetigo and pyoderma (2.7%), and cellulitis (5.0%). Abscess increased by 2.1% in Aboriginal children aged 1 – 4 years ($p = 0.03$). In children aged 5-9 years and 10-15 years, the highest rates of admissions were for abscess, while the highest disparity in admissions between Aboriginal and non-Aboriginal was due to scabies. There were no

significant changes in the admission rate for skin infections during the follow-up period in both these age groups.

Table 3.2 Age-specific frequencies and rates of hospitalisations in Western Australian Aboriginal and non-Aboriginal children discharged with a principal and/or additional diagnosis of skin infections, 1996-2012

Skin condition	Age	Aboriginal		Non-Aboriginal		IRR†	95% CI
		No.	Rate	No.	Rate‡		
Cellulitis	<1 year	396	13.1	583	1.4	9.5	(8.4 - 10.8)
	1 - 4 years	992	9.8	2045	1.5	6.7	(6.2 - 7.2)
	5 - 9 years	513	6.3	978	0.9	7.2	(6.5 - 8.0)
	10 - 15 years	220	5.5	492	0.9	6.5	(5.5 - 7.6)
Abscess	<1 year	285	9.6	378	0.9	10.7	(9.0 - 12.4)
	1 - 4 years	1052	10.4	770	0.7	18.9	(17.2 - 20.7)
	5 - 9 years	760	9.3	433	0.4	23.9	(21.3 - 27.0)
	10 - 15 years	268	6.7	308	0.6	12.3	(10.4 - 14.6)
Impetigo & Pyoderma	<1 year	707	23.8	398	0.9	24.9	(22.0 - 28.2)
	1 - 4 years	887	8.8	556	0.4	22.0	(19.8 - 24.5)
	5 - 9 years	231	2.8	193	0.2	16.3	(13.4 - 19.9)
	10 - 15 years	74	1.9	71	0.1	14.8	(10.5 - 20.7)
Scabies	<1 year	1309	43.6	44	0.1	417.0	(308.8 - 576.7.6)
	1 - 4 years	735	7.3	43	0.0	235.9	(173.4 - 328.83)
	5 - 9 years	160	2.0	12	0.0	181.9	(101.3 - 359.4)
	10 - 15 years	50	1.3	<5	0.0	176.8	(64.9 - 674.3)
Head Lice	<1 year	72	2.4	8	0.0	126.1	(60.7 - 303.3)
	1 - 4 years	388	3.9	128	0.1	41.8	(34.8 - 51.5)
	5 - 9 years	283	3.5	98	0.1	39.4	(31.2 - 50.1)
	10 - 15 years	81	2.0	38	0.1	30.2	(20.3 - 45.6)
Fungal infections	<1 year	259	8.6	154	0.4	23.6	(19.2 - 29.0)
	1 - 4 years	257	2.6	124	0.1	28.6	(23.0 - 35.7)
	5 - 9 years	79	1.0	35	0.0	30.8	(20.4 - 47.2)
	10 - 15 years	18	0.5	23	0.0	11.1	(5.6 - 21.4)
All Skin Infections	<1 year	2371	78.9	1493	3.5	22.3	(20.9 - 23.8)
	1 - 4 years	3425	34.1	3437	2.5	13.8	(13.1 - 14.4)
	5 - 9 years	1625	19.8	1612	1.4	13.8	(12.8 - 14.7)
	10 - 15 years	578	14.5	836	1.5	9.8	(8.8 - 10.9)

‡Rate of admission per 1000 child-years.

† Relative rate of Aboriginal to non-Aboriginal admission rate.
CI, confidence interval.

*Note the sum of the individual diagnostic categories doesn't add up to the total skin infections, as some patients present with multiple skin infections.

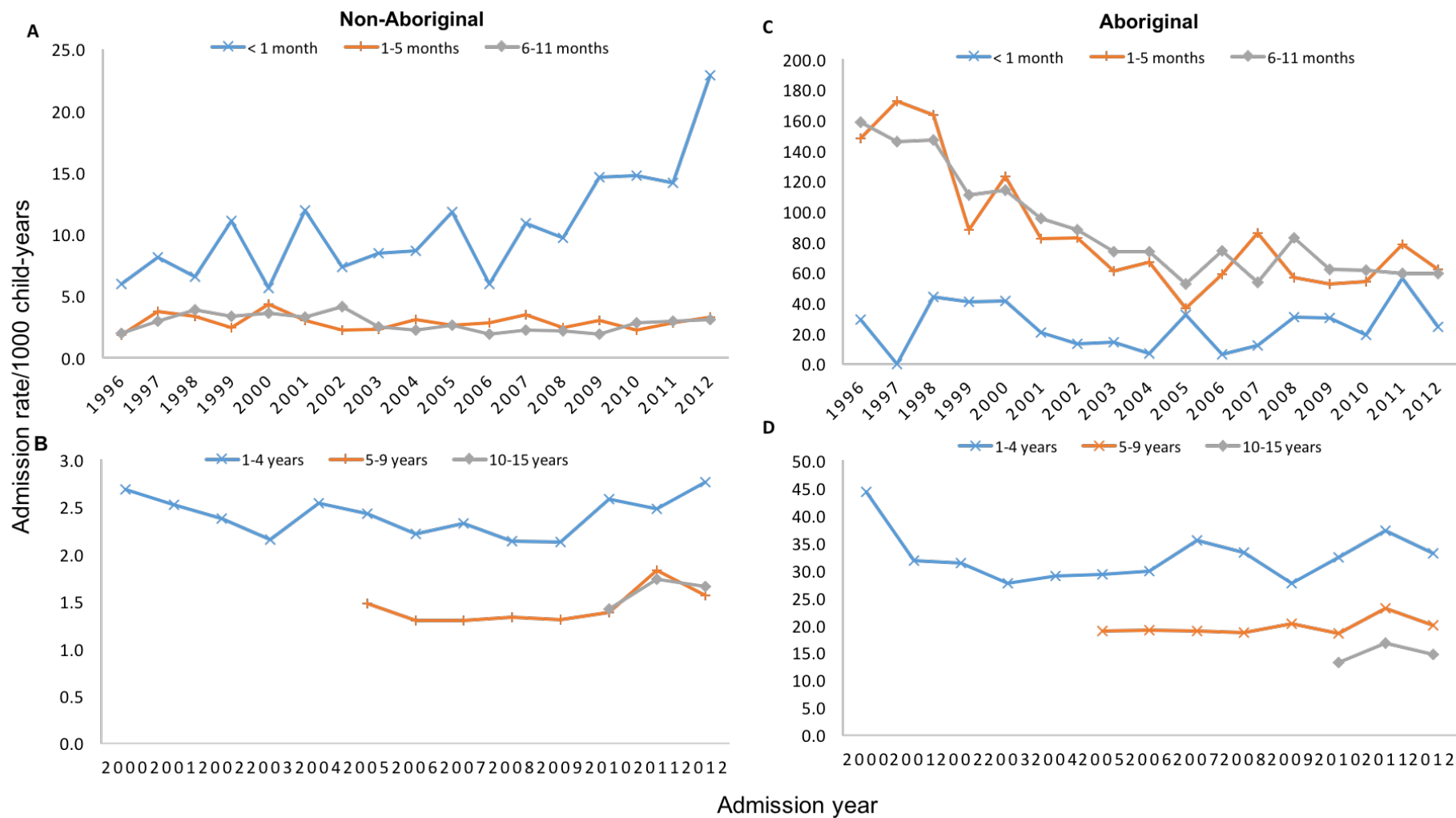


Figure 3.1 Hospital admission for skin infections in non-Aboriginal (A & B) and Aboriginal (C & D) hospitalised patients aged <16 years in Western Australia, 1996-2012. The calculated admissions included all hospital discharge records with evidence of scabies, impetigo and pyoderma, cellulitis abscess, fungal infections, head lice and other skin infections. Note differences in scale

3.4.5 Geographical and seasonal variations in admissions

The highest rates of admissions for all skin infections in Aboriginal children aged <16 years were observed in the remote regions (Pilbara (46.9/1000; 95% CI 44.2-49.7), Kimberley (45.3/1000; 95% CI 43.6-47.0), and Goldfields (42.1/1000; 95% CI 39.1-44.9). This finding was consistent for every type of skin infection. In rural regions, the rate in Aboriginal children aged <16 years was highest in the Midwest-Murchison area (31.1/1000; 95% CI 29.2-33.2) (Appendix Table App B.2). Table 3.3 present the number and rate of hospital admissions by remoteness. The highest disparities in admissions between Aboriginal and non-Aboriginal children were observed in infants aged <1 years in remote areas. Whilst hospitalisation rates remained high, there was a declining trend over time across all geographical areas. The overall hospitalisation rate in Aboriginal infants aged <1 years declined significantly by 7.5%/year in the metropolitan region, 5.3%/year in rural and 5.3%/year in remote regions (all $p<0.001$) over the study period.

Excess hospitalisations in the number of principal hospital admissions for skin infection were observed among Aboriginal children during the wet season in the Kimberley region ($p<0.001$) and during summer in the Perth metropolitan areas ($p=0.04$). The observed increase in admissions during these months were predominately due to scabies, abscess and cellulitis in children aged 1-4 years.

Table 3.3 Number and rate of hospital admissions for skin infections* in Aboriginal and non-Aboriginal children born in WA between 1996-2012, by age and WA region of residence

Age Group	Non-Aboriginal (438, 241)			Aboriginal (31,348)			IRR§	(95% CI)
	No.	Rate†	Regional IRR (95% CI)	No.	Rate†	Regional IRR (95% CI)		
<1 month								
Metropolitan	316	11.4	1	17	18.6	1	1.6	(1.0 - 2.7)
Rural	51	8.8	0.8 (0.6 - 1.0)	8	13.3	0.7 (0.3 - 1.7)	1.5	(0.7 - 3.2)
Remote	24	10.4	0.9 (0.6 - 1.4)	38	37.3	2.0 (1.1 - 3.6)	3.6	(2.1 - 6.0)
1-5 months								
Metropolitan	404	2.9	1	247	54.1	1	18.5	(15.8 - 21.6)
Rural	79	2.7	0.9 (0.7 - 1.2)	177	58.8	1.1 (0.9 - 1.3)	21.5	(16.5 - 28.1)
Remote	36	3.1	1.1 (0.8 - 1.5)	641	125.8	2.3 (2.0 - 2.7)	40.2	(28.7 - 56.3)
6-11 months								
Metropolitan	456	2.9	1	243	46.2	1	16.1	(13.8 - 18.8)
Rural	80	2.4	0.8 (0.7 - 1.1)	203	58.3	1.3 (1.1 - 1.5)	24.5	(18.9 - 31.7)
Remote	46	3.4	1.2 (0.9 - 1.6)	790	133.6	2.9 (2.5 - 3.3)	38.8	(28.8 - 52.2)
1-4 years								
Metropolitan	2697	2.5	1	779	22.1	1	8.6	(7.9 - 9.3)
Rural	474	2.1	0.8 (0.7 - 0.9)	585	24.7	1.1 (1.0 - 1.3)	12.0	(10.6 - 13.6)
Remote	263	2.9	1.1 (1.0 - 1.3)	2041	50.5	2.3 (2.1 - 2.5)	17.6	(15.5 - 20.1)
5-9 years								
Metropolitan	1225	1.5	1	408	14.4	1	9.9	(8.8 - 11.1)
Rural	266	1.4	0.9 (0.8 - 1.1)	300	15.8	1.1 (1.0 - 1.3)	11.4	(9.7 - 13.5)
Remote	116	1.5	1.02 (0.9 - 1.2)	910	26.9	1.9 (1.7 - 2.1)	18.1	(14.9 - 22.0)
10-15 years								
Metropolitan	624	1.5	1	170	12.4	1	8.4	(7.3 - 10.2)
Rural	154	1.5	1.0 (0.9 - 1.2)	90	9.8	0.8 (0.6 - 1.0)	6.4	(5.0 - 8.4)
Remote	58	1.4	0.9 (0.7 - 1.2)	317	19.1	1.5 (1.3 - 1.9)	10.5	(10.5 - 18.3)

‡Rate of admission/1000 child-years.

† Regional IRR= relative rate of rural/remote to metropolitan admission rate.

§ IRR= relative rate of Aboriginal to non-Aboriginal admission rate.

* Any mention of skin infection in the principal and additional diagnoses fields.

CI, Confidence interval.

WA, Western Australia.

44 records with missing remoteness information were excluded.

3.5 Discussion

This is the first in-depth analysis of linked hospitalisation data to describe the burden and epidemiology of skin infections for a birth cohort of an entire state of Australia. Our study is based on 17 years of hospitalisation data, incorporating > 6 million child years at risk. We report three key findings: (i) Aboriginal children were 15 times more likely to be hospitalised with a skin infection than non-Aboriginal children; (ii) the highest admission rates for skin infections were in infants aged <1 year (eight out of every 100 Aboriginal children were hospitalised with a skin infection in the first year of life); (iii) skin infections are not just a primary care issue, but also represent a substantial burden on the hospital system (three out of every 100 child hospital admissions). Improving primary care of skin infections is likely to reduce this hospitalisation burden.

We confirmed a very high burden of hospital admissions due to skin infections in infants aged <1 year in both Aboriginal and non-Aboriginal children. Admission rates for this age group were 2.3 and 1.4 times higher for Aboriginal and non-Aboriginal children respectively when compared to the age group with the second highest skin infection hospitalisation rate (1-4 year olds). Although previously published hospital admission data have documented a similar trend in certain settings and for specific skin conditions [55,99,108], to our knowledge this is the first birth cohort study to highlight the steep burden of skin infections leading to hospitalisation in infants. Other studies of skin infection related hospitalisations in children from Turkey [109], New Zealand [110–113] and the USA [114] used wider ranges for their youngest age groups. Our data are consistent with previous observations from remote Australian Aboriginal communities that showed high rates of primary care presentations for skin infections in infants, particularly in the first few months of life [14–16]. We confirm this with high hospitalisation rates for skin infections throughout the first year of life, particularly

beyond the neonatal period. It is possible that this high incidence of skin infection associated hospitalisations is driven by scabies infestations in neonates, making them susceptible to secondary bacterial skin infections in infancy [115].

We show that hospitalisation rates in Aboriginal infants (aged 1-12 months) have been steadily declining, as the gap with the lower rates observed in Aboriginal neonates in the first month of life -although still considerable- has narrowed. This decline was also observed in the 1-4 year age group of Aboriginal children and may be consistent with improvements in primary health care access and delivery, a different threshold for hospitalisation, or overall improving trends in the burden of infectious diseases in infancy. We now plan to investigate the temporal trends in hospitalisation rates for other infections, namely acute lower respiratory infections, which can be compared with these trends presented here. Interestingly, and counter to our observations in Aboriginal children, skin-related hospital admissions for non-Aboriginal children peaked during the first 30 days of life. Furthermore, our data shows an upward trend in skin infections in this particular group of neonates. These observations are possibly consistent with increasing admissions for omphalitis, staphylococcal scalded skin and periungual cellulitis in the early post-natal period in non-Aboriginal children [116,117].

Aboriginal children are more likely to be admitted to hospital for skin infection, stay longer and have more episodes of abscess. This is consistent with community prevalence studies that confirm a high, sustained burden of skin infections in Australian Aboriginal children [13,33]. Hospital admission data only captures a segment of health service utilisation associated with skin infections. A study set in a disadvantaged region of New Zealand estimated that for every one skin infection related hospitalisation there were 14 primary care cases [118], further illustrating that skin infections are predominantly a primary care issue. In Australia, other datasets confirm a high burden of skin infections at the primary care level for Aboriginal Australians (6.6 out of every 100 GP

consultations, compared to 2.1 for non-Aboriginal Australians) [119]. Furthermore, as confirmed in our analysis, the burden of skin infections in children is highest in remote Aboriginal communities [14–17,33]. This is illustrative of the overall burden of infectious diseases in remote Aboriginal communities, which has been associated with a wide range of health service, sociocultural and environmental factors, including high primary care staff turnover rates, socioeconomic disadvantage and poor housing conditions [13].

We observed seasonal trends in skin infection hospitalisation rates among Aboriginal children living in the Kimberley (tropical and sub-tropical climate) and the Perth metropolitan area (temperate climate). Seasonality trends in consultation and hospitalisation rates for bacterial skin infections have previously been observed in temperate and tropical areas, with peak incidences often occurring in summer and autumn [110,120–122]. Factors related to pathogen survival, vector abundance and host behaviour and immune function might underpin such seasonal variation [123]. Our data also show that skin infection associated hospitalisation rates for Aboriginal children living in the Kimberley are at their highest during the tropical, high humidity months of the year. It is possible that these conditions may promote microbial growth on the skin [37,124–126], increase the risk of infection-prone insect bites [77,127–130] and contribute to the survival and transmission of scabies mites [49,53,131,132].

This vast dataset constitutes 17 years of hospitalisation data for almost 500,000 children. We have found important socio-demographic trends, with infants and Aboriginal children at a much higher risk of developing skin infections requiring tertiary care. The limitation of analysing a hospitalisation dataset is that it only captures the severe end of the disease burden, since skin infections remain a primary care issue first and foremost [33,118]. Despite the high reported burden, lack of clinical documentation about skin infections in the hospital record may underestimate the true burden of skin infections [78]. This

suggests that skin infections are underdiagnosed in hospital settings, presumably due to under-recognition or normalisation associated with the high ongoing burden of skin infections.

Our data demonstrate that in Australia, Aboriginal children living in rural and remote areas are at a disproportionately high risk of being hospitalised for skin infections. These findings are in line with previous studies that have documented an extremely high prevalence of skin disease in children living in these settings [33]. The impact of skin infections in remote communities extends well beyond the need for acute care, as its ubiquity affects childhood development [31], poses a risk for developing other acute and chronic health conditions [37] and incurs a significant cost to the public health system when hospitalisation is required [55]. Reducing the need for hospitalisation as the end-point in care through improved community-level prevention of skin infections and the provision of effective primary care are crucial.

CHAPTER 4 FACTORS IMPACTING ON HEALTH SERVICE UTILISATION FOR SKIN INFECTIONS IN A REMOTE REGION OF WESTERN AUSTRALIA

4.1 Preamble

In this chapter, the focus is shifted from describing the burden of skin infections to documenting community attitudes and practices regarding skin infections in the same four remote communities that were the focus of chapter 2. This qualitative study consisted of semi-structured interviews, *yarning sessions*, and focus group discussions with parents/carers, healthcare practitioners and other service providers. The findings presented in this chapter describe the outcomes of our analysis of factors that affect health service utilisation for skin infections in this remote part of the Pilbara. We highlight the importance of cultural competency, patient-centred care and relationship building in ensuring access to health services, and describe how normalisation of skin infections and the use of benzathine penicillin G can also negatively impact on health service utilisation.

4.2 Introduction

Almost 40 years after the Alma-Ata declaration, where the international community set its sights on the goal of “Health For All”, health and health service access inequities persist between and within countries [133]. This lack of progress is illustrated by the need to still include universal health coverage as a target in the United Nation’s 2015 Sustainable Development Goals [134]. An example of this is the ongoing health inequity and comparative disadvantage of Indigenous populations and the disproportionate burden of disease they experience [135].

In Australia, Aboriginal and Torres Strait Islander peoples¹ have a lower life expectancy, a higher infant mortality rate, are overrepresented in hospitalisation admission data when compared to the general population, and suffer from a high burden of infectious and chronic diseases [10–12,136]. Furthermore, the majority of Aboriginal people live in rural and remote areas [7]. Here environmental factors, housing and living conditions are associated with a high prevalence of infectious diseases [13,18,19,28], including excessive rates of childhood ear, skin and respiratory infections [14–17,20]. Further exacerbating this are the difficulties Aboriginal people face in accessing health services [137,138]. This extends beyond the physical availability of a health service and includes more ‘wicked’ determinants [139], such as prejudice, racism and culturally insecure practices and services [137,140–143]. The impact of these barriers and the effect they have on Aboriginal people’s health service utilisation undermine genuine, inclusive universal health coverage in Australia [142].

¹ While acknowledging that ‘Aboriginal and Torres Strait Islander people’ is the appropriate term to describe the diversity of Australia’s Indigenous population, we will use the term ‘Aboriginal people’ in the remainder of this paper for brevity.

Previous work on early childhood development in remote Aboriginal communities located in Western Australia's (WA) Pilbara region provided anecdotal evidence of a high burden of common childhood infections, including a marked prevalence of skin infections [30]. We report elsewhere on the outcomes of a retrospective review of childhood clinic presentations that we performed in four remote Aboriginal communities located in this region to ascertain the burden of skin and other infections [*see chapter 2*]. In parallel, we set out to undertake a qualitative study in these same communities to document the attitudes and practices of community parents/carers, healthcare practitioners and service providers regarding skin infections. Framed within our ongoing collaborations with communities and services in the region, the outcomes of this qualitative work will be used to inform the development of appropriate strategies for the prevention and control of skin infections. Here we report on our qualitative findings around the factors that impact on health service utilisation in this remote setting, with a particular focus on skin infections.

4.3 Methods

4.3.1 Study setting

The study setting is a sparsely populated area of the remote Pilbara region, WA, Australia. This is the traditional country of the Martu, an Aboriginal people that up until the 1960s had only had intermittent contact with European Australians [21]. The study included participants from four remote Aboriginal communities (communities A to D) and a regional mining town (Town E). Town E provides regional services and includes a small Aboriginal settlement on the outskirts. The Martu are a mobile people and travel throughout the wider region and between the communities and town E is common. Driving distance from the town to the remote

Box 1: Glossary of terms

AHWs – Aboriginal Health Workers. Formally trained Aboriginal people whose role includes community liaison, health promotion and preventative health services roles. Often live in the community they work in. [163]

BPG - benzathine penicillin G, a long lasting intramuscular injectable antibiotic. It is also known as benzathine benzylpenicillin and LA Bicillin. [37]

CARPA manual - a regional treatment guideline that facilitates treatment under standing orders by Remote Area Nurses. It is an evidence based guideline that is regularly reviewed. [58]

Closing the Gap - a government strategy aimed at reducing disadvantage among Aboriginal people with respect to health outcomes. [192]

DCPFS - Department for Child Protection and Family Support [236]

PBS - the Pharmaceutical Benefits Scheme provides subsidised prescription drugs to Australians. Additional subsidies are available to Aboriginal people. [237]

communities varies from 150 to 700 km, over well maintained, unsealed roads. Each of the four communities has a functional airstrip (which at the height of the ‘wet season’, from January to March, may become inaccessible), a school (kindergarten to year 12), a local administration office and a small store that stocks basic food and other goods. Table 4.1 summarizes characteristics of each of these localities.

All four communities have a clinic managed by the same Aboriginal Medical Service (AMS), which provides primary health care to Aboriginal people living in the region. At the time of the study, the clinics in the three smaller communities (B, C, D) were operated

by one or two nurses at any one time. The clinic in the larger community (A) was usually serviced by two to four nurses and a permanent General Practitioner (GP) who would visit the other three communities via a chartered plane once a month over a three-day period. Allied health professionals and specialist health services (including a paediatrician) visit the communities on a regular schedule. Town E is not serviced by an AMS, but does provide health services via a private GP clinic and a small public hospital with emergency services. The Royal Flying Doctor Service provides emergency medical care and medical evacuations to the region as required, including all four study communities [144].

4.3.2 Data collection and study population

Employing an inductive qualitative research strategy, we performed a series of semi-structured interviews and focus group discussions (FGDs; using a *yarning* methodology, which employs a way of facilitating a discussion that conforms to Aboriginal conversational norms and practices [145,146]) between October 2014 and November 2015. To inform our understanding of child health and community attitudes and practices regarding skin infections, we purposively selected [147] three distinct groups of participants who, through their family relationships or the roles they fulfilled in community, interacted with children on a daily basis. Table 4.2 provides a summary of our data collection activities.

Table 4.1 Description of study area localities

	approx. population*	% Abl*	AMS clinic	GP clinic	school	shop	police station	swimming pool	public hospital	road access	access by air
Community A	250-500	76%	yes	no	yes	community store	yes	yes	no	unsealed	airstrip
Community B	100-200	91%	yes	no	yes	community store	no	no	no	unsealed	airstrip
Community C	100-200	88%	yes	no	yes	community store	no	no	no	unsealed	airstrip
Community D	<100	88%	yes	no	yes	community store	no	no	no	unsealed	airstrip
Town E	5000+	10%	no	yes	yes	supermarket	yes	yes	yes	sealed	airport

Abl= Aboriginal people; AMS= Aboriginal Medical Service; GP= General Practitioner

* Source: Australian census 2011

Table 4.2 Summary of data collection activities

	description of participant group	# of interviews	# of FGDs	# of participants		sampling method
				total	Abl	
Group 1 - parents/carers	mothers, 'aunties'^, 'uncles'^ of young Aboriginal children	8	3	16	16	convenience & snowball
Group 2 - healthcare practitioners*	remote area nurses, nurse practitioners, child and community health nurses, midwives	8	2	15	2	purposive
Group 3 - other service providers	teachers, Aboriginal education workers, early child care workers, community organisation staff	18	4	25	2	purposive

= number; FGDs = focus group discussions; Abl = Aboriginal people

^ In Aboriginal culture, the terms *auntie* and *uncle* are used to refer to an older person and connotes respect.

* none were Aboriginal Health Workers or Aboriginal Health Providers (there were no active AHWs or AHPs based in the communities at the time of data collection)

Group 1 consisted of Aboriginal parents and carers who were selected using convenience sampling from community play groups, with snowball sampling to identify additional participants [147]. Group 2 were nurses employed by the AMS or were part of other health services that operate in the region. All healthcare practitioners had at least several years of experience in the field of remote Aboriginal health and had been working in the Pilbara region for varying amounts of time, ranging from one month to multiple years. Some were temporary agency staff. One healthcare practitioner was an Aboriginal person. Group 3 were other service providers who interact daily with Aboriginal children such as school staff and community organisation workers. All interviewed service providers had been working in the region for a minimum of several months, while others had been working in the regions for many years. Three interviewed service providers were Aboriginal. While acknowledging the distinctness of Martu people and culture, we used the generic adjective 'Aboriginal' in describing our study participants for the purpose of de-identification and anonymity.

We performed 34 semi-structured interviews and nine FGD's (Table 4.2). The comparably high number of interviews in Group 3 is due to the heterogeneity of this group. The number of participants for each FGD varied between two and four, a relatively low number to facilitate a greater depth of discussion. Data collection continued until participants from across the whole study area had been recruited and until no new themes were emerging (data saturation).

All interviews and FGDs were performed by either DH (male) or ID (female). To ensure cultural safety, Group 1 interviews and FGDs, with mostly Aboriginal female carers (one male participant), were performed by ID. RW, a senior researcher in Aboriginal health

with extensive experience in the Pilbara region provided support. Particular care was taken in organising interviews and FGDs with the parent/carer group to ensure an open, reciprocal exchange that was in line with the yarning methodology developed by Aboriginal health researchers [145,148]. Such culturally appropriate adaptations to the classic FGD data collection method are crucial, and have shown to be an effective and empowering research tool in the context of Aboriginal health research [149].

The semi-structured question guide covered five major topics: i) perceived child health issues in the community; ii) knowledge, attitudes and practices around skin infections; iii) perceived underlying causes of child health issues; iv) perceived barriers and enablers to child health care provision in general and for skin infections in particular; v) suggestions on how child health care provision in the region could be improved.

4.3.3 Data analysis

All interviews and FGDs were audio recorded and transcribed verbatim, with one exception: handwritten notes were taken during an interview with one carer who declined voice recording. During FGDs, the facilitator used notes on butchers' paper to facilitate discussion. All transcripts were imported into QSR NVivo 10 for data analysis.

We employed a conventional content analysis strategy to systematically identify and structure themes as they were reflected in our data [150]. The two principal investigators (DH and ID) familiarised themselves with the data through the transcription process and a rereading of the final transcripts. The coding process used the five main themes from the semi-structured question guide to construct a generic coding tree. RW, a senior Aboriginal health researcher with extensive experience in the Pilbara region, reviewed the coding and provided support in the interpretation of the data. Additional hierarchical

levels of subthemes were added to this structure as new themes emerged from the data. While the overall aim of the study was to document the broader issues around knowledge, attitudes and practices regarding skin infections in the communities, the prominence of the health service utilisation theme in our initial analysis warranted a more thorough examination of this topic.

We applied Andersen's base conceptual model of health service utilisation [151] to structure our findings, as it is well established in the literature and because it is not overly prescriptive in the types of barriers and enablers it articulates, making it well suited to a first broad exploration of this theme in our setting [152]. The model proposes three major factors that affect access to health services: i) *predisposing characteristics*, in reference to demographic, social, economic and cultural factors, including beliefs and attitudes; ii) *enabling resources*, or contextual factors that influence health service utilisation, such as social relationships (e.g. family, support groups), community characteristics (e.g. remoteness, availability of health services) and the health system; and iii) *need*, whether perceived (by community and patients) or evaluated (based on the judgment of healthcare professionals). We examined the degree to which these factors affect health service utilisation for skin infections at three distinct levels: that of the client (family, carers, children), the provider (the community clinic and its staff) and the system level (in reference to the wider health system, its values, policies and socio-economic characteristics). We created a health service utilisation matrix (see Figure 4.1) that we used to systematically categorise all of the factors impacting on health service utilisation that had emerged from our analytical process.

		level that a barrier/enabler relates to		
		client	provider	system
Andersen model components	predisposing			
	enabling			
	need			

Figure 4.1 The health service utilisation matrix

In our description of the results we will discuss our findings in three main sections, akin to the three main components of the Andersen model (predisposing factors, enabling factors, need factors). Each section will present our findings for each of the three analytical levels of the health service utilisation matrix (client, provider, system).

4.3.4 Ethics

Written informed consent was sought from all patient/carers, healthcare practitioners and other service providers who participated in the study. One participant declined voice recording and gave verbal assent to participate. Ethics approval for the study was obtained through the Western Australian Aboriginal Health Ethics Committee (HREC 510) and the University of Western Australia Human Research Ethics Office (RA/4/1/6563). A reference group of senior Aboriginal and non-Aboriginal health researchers provided oversight during the design and implementation of the study.

4.4 Results

The interviews and FGD's provided a rich dataset for interpretation through the health service utilisation matrix lens. To adequately describe the wide range of themes elicited, we stratified our findings into three separate health service utilisation matrices (Tables 4.3, 4.4 and 4.5), one for each participant group. Themes that were discussed by all three participant groups were marked with an asterisk. Themes that were discussed by parents/carers *and/or* service providers, but *not* by healthcare practitioners are marked in bold. This provides a structured overview and allows for the comparison of similarities and differences between the three groups. An extensive structured selection of quotes representative of the themes documented here are provided in the supplementary materials (see Appendix C).

Table 4.3 Factors that affect health service utilisation in remote Pilbara communities according to parents/carers

	Carer & Child (Client)	Clinic & Staff (Provider)	System
Predisposing	Shyness & shame* Traditional remedies & self-treatment * Negative past experiences with clinic* Language barrier Fear of judgement (incl. DCP&FS)	prejudice	
Enabling	Low costs associated with medical care* Good perception of clinic staff* Access to 'Closing the Gap' benefits	Engaging & culturally secure staff & practices* Established relationship between staff & client* Clinic waiting time not too long* Comfortable, inviting clinic facility* Acceptability of treatment* Clinic does outreach activities Clear communication re visiting health services Patient engagement	Trained Aboriginal health workers* Ensuring adequate medical supplies
Need	Lacking awareness re skin infections* Delayed presentations & self-treatment* Normalisation of skin infections*	Clinic not providing sufficient health education*	

DCP&FS = Department of Child Protection and Family Support

* = theme was discussed by all three groups of participants

themes marked in bold indicate topics that were discussed by parents/carers and/or service providers but not by healthcare practitioners

Table 4.4 Factors that affect health service utilisation in remote Pilbara communities according to healthcare practitioners

	Carer & Child (Client)	Clinic & Staff (Provider)	System
Predisposing	Shyness & shame* Traditional remedies & self-treatment* Negative past experiences with clinic* Apathy & disempowerment Priorities, values & norms - health & child rearing Cultural taboos Tolerance for discomfort & pain Lacking (health) education	Stressors associated with work environment Jadedness/frustration Training/knowledge gaps	Reconciling traditional and modern medicine
Enabling	Low costs associated with medical care* Good perception of clinic staff* Access to 'Closing the Gap' benefits	Engaging & culturally secure staff & practices* Established relationship between staff & client* Clinic waiting time not too long* Comfortable, inviting clinic facility* Acceptability of treatment*	Trained Aboriginal health workers* Ensuring adequate medical supplies Free or low-cost medical care Adequate staff levels & low turnover AMS governance & stability Efficient use of resources Good collaboration with other services Community engagement & outreach policies
Need	Lacking awareness re skin infections* Delayed presentations & self-treatment* Normalisation of skin infections*	Clinic not providing sufficient health education*	

AMS = Aboriginal Medical Service

* = theme was discussed by all three groups of participants

Table 4.5 Factors that affect health service utilisation in remote Pilbara communities according to other service providers

	Carer & Child (Client)	Clinic & Staff (Provider)	System
Predisposing	Shyness & shame* Traditional remedies & self-treatment* Negative past experiences with clinic* Language barrier Fear of judgement (incl. DCP&FS) Apathy & disempowerment Priorities, values & norms - health & child rearing Cultural taboos Tolerance for discomfort & pain Lacking (health) education	Stressors associated with work environment Training/knowledge gaps	Reconciling traditional and modern medicine
Enabling	Low costs associated with medical care* Good perception of clinic staff* Carer is healthy	Engaging & culturally secure staff & practices* Established relationship between staff & client* Clinic waiting time not too long* Comfortable, inviting clinic facility* Acceptability of treatment* Clinic does outreach activities Clear communication re visiting health services Patient engagement	Trained Aboriginal health workers* Free or low-cost medical care Adequate staff levels & low turnover AMS governance & stability Efficient use of resources Good collaboration with other services Community engagement & outreach policies
Need	Lacking awareness re skin infections* Delayed presentations & self-treatment* Normalisation of skin infections*	Clinic not providing sufficient health education* Actively encourage child/carers to go to clinic	

DCP&FS = Department for Child Protection and Family Support; AMS = Aboriginal Medical Service

* = theme was discussed by all three groups of participants

themes marked in bold indicate topics that were discussed by parents/carers and/or service providers but not by healthcare practitioners

4.4.1 Predisposing factors

4.4.1.1 At the client level

All study participants described the impact of beliefs, norms and attitudes in the decision to seek care for skin infections. Carers spoke of a general shyness and shame around presenting to the clinic, whether it was out of fear of judgement in general or in relation to skin infections more specifically. Some healthcare practitioners and service providers also spoke on this topic. Some service providers highlighted that carers might sometimes be reluctant to take their child to the clinic for fear of the Department for Child Protection and Family Support (DCPFS; see box 1) being informed, if the healthcare practitioner were to judge that the carer was not taking appropriate care of their child. This barrier was mentioned both generally and in relation to skin infections in particular.

Shame was also discussed in relation to experiencing pain. Both healthcare practitioners and service providers spoke extensively about their perception that Martu children have a high tolerance for physical discomfort and pain. The argument went that children would not easily complain about health issues -including skin infections- unless the problem became more severe, thus leading to delayed presentations. In general, it was suggested that this was a cultural construct, where complaining about physical pain was considered taboo. A few service providers also wondered whether Martu children were inherently less sensitive to physical discomfort compared to their own personal experiences of pain and ill health.

The majority of healthcare practitioners and service providers commented on how differing norms around health and child rearing might affect clinic utilisation by carers of children. A commonly held belief was that the Martu place other priorities above personal health, such as family, country and cultural practice. However, when it came to child

health, a number of healthcare practitioners and service providers shared a perception that some carers are not proactive enough in bringing their children to the clinic. In such cases, negative connotations around not taking responsibility and expecting children to fend for themselves were raised by participants of both respondent groups.

Other predisposing factors discussed by healthcare practitioners and service providers included a perceived lack of carer education and health literacy, social taboos (restrictions around family relationships, skin groups and gender that can affect clinic visiting behaviour), negative past experiences in the clinic (this was related in particular to painful benzathine penicillin G injections (BPG, see box) administered for the treatment of skin sores), language barriers (carers not feeling confident that they can express themselves adequately in English or understand what the healthcare practitioner says), a possible preference in some cases to try bush medicine prior to presenting to the clinic (leading to delayed presentations), and apathy and disempowerment (a sense that some Martu might not feel like they have control over their lives, which affects health seeking behaviour).

4.4.1.2 At the provider level

In referencing mainstream health services in Town E, some carers reported that healthcare practitioners held prejudiced views of them, leading to the fear of judgement and shame experienced by clients. Healthcare practitioners described several predisposing factors affecting their ability to deliver high quality care and appropriately interact with clients. Some described the challenges of working in these small, remote communities. Physical remoteness and a sense of isolation were on occasion described as stressors, particularly in reference to the smaller communities where only one or two resident healthcare practitioners may be stationed. Long working hours, limited opportunities to prioritise preventative health and the stress of managing acute medical emergencies without back up or medical support were mentioned. In addition, one healthcare practitioner

commented on the frustration they felt because of a perceived lack of progress in the communities' health status.

A few healthcare practitioners discussed perceived training gaps. Of direct relevance to skin infections was the sense that healthcare practitioners are not always adequately trained in administering BPG, a painful intramuscular injection that remains the standard of care for treatment of skin sores. One healthcare practitioner recalled her surprise at how little cultural orientation she was provided prior to starting her role in a remote Aboriginal community. This was also reflected in several anecdotes reported by participants in each of the groups around culturally inappropriate practices of healthcare practitioners.

4.4.1.3 At the system level

The dominance of the western biomedical model permeating health service practice was an important theme for service providers and healthcare practitioners. Both groups described through anecdotes and conceptual discussion how traditional beliefs and practices around health and healing remain important for the Martu. Most healthcare practitioners recognised the need to engage with such traditional viewpoints in delivering health care, although occasional dismissive comments were also noted. In the healthcare practitioner reported anecdotes, traditional beliefs or practices were incorporated for pragmatic purposes: to humour patients or to improve overall compliance, but only if it did not undermine medical treatment.

The dominance of the biomedical model over more holistic conceptions of health was also illustrated in healthcare practitioners' responses to local child health priorities. While mentions of infectious and chronic diseases were elevated, prioritisation of social and emotional wellbeing was notably absent. This was in contrast to service providers,

particularly teachers, who highlighted concerns around mental health and psychological stressors children might be exposed to.

4.4.2 Enabling factors

4.4.2.1 At the client level

An important consideration in accessing health services from the carer perspective is the real or perceived costs of health care. In this study, free care is available at the AMS clinics in communities A-D, but not always in Town E. Healthcare practitioners reportedly are not always aware of the benefits that Aboriginal people have access to (such as the Closing the Gap Pharmaceutical Benefits Scheme (PBS; see box)), leading to unnecessary out-of-pocket expenditure. Some carers in Town E reported driving to the nearest remote community three hours away to access the free AMS clinic. Furthermore, carers also expressed concern about the possible costs incurred if referral to tertiary services is required in Perth (the state capital) or to the Hedland Health Campus (the region's main hospital located in South Hedland). Comments by some service providers and healthcare practitioners echoed these financial issues and considerations.

Carers discussed how their impressions of healthcare practitioners' personalities, professional capabilities and their overall attitudes played a role in the degree to which they would access health services in the communities. Some spoke about their lack of trust in certain healthcare practitioners' medical knowledge and practice. While some service providers (who are also reliant on clinic staff for health care, and most of which were non-Aboriginal) echoed similar concerns, others were more positive about the care they had received.

Reflecting on other factors that might affect care seeking behaviour, one service provider pointed out the need take into consideration the carers' own health status. Many struggle with physical and mental health problems of their own, which constitute an additional barrier to taking their child to the clinic, particularly for skin infections or other health issues that might not be considered an acute health problem.

4.4.2.2 At the provider level

From the carer perspective, the most widely discussed enabling factor for health services utilisation in regards to the provider level related directly to the characteristics of the clinic staff and their practices. Staff that actively establish relationships with clients and demonstrate culturally secure practices were described as enabling factors. Conversely, carers discussed the difficulty of establishing such relationships in the midst of high turnover of healthcare practitioners at the AMS clinics. The need for Aboriginal Community Health Workers (AHW; see box) was also underlined by carers. To illustrate the importance of relationships in the remote health care context, carers and service providers spoke of AMS healthcare practitioners who had spent extended periods of time in the communities and with whom carers, children and other Aboriginal people living in the communities had established trusting, personal relationships. One former healthcare practitioner based in the communities for >10 years was frequently mentioned as a positive example by both carers and service providers. In contrast, one of the current healthcare practitioners had a more negative view on this person's approach and felt that the healthcare practitioner's open-door policy and strong personal affinity with community members had resulted in unrealistic community expectations of clinic staff that extended beyond normal practice (e.g. basic health service outside of official clinic hours, providing assistance with administrative matters). The long hours and possible late night visits were described as a stressor by some healthcare practitioners.

Carers generally described their experiences of clinic consultations as a passive experience with little space or time for participation, negotiation and learning. Carers were particularly negative about their experiences of mainstream staff and services in town E. Long waiting times and poor communication about upcoming specialist (e.g. paediatrician) and service (e.g. allied health) visits were also discussed by carers and service providers in relation to the AMS clinic in some communities. While some healthcare practitioners and service providers echoed the importance of culturally secure practices, negative experiences conveyed by carers suggested that theory and practice are not necessarily concordant.

Treatment acceptability for skin infections was discussed by all groups. The use of BPG injections for the treatment of skin sores was particularly contentious. Carers talked about the pain associated with the injection and the traumatising effect it could have on their children. In children, the association between skin sores and the need for a painful injection was reportedly easily made, while carers can also be affected by the experience of seeing their child undergoing the painful procedure. Carers, service providers and healthcare practitioners all spoke on how such experiences can affect future care seeking behaviour for skin infections. Some healthcare practitioners spoke specifically on how they wanted to try and ensure that children overall see the clinic as a positive place, not a place to be avoided. They would therefore consider the use of oral antibiotics instead of the injection, usually on a case-by-case basis and depending on how confident they felt about the carer adhering to the oral antibiotic schedule. In contrast, some carers preferred BPG injections for skin sores to avoid the need to administer oral antibiotics as they thought that these might not be taken. Parents/carers however indicated that they were generally not provided with any treatment options for skin infections or were often not properly informed about treatments and how to administer them (creams, oral antibiotic schedules). Furthermore, parents/carers elaborated on other challenges they experienced

with oral antibiotics. Some commented on the taste of the syrup (for liquid antibiotics) and the size of oral tablets for the treatment of skin sores. The complexity of oral antibiotic treatment schedules and the need to remember to administer them in a timely manner was also mentioned. Some parent/carers, healthcare practitioners and service providers mentioned that the lack of a functional refrigerator to properly store antibiotics at home could also be an issue. Some carers also spoke of the smell and texture of creams for the treatment of scabies and skin sores as a barrier to treatment uptake.

Several service providers and a healthcare practitioner discussed the importance of ensuring that community clinics were a clean and inviting space for carers and children to visit. This aspect was also touched upon by a few carers. This included making it a culturally secure space, reflective of the local community and by providing health education materials in the Martu languages. Some service providers described the clinic in community A as a meeting place, where people like to sit and talk. A healthcare practitioner in one of the smaller communities suggested that the clinic could be used more pro-actively as a social and learning space, making it more openly available to community members. Finally, carers and service providers discussed a considerable perceived lack of outreach activities by the AMS clinic and its staff. A lack of collaboration with the school for screening and treatment activities was an example provided by multiple service providers. There was an impression that such activities were more common in the past. An example provided by a carer was having a clinic staff member driving around to remind people of clinic appointments and providing a lift to and from the clinic.

4.4.2.3 At the system level

Enabling factors (and the lack thereof) for health care utilisation at the system level were mostly discussed by service providers and healthcare practitioners. Major recurring

themes included community clinic staff shortages and rapid turnover, the perceived instability of the AMS servicing the region at the time of the study, a lack of communication and coordination between community services particularly the school and AMS clinics, and a perceived lack of AMS community engagement and outreach policies. The overall perception was of a passive and reactive health service. In addition, the occasional occurrence of stock shortages in community clinics for medications and other medical supplies (including permethrin for scabies and first-line antibiotics for the treatment of skin sores) was mentioned by a few healthcare practitioners.

A few service providers were frustrated by perceived inefficiencies in use of financial resources for health provision. For example, fly-in fly-out specialist health services that visit the communities without appropriate coordination were perceived to be ineffective, underutilised and costly.

Another issue reported by all three participant groups as an important barrier to health service utilisation was the lack of AHWs in the communities. Healthcare practitioners talked about how this hampered the implementation of outreach activities, while service providers commented on the lack of a genuine point of cultural interface between the community and the clinic. Some healthcare practitioners and service providers suggested that community pressures, expectations and perceived cultural limitations around community interactions were barriers to the training and recruitment of Martu AHWs.

The provision of free care for Aboriginal people in community AMS clinics and for children in mainstream health services in town was considered an important enabler for health service utilisation. However, as discussed earlier, some carers and service providers indicated that healthcare practitioners working in mainstream services are not always aware of the financial benefits awarded to Aboriginal people under the Closing the Gap PBS scheme.

4.4.3 Need factors

4.4.3.1 At the client level

Service providers and healthcare practitioners generally highlighted the normalisation of skin infections as an important issue. Some carers echoed this by indicating that there is widespread lack of knowledge around skin infections and their impacts on overall health amongst the community. Skin infections may therefore not be considered a priority health issue, leading to delayed presentations to the health service. Some service providers and healthcare practitioners suggested that seeking care for skin infections is often delayed until symptoms become more severe, causing discomfort, whether by pain or by itching. Some also commented on how they believed carers might opt to self-treat skin sores, or use bush medicine, before seeking treatment through health services.

4.4.3.2 At the provider level

Parents/carers, service providers and healthcare practitioners all indicated that the AMS provides insufficient education on health, including skin health. Some argued that carers would be motivated to visit the clinic for a skin infection if culturally appropriate education were prioritised and carers were made more aware of the importance of skin infections. This was also voiced strongly by parents and carers themselves. Some service providers talked about their own active role in encouraging carers to take their child to the clinic when they notice skin infections, some spoke of providing basic care by disinfecting and dressing sores themselves.

4.4.3.3 At the system level

No need factors at the systems level were documented.

4.5 Discussion

Our study reveals several factors that affect health service utilisation by Aboriginal people living in the Pilbara, WA, Australia (see box 2). These include: the importance of relationship building between healthcare practitioners and clients; the need to advocate for a more culturally responsive, patient-centred approach that actively resources and engages clients in their own health care and facilitates health education; and, the need to improve cross-sector communication and collaboration around health in the communities. The dominant barriers that emerged regarding health service utilisation for skin infections were the pain and negative experiences associated with the intramuscular injection of BPG for treatment of skin sores on the one hand, and the normalisation of skin infections and a lack of understanding of the importance of skin health and its potential long-term impacts on the other.

Box 4.2: factors that facilitate health service utilisation and associated themes

in general

The importance of establishing a relationship between healthcare practitioners and parents/carers.

- client:* good perception of clinic staff.
- provider:* established relationship between staff & clients; stressors associated with work environment; jadedness/frustration.
- system:* adequate staff levels & low turnover; AMS governance & stability.

The need for the active engagement of parents/carers in their health care through culturally appropriate practice.

- client:* shyness & shame; language barrier; fear of judgement; cultural taboos.
- provider:* prejudice; engaging & culturally secure staff & practices; patient engagement; training/knowledge gaps.
- system:* trained Aboriginal health workers; reconciling traditional and modern medicine; AMS governance & stability.

The need for cross-organisational communication and collaboration around child health

- provider:* clear communication re visiting health services.
- system:* efficient use of resources; good collaboration with other services; community engagement & outreach policies.

for skin infections

The need to address normalisation and provide parent/carer education on the importance of skin health and skin infections.

- client:* lacking (health) education; lacking awareness re skin infections; delayed presentation and self-treatment; normalisation of skin infections; tolerance for discomfort and pain.
- provider:* clinic not providing sufficient health education; actively encourage child/carer to go to clinic.

Negative experiences associated with BPG injections

- client:* negative past experiences with clinic.
- provider:* acceptability of treatment; training/knowledge gaps.

The need for establishing and maintaining trusting relationships between health services and the community was a recurrent theme. Parents/carers, service providers and healthcare practitioners all spoke on this topic, all acknowledging the importance of this.

The retention of culturally competent healthcare practitioners is a crucial factor in ensuring the staff stability that is an indispensable condition for such relationships to occur [142]. Many elements can affect the stability of the remote health workforce. Healthcare practitioners in our study spoke of stressors around understaffing, organisational instability, long working hours and the isolation that comes with working in remote communities. Similar findings are reflected in other studies regarding the retention of healthcare practitioners in remote Aboriginal community settings [153–155]. Other factors that have been associated with remote healthcare practitioner retention include the provision of training and professional development opportunities, good clinic infrastructure and comfortable housing conditions, competitive remuneration, and building a supportive work environment that recognises and rewards individual contributions [156]. Furthermore, actively encouraging healthcare practitioners to form relationships with community members can in itself be an important promoter of healthcare practitioner retention [157]. AMS organisations might therefore consider implementing policies and guidelines that facilitate the introduction of new healthcare practitioners to a community through an orientation package. This might not only improve health service utilisation, but could also curtail high staff turnover. To facilitate staff retention, training and morale, adequate funding of health programs and services is crucial to ensuring good quality health care. However, health service investments are lacking in the Pilbara region [25]. Additional investment is required to create a strong foundation for the provision of good quality, culturally-secure health services to the Pilbara's communities.

An additional strategy to facilitate a positive patient experience for Aboriginal people is the employment of local AHWs [157–160]. AHWs fulfil the role of a primary health care worker, serve as a cultural broker that facilitates interaction between the health service and the community, and work in close partnership with non-Aboriginal healthcare

practitioners to help assure culturally appropriate care [161,162]. Although AHWs have been trained and employed by the AMS at certain times, no AHWs were based at any of the community clinics at the time of our study. This shortage of AHWs is not unique to our study setting. While our findings pointed towards the complexity of AHWs having to negotiate community and cultural roles and expectations on the one hand and health service expectations on the other, other challenges documented elsewhere include community pressures, inadequate training and career pathways, not wanting to leave the community for training because of family and cultural ties, inequitable working conditions and challenging working relationships [156,158,163].

Our study findings illustrate how the clinic is a space where the different worldviews of parent/carers and healthcare practitioners meet. While the healthcare practitioners we interviewed demonstrated a strong general awareness of the role that culture and traditional knowledge play in health beliefs and practices in the communities, only a few described instances in which they had actively engaged with them in a clinical setting, whether through the use of traditional concepts when discussing health issues with parents/carers or by being open to traditional methods of care as a means to improving overall treatment acceptability and adherence. There is a need for non-Aboriginal healthcare practitioners to understand how Aboriginal people experience and interpret illness, and to engage with the logic and rationale of that system of thought, the concept of holistic health and the impact of colonisation [142,164–166]. This relates to cultural competency [143] and the ability of non-Aboriginal healthcare practitioners to incorporate culturally responsive practices into their routine interactions with Aboriginal clients [142]. Such practices are in line with the paradigm of patient-centred care [167,168], which parents/carers and service providers considered to be an important enabling factor for health service utilisation in the communities. Integrating aspects of Aboriginal health knowledge and practice into medical and nursing curricula and teaching

methods of engaging with Aboriginal clients in health care settings, such as through the use of ‘clinical yarning’ [148], could therefore help develop a more culturally secure health workforce and hence a more accessible and effective health service.

Furthermore, racism and prejudice are important barriers to health service utilisation by Aboriginal people [142,169–172]. Although only a few parents/carers mentioned this explicitly, the wording and tone of some of the quotes by healthcare practitioners and other service providers that are described in the results (negative connotations when discussing, for example, child rearing practices, parent apathy, healthcare provider frustration about lack of progress) and included in appendix C, illustrate that such attitudes and assumptions are clearly present. High quality, culturally responsive, patient-centred care in the Aboriginal health setting requires a sensibility and self-reflexivity around these aspects to avoid further contributing to victim blaming and inciting feelings of shame [143,171,173], both of which have been shown to negatively impact on health service utilisation [172,174]. In this context, comments about child neglect and a lack of parental care by some healthcare practitioners and service providers suggest that a deeper understanding and recognition of traditional child rearing is also needed. Traditionally, Aboriginal children are seen as free agents who are able to roam and do as they please within very broad limits in a socio-cultural context that encourages learning by doing and experiencing [22]. This promotes autonomy, assertiveness and self-reliance, which are important values in Aboriginal culture [22]. This stands in stark contrast with Western norms where children are tightly managed and are only given greater freedoms as they progress towards adolescence. Although some healthcare practitioners and service providers acknowledged these differences and reflected on them in the context of their practice, this was not universally the case.

Service providers and parents/carers often referred to a perceived lack of communication and collaboration around child health in the communities. This included insufficient

communication around visiting health services, clinic representatives not participating in community coordination meetings and a lack of community engagement through outreach and prevention activities. Few healthcare practitioners acknowledged these issues, although one long-term healthcare practitioner did discuss it at length and considered improvements in this area as a strategic priority going forward. Suggestions as how to address these issues included improved participation of all community services in regular coordination meetings, the implementation of an online message board or mailing list for information sharing and coordination between community services, and establishing structured child health programs in collaboration with the community schools which would include regular health checks. Some service providers acknowledged that a lack of staff (particularly in the smaller communities) and often busy clinics could make it hard for healthcare practitioners to invest time in such activities. However, they argued that by doing so on a regular basis, more clinic presentations could be prevented, thereby decreasing the overall pressure on healthcare practitioners and health services. Comments from some service providers indicated that some healthcare providers who had worked in the community in the past did perform regular outreach and prevention activities. However, once these healthcare providers moved on, these activities ceased. Continuity is therefore problematic and could be addressed by implementing AMS policies and protocols that encourage healthcare practitioners to include outreach and health prevention activities in their routines, for example by ensuring fixed timeslots in healthcare practitioner's work plans are reserved for such activities. However, the overall high acuity and acute health care needs in remote Aboriginal communities regularly overwhelm these attempts to prioritise outreach and health prevention activities.

The pain and discomfort from an injection of BPG for the treatment of skin sores impacts on care seeking behaviour in these communities. This novel finding has previously been alluded to as a likely reason for poor treatment uptake in skin control programs [68] and

formed the basis of the Skin Sore Trial where a short course of oral antibiotics was trialled to improve treatment uptake for skin sores [70], but has never been documented consistently from parents/carers, healthcare practitioners and service providers. This is the first study to provide evidence for BPG being a barrier for health service utilisation and skin sore treatment uptake. This obstacle has been well documented in the management of patients with acute rheumatic fever and rheumatic heart disease previously [69,175,176]. The administration of BPG is especially painful because of the high viscosity of the liquid and the large volume required (2.1mL) to be injected into the thigh or buttock muscles [58]. Children can be particularly anxious about the injection and experience higher subjective pain compared to adolescents and adults [177]. An earlier study showed that one third of children have ongoing pain two days after the injection, and several consented children declined participation in a trial when randomised to BPG confirming this finding [70]. We also found that the procedure can be distressing for carers and may be an additional barrier to care seeking behaviour, an issue that has also been reported in other remote settings in Australia [69]. Strategies suggested to alleviate the pain of these injections include warming the needle, mixing lignocaine with the BPG prior to injection, the application of a cold pack prior to injection and the use of novel pain minimisation tools [69,177,178]. Despite this, the CARPA manual [179] (see box 1) does not describe such techniques in the relevant section on skin sore management and their implementation will therefore depend on the individual healthcare practitioner's training and experience.

Normalisation of skin infections and a lack of knowledge around the importance of skin health was another strong theme that emerged from our study. It was described mostly from the perspective that parents/carers and children did not recognise the significance of such infections, leading to delayed presentations. Our findings underline the importance of health education as a means of increasing awareness about the importance of skin

health amongst parents/carers, children and young people. This also relates back to the concept of patient-centred care, which describes health education as an important factor in empowering patients and making them feel engaged in their care [180]. Other studies have pointed out that normalisation of skin infections also occurs from the healthcare practitioner side, as is reflected in clinical guidelines that have set treatment thresholds for skin sores too high in the past [68] and a propensity to underdiagnose skin infections in the regional hospital setting [78]. The principle of ‘normalisation of deviance’ suggests that normalisation in healthcare delivery occurs gradually and can persist for long periods of time if not identified and addressed [181]. This suggests that healthcare practitioners working in rural and remote health settings require regular reminders of the importance of common health issues in remote communities, such as skin infections, in addition to training to support their ability to diagnose and treat them.

An additional analysis of the qualitative dataset described above, with a particular focus on health service provider knowledge, attitudes and practices around skin infections, was performed in parallel to the work reported in this chapter [182]. This complementary analysis further confirmed the issues around normalisation and the pain associated with the BPG needle we described here, but also highlighted several additional aspects that impact on the prevention and control of skin infections in remote Aboriginal communities. Importantly, it revealed that while healthcare practitioners are generally aware of the various types of skin infections that occur in the community and their impact on child health, their diagnosis and treatment remain challenging. Given the absence of relevant and easy-to-use rapid diagnostic tests in the community clinics, most healthcare practitioners described the precise diagnosis of skin infections as challenging and highly dependent on their personal clinical experience and ability. Some healthcare practitioners acknowledged that this difficulty can lead to a process of trial and error in terms of treatment. Furthermore, this analysis also showed that healthcare practitioners did not

always adhere to the CARPA treatment guidelines for skin infections that were in place at the time of the study [179]. This included a preference to prescribe an antibiotic treatment when a BPG injection was recommended, the spot-treatment of scabies infestations where whole-body application of permethrin cream is required, and the dismissal of the CARPA requirement to ensure the provision of sufficient permethrin cream for all household contacts upon diagnosis of a scabies case. The latter practice was put down to a perceived lack of permethrin cream supply in the community clinic, and a belief that household members would not apply the cream if it was provided to them. These issues around treatment highlight a need for clinical resources to support remote healthcare practitioners in their diagnosis and clinical management of skin infections, and also points toward the necessity for a more consistent implementation of skin infection treatment guidelines.

Several limitations need to be considered in interpreting the findings of this study and placing them in a broader context of health services utilisation for Aboriginal parents and carers of young children living in remote communities. Our findings are reflective of common attitudes and practices among healthcare practitioners and service providers present in the communities during the timeframe of our data collection activities. However, since this is largely a transient workforce, the views documented in our analysis are not necessarily representative beyond the study period. Similarly, the relative importance of some barriers and enablers documented here might differ in other communities. Nevertheless, the framework that we used to describe the factors that affect health service utilisation for skin infections and the concepts that emerged from our analysis, provide a useful lens through which to do similar research in other remote Aboriginal communities. Furthermore, as described above, the Andersen model was a post-hoc addition to our data analysis, with the intent of providing a structured overview of the barriers and enablers that had emerged from our principal analysis. It is likely that

if we had constructed our question guides around the concepts of the Andersen model to start with, we would have been able to provide more depth to the findings presented here. Doing so would also have allowed us to collect more data on additional systems barriers that are specific to the context of Aboriginal health, such as the impact of racism, prejudice and power relationships on health service utilisation. While the Andersen model has not previously been used to document health service utilisation barriers and enablers in the setting of remote Aboriginal communities in Australia, past studies have applied the framework in relation to ethnic minority groups and other Indigenous populations [152,183], with one example of an application in rural Aboriginal health [169]. Nevertheless, the flexibility and broad scope of the Andersen model allowed us to capture an extensive range of factors, illustrating its usefulness in this setting. Furthermore, while the Andersen model is primarily used as an analytical framework for quantitative, survey-based studies [152], our study sets a rare and valuable example of a qualitative application of the Andersen model and its ability to discern insightful health service utilisation observations from rich, semi-structured qualitative data. More recent iterations of the Andersen model have incorporated additional conceptualisations and analytical categories that more explicitly address health service utilisation issues that are of great importance in the context of Aboriginal health and wellbeing, such as beliefs, culture, psychosocial factors and ethnicity [151,152,184,185]. There is therefore significant potential for the Anderson model to be applied in this field of research.

Our study outcomes illustrate how practices around health service utilisation for skin infections are the product of an interplay between many different factors at the client, health provider and health systems level. Public health strategies aimed at improving care seeking practices in relation to skin health should aim to reflect this complexity in the interventions that they propose. Through its conceptualisation of need, enabling and predisposing factors, the Andersen model provides a basic framework around which the

development of such a program can be built. Following on from these three factors, the outcomes of our study suggest that health service utilisation for skin infections could be significantly improved in the study area by (i - need) de-normalising skin infections in the community and amongst (health) service providers; (ii - enabling) creating the circumstances in which a trusting and patient-centred relationship can be formed between clients and healthcare practitioners, while also ensuring that healthcare practitioners are adequately trained in administering BPG injections and are aware of pain minimisation techniques; and (iii - predisposing) improving cultural awareness among healthcare practitioners and encouraging them to actively engage with traditional knowledge and practices where appropriate and feasible.

CHAPTER 5 A SYSTEMATIC REVIEW OF THE EVIDENCE THAT SWIMMING POOLS IMPROVE HEALTH AND WELLBEING IN REMOTE ABORIGINAL COMMUNITIES IN AUSTRALIA

5.1 Preamble

A number of participants in the qualitative study described in chapter 4 ascribed a perceived reduction of skin infections over time to availability of a well-maintained swimming pool in one of the study communities. A study performed in this community around the time that the pool opened in the year 2000 indeed found some evidence in support of this observation. In this chapter, we explore this further and summarise the outcomes of a systematic review on the potential health benefits that have been associated with the provision of swimming pools in remote Aboriginal communities. While not conclusive, the outcome of our review does indicate a likelihood that well managed and maintained swimming pools in remote Aboriginal communities can lower the burden of skin infections. Furthermore, swimming pools may provide other benefits to communities and the social and emotional wellbeing of the people living there.

5.2 Introduction

The health and wellbeing disparities between the Aboriginal and Torres Strait Islander¹ people and other Australians are well documented.[186–190] Young Aboriginal people in particular suffer from a disproportionately high burden of infectious diseases[56], with respiratory, ear and skin infections being the most common reasons for children living in remote Aboriginal communities to present to clinics.[14,16] Approximately one quarter of Aboriginal Australians live in such remote or very remote areas[191] with poor housing conditions and limited access to many amenities considered a given in regional and urban areas.[29]

The National Partnership Agreement on Remote Service Delivery, a key component of the Council of Australian Governments 'Closing the Gap' strategy,[192] aims to provide a framework for ensuring that Aboriginal families have access to more equitable services consistent with those provided to other Australians.[193] Since aquatic sports and leisure activities are a staple of Australian life, it has been argued that remote Aboriginal communities should also have access to safe and well-maintained swimming pools. This is especially relevant considering the potential for community swimming pools to address most of the seven building blocks of the 'Closing the Gap' strategy². [194]

Advocates have argued that the health and wellbeing benefits associated with providing communities with well-managed swimming pools are substantial. They include improved health outcomes by possibly reducing the prevalence of skin and ear infections (by cleaning the skin and flushing bacteria from the middle ear respectively), a safe place for leisure activities, teaching swimming and water safety skills, as well as additional

¹ For the purpose of brevity, Aboriginal and Torres Strait Islander people will be referred to as Aboriginal people throughout this paper.

² The seven 'Closing the Gap' building blocks: Early childhood; Schooling; Health; Economic Participation; Healthy Homes; Safe Communities; Governance and leadership.

employment and personal development opportunities.[194] Swimming pools may therefore provide a way of addressing Aboriginal people's holistic understanding of health which encompasses the social, emotional and cultural wellbeing of the whole community.[195]

The potential health benefits of swimming pools in remote Aboriginal communities were first suggested in a research paper in 1984.[196] This study showed that the presence of a swimming hole, pool or ocean was associated with lower prevalence rates of otitis media (OM). Since then various studies have set out to evaluate the effectiveness of swimming pools as a means for improving various health outcomes in remote Aboriginal communities, including reducing rates of infectious diseases in school and pre-school children. This paper presents an overview of those studies, while also exploring evidence for other wellbeing and community benefits that may be gained through swimming pools.

The review's particular aim is summarised in two linked research questions: i) What evidence does the existing body of literature provide in support of improved health and wellbeing outcomes that have been associated with swimming pools in remote Aboriginal communities in Australia; and ii) which evidence gaps (whether methodological or in relation to particular potential benefits) currently exist in the literature?

5.3	Methods
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Initial searches for relevant publications were carried out using online bibliographical databases. Bibliographies of publications included in the review were systematically searched for additional relevant references, a process that was repeated for every publication identified through this procedure (snowballing). Where references could not be located online, we contacted the authors directly to request access to the publication. We used the PRISMA Statement as a guide for performing this review.[197] A copy of the completed PRISMA checklist can be found in Appendix Table App D.1 Supplementary File 1.

5.3.1 Search strategy

The following online databases were systematically searched for relevant publications from 1 January 1990 to 9 November 2014: Pubmed (Medline), EMBASE, Scopus, Web of Science, AustHealth and the Australian Indigenous HealthInfoNet. The latter two include grey literature references that are particularly relevant to the Australian context. We applied a broad key word search strategy using the following search string: (swimming pool* AND community) OR (swimming pool* AND benefit). The search was last performed on 9 November 2014.

All publications that presented first-hand data on the potential health and wellbeing benefits of swimming pools to remote Aboriginal communities in Australia were included. In order to ascertain eligibility for inclusion in our review, publication titles and abstracts were screened for references to (i) various infectious diseases and the possible beneficial effects swimming pools may have in reducing their burden in remote Aboriginal communities; (ii) social and emotional wellbeing outcomes that may be

associated with swimming pools in these settings; and (iii) other potential benefits swimming pools may bring to communities. Where eligibility was unclear on this basis, the full text was considered. If no abstract was available, as was the case for some grey literature publications, the full article or report was screened. No restriction was placed on the study or publication type to ensure the included studies reflected the broad spectrum of research questions and approaches that have been applied to evaluate possible benefits associated with swimming pools. Conference research papers offering detailed accounts of work were considered, although published conference abstracts were not. Articles discussing issues such as water quality, water borne pathogens, disinfection by-products and other health risks were excluded. Using these selection criteria, two researchers (DH and AS) performed the systematic search independently. Disagreements between both reviewers were resolved by consensus.

5.3.2 Appraisal of included studies

The level of evidence provided in the studies included in this review was described by employing an evidence classification scale adapted from National Health and Medical Research Council guidelines[198] and a similar review that was published previously.[94] The main change we introduced was to include qualitative studies as a distinct study type and differentiate between *anecdotal* and *rigorous* qualitative studies to underline the methodological nature of the latter and make it clearly distinct from purely anecdotal data. This classification is summarized in Table 5.1.

5.3.3 Data extraction

A study information sheet consisting of 15 discrete study descriptors and characteristics, including details regarding research methods, measures and study outcomes, was prepared for every publication that was included in our review. Key information taken from these study information sheets for each reviewed study has been summarised in Table 5.2. An extended version of this table is available in Appendix D. It includes details on study design and methodological considerations for each included study. These are not intended to be exhaustive evaluations of the included studies, but instead aim to highlight some of the major methodological considerations we have come across in our review. A copy of the study information sheet template is also available in appendix D.

Table 5.1 Evidence classification scale used to describe study types included in review

Classification	Definition
A	Systematic review – systematic location, appraisal and synthesis of evidence from scientific studies.
B1	Randomised controlled trial – subjects are randomly allocated to intervention and control groups, outcomes are compared.
B2	Pseudorandomised controlled trial – subjects are allocated to intervention and control groups using a non-random method, outcomes are compared.
C1	Pre/post intervention case series – A single group of subjects are exposed to intervention, outcomes are measured before and after for comparison.
C2	Post intervention case series – A single group of subjects are exposed to an intervention, only outcomes after the intervention are recorded, no comparison can be made.
D1	Representative survey study – A representative sample of a population is surveyed, generalization of outcomes is possible.
D2	Key informant survey – Opinions and experiences of key subjects are recorded in a survey.
Q1	Methodological qualitative study – qualitative data is methodologically collected, analysed and reported.
Q2	Anecdotal qualitative study – qualitative data is collected and reported without methodological rigor. No formal data analysis was undertaken.

Table 5.2 Summary of health and wellbeing benefits reported in studies included in this review (detailed table available in Appendix Supplementary file 2)

reference	evidence level	study area	health and wellbeing outcomes reported
Carapetis et al, 1995	C1/B2	Northern Territory	reduction in prevalence (when comparing regular swimmers to non-regular swimmers) and overall severity of skin sore difference found in overall skin sore prevalence, type or distribution
Peart & Szoek, 1998	D2	Northern Territory, Western Australia, Queensland	<i>reduction in skin, eye and ear infections, improvement in overall hygiene, children no longer swimming in hazardous environments, beneficial to social and emotional wellbeing *</i>
Lehmann et al, 2003	C1 + Q2	Western Australia	reduction in prevalence of tympanic membrane perforations and skin infections; measured improvement of school attendance; beneficial to social and emotional wellbeing; reduction in petty crime, kids learn to swim, safe environment for children to play * ; no significant change in prevalence of otorrhea
TICHR, 2006	C1 + Q2	Western Australia	measured reduction in prevalence and severity of skin sores; measured reduction of tympanic membrane perforations; decrease in clinical presentations and antibiotic prescriptions for skin, ear and respiratory infections; beneficial to social and emotional wellbeing; reduction in petty crime, kids learn to swim, safe environment for children to play *
Silva et al, 2008	C1	Western Australia	measured reduction in clinical presentations for ear, skin and respiratory infections; drop in antibiotic prescription rate
Sullivan et al, 2008	C1 + Q2	Northern Territory	measured reduction in prevalence of trachoma follicles, ENT referrals, failed audiometry tests and skin sores; children getting more exercise, beneficial to social and emotional wellbeing; improved school attendance, professional development, employment opportunities
Rubin et al, 2008	Q2	Northern Territory	<i>anecdotal improvement of school attendance, hygiene and skin health; children demonstrated an increased level of physical activity; improved water safety competence</i>
Mathew et al, 2009	C1 + Q2	South Australia	<i>anecdotal evidence for improved school attendance; provides an opportunity for exercise; unchanged prevalence of trachoma; increasing trend of infection and antibiotic prescriptions</i>
Lehmann et al, 2010	C1 + Q2	Western Australia	measured reduction in prevalence of tympanic membrane perforations and skin infections; measured improvement of school attendance; measured reduction in clinical presentations and antibiotic prescriptions for ear, skin and respiratory infections; beneficial to social and emotional wellbeing; reduction in petty crime, kids learn to swim, safe environment for children to play *
HPE, 2010	C1/C2 + D2	South Australia	measured reduction in prevalence and severity of skin sores; children getting more exercise, pools provide alternative to hazardous swimming environments; pool as incentive to attend school, may decrease petty crime, safe and healthy environment for children to interact, skills development in young people, provides employment opportunities; no change in school attendance rates; no change in prevalence of tympanic membrane perforations
Sanchez L et al, 2012	B2	South Australia	no evidence of improvements in any ear health outcomes or school attendance indicators
Stephen et al, 2013	B1	Northern Territory	no evidence of improvements in any ear health outcomes

bold = empirical / italic = anecdotal

* positive outcomes listed were not consistently found in all communities included in the study

5.4 Results

Figure 5.1 summarises our search process. After reviewing publication titles and abstracts, nine publications were selected for inclusion in this review. An additional three studies were included through snowballing. Table 5.2 provides a snapshot of all included studies, as described above.

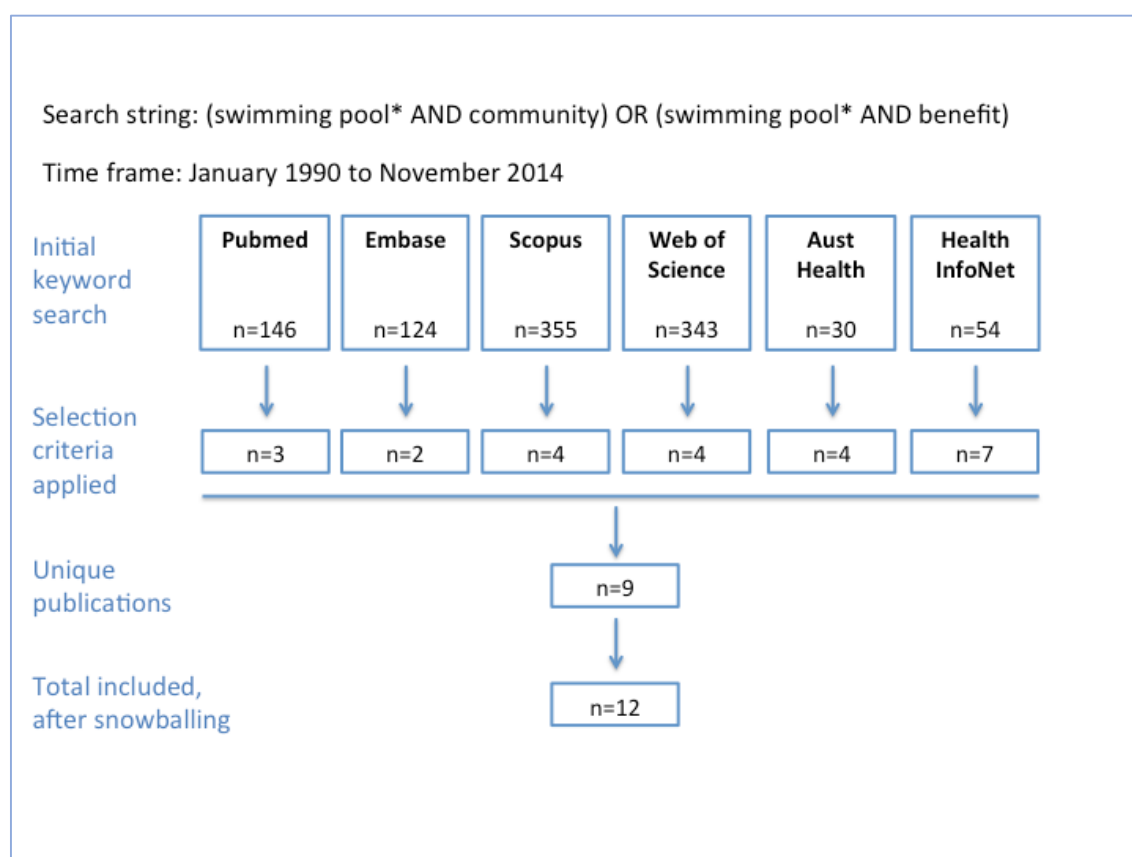


Figure 5.1 Summary of the search strategy performed for this review

5.4.1 Benefits to ear health

We identified ten studies that considered the potential association of ear health with swimming pools. A 1998 audit report by Peart & Szoek for the National Centre for Epidemiology and Population Health (NCEPH) indicated the possible role of swimming

pools in reducing the prevalence of ear infections in remote Aboriginal communities.[199] The study consisted of a key informant survey in 39 remote Aboriginal communities throughout Australia. A reduction of ear infections after installation of a community pool was mentioned in two of 13 communities that had a swimming pool at the time. Although anecdotal in nature, it was reports such as these that spurred more in-depth studies.

The first systematic study of health benefits of community swimming pools in remote Aboriginal communities over a longer period of time was performed by a research team at the Telethon Kids Institute (then the Telethon Institute for Child Health Research). Several papers published between 2003 and 2010 reported on the effect that the opening of swimming pools in two West Australian remote communities (Jigalong and Burringurrah) had on the prevalence of tympanic membrane perforations due to OM in under 17 year olds.[57,200,201] Comparing screening data collected before the pools opened to data collected at multiple 6-monthly intervals afterwards, they found the prevalence of perforations to be very variable. In Burringurrah (n=83) the prevalence of perforations had dropped by more than half during the period of 2000 to 2005 when compared to the pre-pool baseline (down from 33% to 15%¹). In Jigalong (n=79) the prevalence of perforations had returned to pre-pool levels (32%) after an initial drop to 18% ($\chi^2=2.18$; $p=0.14$). The authors suggested the variable outcomes may have been due to unforeseen pool closures and population mobility.

A second Telethon Kids Institute study by Silva et al in two remote Aboriginal communities in Western Australia (Jigalong and Mugarinya, published in 2008) performed a retrospective review of outpatient clinical records from 1998 to 2005,

¹ No p or χ^2 values provided for this particular trend from 2000 to 2005, although Lehmann et al. 2003 do report $p=0.04$ and $\chi^2 = 4.32$ for this trend up to 2002 where the prevalence of perforations had dropped to 13% (n Burringurrah = 83).[57]

comparing mean morbidity rates throughout that period.[17,201] In Jigalong (n=131) they found a 61% decrease in ear infections reported in the outpatient data compared to the pre-pool baseline, with an annual decline of 15% in the morbidity rate ($p<0.05$; 95%CI: -21, -8). On the other hand, no significant changes were documented in Mugarinya (n=128), which the authors suggest might be due to differences in disease burden and health service provision in the two communities.

Possible improvements to ear health outcomes were also suggested in a small study performed by Sullivan et al. in a remote Aboriginal community in Australia's Northern Territory (Naiyu Nambiyu), which evaluated various potential benefits associated with the implementation of a community swimming pool program that supposedly increased swimming pool exposure (although no data on the frequency of pool use was reported).[202] The study, published in 2008, consisted of two health screenings of school age children conducted one year apart. Ninety-two children were screened on the first occasion and 72 on the second, one year later. Although the prevalence of tympanic membrane perforations was not recorded, the study did report a 100% decrease in ENT referrals, from 6 to 0, and failed audiometry tests, from 2 to 0, when comparing data collected before the launch of the program with data collected one year later.

These positive findings contrast with several other studies that reported no ear health benefits of swimming pools. A study performed by Mathew et al. in a South Australian community from 2007 to 2009 showed no decrease in ear infections after the opening of a community swimming pool, as reported in outpatient records (n=166; age range = 1-15 years).[203] Similarly, two studies in South Australia's Anangu Pitjantjatjara Yankunytjatjara lands found no improvements in ear health outcomes either.[204,205] The latter of these two studies, by Sanchez et al and published in 2012[205], was the most comprehensive and evaluated a combination of ear health outcome measures that are

associated with OM. It consisted of screening for eardrum perforations, middle ear function and hearing acuity. The research team prospectively screened these outcome measures over three years (2009 to 2011; n=813; age range 5-18 years), comparing a group of four communities that had previously acquired a swimming pool to a second group of seven communities that did not have swimming pools. The study found no differences between these two groups of communities in terms of any of the considered outcome measures.

A recent randomized controlled trial (RCT) published in 2013 and performed in Australia's Northern Territory by Stephen et al. found no evidence that swimming is associated with short term reductions in severe ear disease in remote Aboriginal communities.[206] A total of 89 Aboriginal children aged 5-12 years with a tympanic membrane perforation were randomized to receive daily swimming classes of 45 minutes or a swimming restriction for four weeks. At follow-up there was no difference in the proportion of children with ear discharge between swimmers and non-swimmers (RD: -8%; 95%CI: -29, 12). No significant difference between study groups was detected for the prevalence of bacteria associated with OM in the nose and the middle ear.

5.4.2 Benefits to skin health

Our search brought forward 10 studies that explored the potential benefit of swimming pools to skin related conditions. A before/after comparison study by Carapetis et al. that was published in 1995 evaluated the effect the opening of a swimming pool in a remote Aboriginal community in the Northern Territory had on the prevalence, severity and distribution of skin sores in schoolchildren.[207] Skin checks using a standardized 'sore score' and performed several months after the opening of the swimming pool (n=54) showed sores to be generally less severe than prior to the pool opening (n=81). While the

pre-pool skin check classified 90% of skin sore presentations as ‘mild’ (<5 lesions) and 10% as ‘moderate’ (5-20 lesions), all skin sore presentations were categorized as ‘mild’ during the post-pool skin check. Skin sore prevalence was lower for those children who reported swimming more than once per week than in those who reported swimming only once or less (30% vs 57%, $\chi^2=3.38$, $p=0.05$). This difference was most pronounced in children aged <9 years, the population at highest risk of skin sores prior to the swimming pool opening (22% vs 56%, $\chi^2=4.15$, $p<0.05$). In just the older age group however, there was no difference in the prevalence of lesions between regular and occasional swimmers.

Anecdotal evidence from the 1998 audit report by Peart & Szoeké seems to support this finding.[199] Seven out of 13 audited communities that had recently acquired swimming pools reported seeing less skin infections. The series of studies performed by researchers at the Telethon Kids Institute provided more tangible indications that swimming pools might be beneficial to skin health. The series of papers published between 2003 to 2010 by Lehmann et al. that documented health check outcomes both prior to and at six-monthly intervals after the opening of community swimming pools showed a strong downward trend in the prevalence of skin infections in the community of Burringurrah (from 62% in 2000 to 12% in 2005²), although outcomes in Jigalong were more mixed.[57,200,201] As with ear disease, the authors suggested this might have been due to unforeseen pool closures and population mobility.

The second Telethon Kids Institute study, by Silva et al., showed a similar downward trend in mean rates of children presenting to the clinic with skin infections after the opening of a swimming pool in Jigalong (an overall prevalence drop of 68%, with an annual percentage change of -15% ($p<0.05$; 95%CI: -20, -10). Mixed outcomes were

² No p or χ^2 values provided for this particular trend from 2000 to 2005, although Lehmann et al. 2003 do report $p<0.0001$ and $\chi^2 = 24.88$ for this trend up to 2002, where the prevalence of skin infections had dropped to 18%.[57]

reported in Mugarinya, with an initial reduction in skin infection rates of 53 to 77% annually relative to the pre-pool baseline until 2004, but no such difference in the final year.[17]

A study by Rubin et al. (published in 2008) performed in 11 Northern Territory communities, which consisted of a series of key informant interviews (n=13) on the topic of “no-school-no-pool” programs anecdotally reported improvements in hygiene and skin health as one of the benefits associated with swimming pool use.[208] The Sullivan et al. study in the Northern Territory community of Nauiyu Nambiyu also documented a marked decrease in skin infections.[202] Health checks performed by the community clinic before (n=92) and within a year of the implementation of an intensive community swimming pool program (n=72) showed a drop in skin sore prevalence from 9.8% to 4.2%.

The study by Sanchez et al that was performed in South Australia’s APY lands also recorded reductions in the prevalence and severity of skin infections in the two communities for which pre-pool data were available.[204] In these communities, the proportion of children (age range: 0-<20) presenting with no sores had increased from 32% to 78% one year after the opening of a community swimming pool ($z=3.362$, $p<0.001$), while those presenting with severe skin sores had dropped from 25% to 6% over the same time period ($z=3.103$, $p=0.002$).

In contrast, the Mathew et al. clinical audit study of outpatient records in a South Australian community did not find evidence of decreased rates of children presenting with skin infections at the community clinic after the opening of a community swimming pool.[203]

5.4.3 Benefits to eye health

We found only three studies that considered swimming pools in relation to possible eye health benefits, such as the reduction of trachoma prevalence. Anecdotal evidence from the 1998 audit by Peart & Szoeki suggests that access to swimming pools might be beneficial to eye health, as a reduction in eye infections was reported by two (out of 13) communities after the opening of community swimming pools.[199] Furthermore, the 2008 study by Sullivan et al. in the Northern Territory found the prevalence of trachoma follicles had dropped by 55% (from 17 to 6 cases) within one year of establishing an extensive community swimming pool program.[202]

However, the study by Mathew et al., which actively monitored the prevalence of trachoma in a remote Aboriginal community in South Australia over a period of two years[203] concluded that the proportion of children with follicular trachomatous inflammation had remained low and unchanged.

5.4.4 Other health related benefits

We found a total of 11 studies that considered other health benefits of swimming pools, in addition to ear, health and skin disease. A number of the reviewed studies discuss additional health-related benefits. The Peart & Szoeki audit notes anecdotal indications that community swimming pools improved overall hygiene and stopped children from swimming in dangerous and possibly polluted swimming areas, such as dams, rivers and -in one case- sewage treatment ponds.[199] A 2009 study performed in South Australian communities highlighted similar benefits,[204] and several other studies noted community reports about children being more physically active due to the availability of a swimming pool.[202–204,208]

The study by Silva et al. in Western Australian communities [17] documented an overall decrease of 45% (with an annual percentage change of -11% [$p < 0.05$; 95%CI: -15, -7]) in antibiotic prescription rates following the opening of a swimming pool in Jigalong, but failed to observe a change in such rates in Mugarinya. The authors suggested that these mixed outcomes might have been due to varying prescription practices. This study found the mean rates of children presenting to the clinic with respiratory infections to have decreased by 52% in Jigalong (annual percentage change = -10% [$p < 0.05$; 95%CI: -16, -3]), although no significant change was found in Mugarinya. Similarly, the study performed by Mathew et al. in a remote Aboriginal community in South Australia did not find a decrease in antibiotic prescription rates after the opening of a community swimming pool.[203]

Finally, we found five studies that also touched on the broader social and emotional wellbeing benefits that may be associated with swimming pools and how such leisure facilities may take on the role of a social hub for the community, a place where families can come together and interact in a safe environment. However, these were documented purely anecdotally, since no studies present any methodologically collected data -whether qualitative or quantitative- to support the described benefits.[57,199–202]

5.4.5 Other community related benefits

Nine studies included in our review considered wider community benefits of swimming pools in their research. Several studies addressed the potential role of community swimming pools in improving school attendance. ‘No-School-No-Pool’ policies require children to attend school in order to be allowed access to the swimming pool outside of school hours. The 2003 study by Lehmann et al. in West Australian communities showed a significant improvement in school attendance rates in Burringurrah, where the

proportion of enrolled children with an attendance rate of at least 70% rose from 42% in the pre-pool survey, to 51%, 65% and 67% during the consecutive surveys over a 21 month period ($\chi^2=8.70$, $p=0.003$). However, no real improvement in attendance was documented in Jigalong.[57]

The first of two swimming pool studies in the South Australian APY lands was not able to make any meaningful inferences with the limited school attendance data collected.[204] The second study compared the median school attendance rates of pool and non-pool communities and found no statistically significant difference between the two groups (student t-test, $p=0.994$).[205] Several other studies gathered anecdotal data that suggest no-school-no-pool policies could be effective and were well received in many, but not all, communities.[200–204,208]

Several studies highlighted how the swimming pool provided a safe, supervised area for children to play,[201,204] as well as swimming lessons, water safety training, professional development and employment opportunities[200,202,204,208] Finally, some studies suggested community swimming pools help kids stay out of trouble and thus may decrease petty crime.[57,200,201,204] However, none of these reported hard data to support these propositions.

5.4.6 Limitations to the review

The methods and outcome measures applied by the various studies included in this review differ too much from one another to perform a meta-analysis. Furthermore, this heterogeneity also limited the degree to which our review was able to systematically evaluate potential biases in a standardised manner. We instead opted to provide an

overview of various methodological limitations of the reviewed studies in Table 5.2 and highlight a few key considerations in the discussion section.

This review included several grey literature publications that have not necessarily undergone the same scrutiny as would be expected from peer-reviewed literature.[199,200,202,204,205,208] Nevertheless, we have opted to include them in this review for the following reasons: i) they offer additional perspectives on issues that have not been covered much in peer-reviewed literature; ii) these publications provide both quantitative and qualitative data that might otherwise go unnoticed in the debate surrounding the potential benefits of swimming pools; iii) the grey literature provides cues for more systematic research into the ‘other’ benefits that swimming pools might provide.

5.5 Discussion

In terms of direct health benefits of swimming pools, the evidence around ear infections remains inconclusive with some small-scale studies suggesting a benefit and others – including a RCT- finding none. The same can be concluded in regards to the available data on eye infections, which is very limited. In contrast, all studies that prospectively documented the prevalence of skin infections reported a decline in skin sore prevalence and severity after the opening of swimming pools[57,200,201,204,207] or the implementation of a strong community-based swimming program.[202] Although caution is advised in interpreting the outcomes of these studies, given their lack of true control groups, their shared conclusion is significant and begs to be evaluated in a more rigorous manner considering the burden of bacterial skin infections in remote Aboriginal communities and the long-term sequelae such infections may cause, including kidney and heart disease.[44,45,54,209] It is however also important to acknowledge the potential health risks that swimming pools may pose due to a potential increased risk of exposure to certain pathogenic organisms and disinfection agents and by-products.[210,211] These aspects were however not discussed in any of the reviewed studies.

Several studies suggested social and emotional wellbeing benefits of community swimming pools, including potential for improved school attendance, improved water safety and swimming skills and better socialisation.[57,199–204,208] However, these hypotheses were supported by limited data, so they remain largely conjectural or anecdotal observations that warrant further quantitative and qualitative study.

Most studies investigating direct health benefits compared pre-intervention with post-intervention data in selected communities.[17,57,200–204,207] Because of the lack of control communities, this design is inherently unable to filter out possible confounding factors such as wider temporal trends or the effects of other ongoing programs or

interventions. Only three of the studies included in this review had some form of control groups,[205–207] two of which were non-randomised.[205,207] Furthermore, remote community heterogeneity throughout Australia implies that the generalizability of outcomes of any of the discussed studies is limited.

Only one RCT was identified in our review process,[206] but it took place over a short time period of one month and had a small sample size, limiting its ability to detect more modest benefits of swimming. The study design also did not assess whether swimming impacts on the transmission of bacteria causing OM disease (herd immunity). Changes in prevalence of acute OM and OM with effusion in relation to swimming were also not assessed.

With exception to the studies from WA, the majority of OM-focused studies in the review did not include children under 5 years of age. In the WA studies, up to 37% of participants were less than 5 years of age,[57,200,201] consequently, comparisons to studies with older cohorts may not be justified. Australian and international studies indicate that prevalence and incidence of OM is age dependent with peak risk occurring between two and five years of age.[212–216] Future studies investigating the relationship between swimming and OM should therefore also consider this important age group.

An additional challenge swimming pool studies have yet to address sufficiently is the issue of measuring actual swimming pool use. Having a swimming pool in the community does not necessarily imply regular use, as this may be affected by various factors including community policies (such as no-school-no-pool policies), pool maintenance and management, and the availability of other -natural- swimming locations nearby. The definition of swimming pool use is often based on proxies that do not necessarily accurately reflect actual use, such as school attendance[205] (following from ‘no school no pool’ policies) and self-reported swimming behaviour.[207] Direct measure

of pool use is challenging due to a general lack of existing record keeping systems that monitor swimming pool use up to a level of detail that would be useful to studies evaluating health benefits. The only study to directly observe swimming pool use was the study by Stephen et al.[206] Future studies should consider ways of measuring actual swimming pool use and the dose of the exposure, especially when studying the potential direct benefits to skin, ear or eye health. Other methodological limitations apply to the studies included in our review (see Table 5.2 and the extended version of this table provided in App D.2. Supplementary File 2), such as small sample sizes and variability in terms of data collection staff. Such methodological limitations should heed caution in interpreting outcomes and generalising the conclusions of any one study in particular.

We were surprised at the absence of any systematic and methodologically supported studies that explored possible benefits other than direct health effects of swimming pools in remote Aboriginal communities. At best, these aspects were briefly mentioned on the basis of anecdotal information. This stands in stark contrast with the holistic Aboriginal understanding of health and wellbeing, which goes far beyond a discussion focused on possible direct health benefits, but extends into the domains of community, culture and country.[195] Although the absence of disease is certainly a key factor that contributes to a sense of health and wellbeing, it is only one of many factors in which social and emotional wellbeing are just as important.

Only a wider literature search that included international literature revealed a study that considered in a methodologically underbuilt way the wider wellbeing benefits of community swimming pools. This qualitative study, in deprived neighbourhoods of Glasgow in Scotland, concluded that community swimming pools were important amenities in such settings, as they presented an opportunity for physical exercise, provided stress relief and were beneficial to mental health and wellbeing through the

social role that the swimming pool fulfilled.[217] The lack of a community swimming pool was considered to compound other stresses associated with personal and area disadvantage. Given the importance of social and emotional wellbeing in the context of Aboriginal health, an in-depth study into these ‘other’ factors in the Australian context is long overdue.

We conclude that, although the effect on ear health outcomes remains debatable, there was a consistent finding of an association between swimming pools and reduced rates of skin sores in remote Aboriginal communities. Further studies that include well-defined control groups are needed to confirm this. Additional benefits of swimming pools for remote Aboriginal communities were also discussed and are another important incentive to continue to provide access to swimming pools to improve social and emotional wellbeing. Swimming pools are by no means a silver bullet, but should be considered as one part of a more comprehensive public health strategy to improve health and wellbeing in remote Aboriginal communities.

6.1 Chapter Overview

In this final chapter, the general findings of the thesis are summarised and discussed, conclusions drawn and recommendations for future research and disease control strategies outlined.

While the public health importance of skin infections and its high prevalence in remote Aboriginal communities of Australia's Northern Territory (NT) had been well documented in the past, a review of the literature performed at the outset of this PhD project found that data describing the burden of skin infections in Western Australia (WA) was lacking. Anecdotal evidence and the few data that were available did however suggest that skin infections were indeed a common occurrence impacting on the health, wellbeing and developmental outcomes of children in remote communities in WA [30,81]. Furthermore, skin infection burden data specific to WA are necessary to create public health awareness, highlight at risk groups and inform control strategies. The lack of any comprehensive skin infection control programs in WA to date show that such data are vital.

Our findings presented in chapters 2 and 3 confirmed a high burden of both mild and severe skin infections among Aboriginal children living in remote communities in WA. In chapter 2 we summarised the data that we collected on childhood clinic presentations in four remote Aboriginal communities in WA's Pilbara region. We showed that skin sores were the third most common type of infection that children presented with at the local Aboriginal Medical Service (AMS) clinics (12% of all presentations), just after ear infections (15%) and upper respiratory tract infections (URTIs) (13%). We found that presentations for scabies and dermatophytes were less common (each accounting for 2%

of all presentations), while the least documented skin infection related presentations were crusted scabies and acropustulosis (<0.1% and 0.1% of all presentations, respectively). When analysed as a group (sores, scabies, crusted scabies, tinea), skin infections were the leading cause for clinic presentations in children aged 0-5 years (16%) in the Pilbara, contributing almost one in five clinic presentations. In addition, this is likely to be an under-documented burden [78]. This confirmed earlier reports from the area that had suggested a high burden of skin infections were impacting on early childhood development [17,30,57,92]. In chapter 3, our analysis of hospitalisation data for the whole state of WA showed that Aboriginal children were overall 15 times more likely to be admitted to hospital for skin infections compared to non-Aboriginal children, and that their skin infections were generally more severe and required longer stays in hospital. Hospitalisation rates were highest in infants and in children living in remote areas. Skin infection hospitalisation rates were found to be highest in Aboriginal children living in the Pilbara and Kimberley regions, followed by the Goldfields. Combined, these two datasets at community and state level show for the first time that high rates of milder skin infections also translate to a high burden of severe, and potentially life threatening, infections.

The qualitative findings presented in Chapter 4 provide important new insights that illustrate and inform the complexities surrounding effective skin infection prevention and control in remote Aboriginal communities. Health seeking behaviour for skin infections was found to be affected by many interrelated factors. These included the impact of culturally insecure practice and underlined the importance of healthcare practitioners being able to establish a trusting, respectful and patient-centred relationship with community members that recognises Aboriginal holistic conceptions of health [165]. Our findings suggest that normalisation of skin infections (see box 6.1) among community members may be common and that community awareness of the importance of skin

infections and their sequelae seems to be low. We also found that the levels of marginalisation, discrimination and prejudice experienced by community members, especially in regard to accessing mainstream health services, increased their reluctance to seek help.

The association of skin infections with painful antibiotic injections (benzathine penicillin G; BPG) also poses a significant barrier to seeking health care, particularly for children and their carers. We found that such considerations also influenced the clinical management practices of healthcare practitioners working in the remote communities of the Western Desert. While they seemed generally aware of the importance of adequately treating skin infections, there was a discernible variability between healthcare practitioners in clinical knowledge and compliance with guidelines for treatment of such infections. Crusted scabies was a particularly fraught topic, as interviewed healthcare practitioners were generally not familiar with its signs or epidemiological importance. Moreover, available clinical guidelines for the management of skin infections were not always consulted or followed, with most healthcare practitioners indicating that they rely on their past training and experience. Despite acknowledging the important health priorities, issues such as apathy, a lack of culturally secure practices and limited patient engagement contributed to healthcare practitioner non-compliance to some treatment guidelines by health care workers. This inconsistency in practice and knowledge is likely to be an ongoing driver of skin infections within the remote sector. Simplified education packages, streamlined evidence-based treatment algorithms and improvements in health literacy are all urgently needed to address these gaps.

Finally, chapter 5 reported on the outcomes of a systematic review of the evidence around the health benefits that have been associated with the provision of swimming pools in remote Aboriginal communities in Australia. The findings in terms of the potential of swimming pools to impact directly on the burden of skin infections in remote Aboriginal communities remain inconclusive due to the lack of randomised controlled trials on this topic. However, we did find that all studies that prospectively compared skin sore burden before and after the opening of a swimming pool in a remote Aboriginal community reported a decline in skin sore prevalence and severity. Additional potential benefits included social and emotional wellbeing, reductions in clinic visits for infectious diseases and reduced antibiotic prescriptions. The systematic review illustrated the many ways in which an investment in community infrastructure may positively affect the health and wellbeing of residents, including in ways that go beyond the scope of a controlled trial focused on just one health issue or endpoint.

Box 6.1 - ‘Normalisation’

The concept of normalisation was originally developed to describe the need to create ‘normal’ living conditions for people with disabilities [238]. In more recent times the term has developed to indicate certain adverse health-related behaviours (such as smoking and drug abuse[238,239]) and conditions (such as diabetes [240]) that have become ‘normalised’ and are therefore de-problematised.

Here we apply this term to describe the notion that the ubiquity of skin infections in remote Aboriginal communities leads to an acceptance of their presence, affects healthcare seeking behaviour and thereby further increases the burden of skin infections in these communities. Similarly, normalisation may occur among healthcare providers, leading to underdiagnosis of skin infections [78].

A key aim of this thesis has been to provide state-wide and community-level evidence on the high burden of skin infections that currently exists in WA and to examine the issues affecting their prevention and control in the context of remote communities in the Pilbara. While addressing skin infections in Aboriginal children will provide an immediate benefit to their overall health and development and potentially reduce the incidence of severe acute and chronic sequelae that disproportionately affect the Aboriginal population, the complex factors underlying the existing burden cannot be ignored. As well as improving clinical practice and culturally secure health service provision and prevention, there is an urgent need to address the underlying social determinants such as poverty, housing, employment, education, and the systemic discrimination, racism and disenfranchisement that were also evident in the literature and in our qualitative findings. All of these factors contribute significantly to increased risk of poor health including skin infection and should be considered a public health priority.

6.2 Discussion of Main Findings

The following paragraphs discuss the main findings of the work presented in this thesis and the recommendations that follow from them. Additionally, a summary of the findings and recommendations is presented in box 6.2.

6.2.1 Clinic presentation rates in Western Desert communities: high burden of skin infections.

The work presented in chapter 2 confirmed the high burden of skin infections in four remote communities located in the Pilbara region of the Western Desert. Skin sores accounted for 12% of all paediatric clinic presentations in the communities, and three out of every four children presented to the community clinic for skin sores in the timeframe of our study. While these proportions for skin sore presentations are comparable to those found in remote communities in the Northern Territory [14–16], we found the overall proportion of presentations for scabies in our study communities, while still high, to be significantly lower than those found in the NT. This might be an indication of under-recognition and underdiagnosis by healthcare practitioners [78], a consequence of children not accessing health services for skin infections due to normalisation, or fluctuating scabies incidence over time [53]. Nevertheless, our community clinic data did document particularly high rates of clinic presentations for scabies in infants, a finding that is in line with the outcomes of the NT studies that show that scabies infections spike in the first few months of life [14–16]. High rates in infants are almost certainly indicative of a high burden of scabies in the overall community, even though this might not be reflected in our data. Interestingly, amongst children, there were four cases of crusted scabies identified in the dataset. Crusted scabies cases are considered to be core-transmitters of scabies within a community due to the hyper-infestation of millions of mites [52]. Crusted scabies is more common in adults than children [52], hence the

diagnosis of crusted scabies in several children, if correct, suggests that this form of scabies may be present in these communities, which would signify a key driver of scabies similar to in the NT [52,74]. Overall, the diagnosis and community management of scabies is likely to be a much higher priority than our community-level data reflect because of underdiagnosis. Similar studies in the NT, where long standing initiatives to tackle skin infections in remote communities are likely to have sensitized healthcare practitioners and improved their ability to diagnose scabies infestations in children, might have been more insulated from this effect.

We found the rate of skin sore presentations to be high and largely consistent across the age spectrum of our study, with a slight increase in the oldest age group (5 to 6 year olds). The underestimated burden of scabies is likely to be a driver of high skin sore presentation rates [35,50]. Other factors, such as inadequate housing, overcrowding, environmental health factors, hygiene practices and delays in seeking care for skin sores (thereby increasing the risk of infecting others), and skin trauma through abrasions and insect bites might also be adding to the prevalence of skin sores [18–20,28,77,121]. Anecdotally, service providers often mentioned issues with ‘hard water’ in the communities; showering would result in dry skin, requiring copious use of moisturiser to avoid discomfort and cracking skin. This could potentially be an additional contributing factor to the high burden of skin sores in the four communities we have focussed on here. Nevertheless, it is also possible that scabies is relatively underdiagnosed in WA compared to the NT, where long standing initiatives to tackle skin infections in remote communities are likely to have sensitized healthcare practitioners and improved their ability to diagnose scabies infestations in children.

6.2.2 Skin infection associated hospitalisation rates in WA are highest in infants and in Aboriginal children living in remote communities.

Our analysis of hospitalisation data showed that 3 out of every 100 paediatric hospital admissions in WA is associated with skin infections, illustrating that skin infections are more than just a primary care issue. Hospital admission rates for Aboriginal children were 15 times higher than those of non-Aboriginal children, and Aboriginal children were also more likely to be hospitalised for a longer period of time and for more severe infections. Higher hospital admission rates for skin infections were also associated with higher degrees of remoteness and lower socio-economic status. The highest rates were reported for children living in the Pilbara and the Kimberley.

A comparison of age groups showed that infants (both Aboriginal and non-Aboriginal) were more likely to be hospitalised with a skin infection compared to older age groups. However, while in non-Aboriginal infants the hospital admissions occurred primarily in the first month of life, the majority of skin infection associated hospitalisations in Aboriginal infants occurred after the first month of life (months 2 to 12). Our data show that this high rate of skin infection associated hospitalisations in Aboriginal infants up to the age of one year is largely driven by scabies infections (accounting for 55% of skin infection associated hospitalisations in Aboriginal infants). This conforms with the primary care data we collected for remote communities in the Pilbara, which showed that community clinic scabies presentations were most common in infants, a trend also documented in the NT [14–16].

6.2.3 Skin infection diagnosis and treatment guidelines are useful resources, but contextual and subjective factors also inform clinical management.

While the Central Australian Rural Practitioners Association (CARPA) manual [58] for primary health care practitioners in remote Indigenous health services is a well-established resource amongst healthcare practitioners in the Pilbara region, our qualitative findings illustrate that more subjective factors such as past training, previous experiences and familiarity with the patient (and their carer, in the case of children) also inform the clinical management of skin infections. While the CARPA manual provides a clear algorithm for the treatment of scabies and skin sores, neither are necessarily followed to the letter.

Regarding scabies, not all interviewed healthcare practitioners were familiar with the application procedure of permethrin. Some specified that they would not cover the head or would apply permethrin just to the area of the skin they assumed was affected. In contrast, the CARPA manual specifies that the cream needs to be applied to the whole body, including the head and face, while taking care to avoid the eyes and mouth. CARPA also instructs healthcare practitioners to treat close family and household contacts of a diagnosed case with permethrin to avoid reinfection. Based on our qualitative findings and the review of patient notes we undertook, it was clear that this was rarely done. Healthcare practitioners provided two reasons for this in the interviews we conducted with them: the limited availability of permethrin cream in the communities to treat contacts of scabies cases (including the associated cost to the health service), and the belief that household members would not apply the cream even if it was provided to them, a finding that was found to be true in the East Arnhem Healthy Skin Program [61].

For skin sores, the CARPA manual specifies that mupirocin cream should not be used for treatment due to the rapid development of resistance. However, analysis of the Pilbara community clinic audit data showed that the cream was still used in 13% of skin sore presentations during the timeframe of the collected data (2007 to 2012), illustrating that

there was a discrepancy between clinical practice and current guidelines. The limited use of an injection of benzathine penicillin G for the treatment of skin sores provides another example of this. CARPA recommends this as the treatment of choice for infected sores, unless “*injection is not possible*”, which it describes as “*very rare*” [179]. Our data nevertheless show that this procedure was only performed in 5% of skin sore presentations, with oral antibiotics being prescribed in 34% of skin sore presentations. Some healthcare practitioners described how, while preferring benzathine penicillin G as the more effective treatment option, they would consider a course of oral antibiotics out of concern that the painful benzathine G penicillin injection might adversely affect future health seeking behaviour. Treatment decisions would often be made on a case-by-case basis when treating children presenting with a skin sore, and would depend on the healthcare practitioner’s assessment of the severity of the infection and how confident they were that the child would successfully complete the 5-10-day course of oral antibiotics, whether through daily clinic visits or administration of antibiotics at home. Furthermore, only few healthcare practitioners indicated that they would take the preference of the carer into consideration. Interviews with carers confirmed that this rarely happened and that they wanted to be informed about treatment options and be given a choice. Our qualitative data also suggest that little consideration is given by healthcare practitioners to the possibility of finding alternate ways of ensuring children take their antibiotics, such as providing them through the school or through outreach such as home visits. However, potential reluctance of teachers to provide treatment at school, clinic understaffing and a lack of Aboriginal Health Workers might make the implementation of such strategies challenging. Nevertheless, strategies to this end are currently being explored in the Pilbara communities, with the potential to have locally trained community care workers involved in treatment support, follow-up and parent/carers engagement.

The CARPA manual was the only clinical management guideline that healthcare practitioners referred to in the context of skin infection diagnosis and treatment. Despite the above discussion where compliance with the CARPA guidelines treatment recommendations is inconsistent, it is important that the primary reference for treatment is well known and referenced. Limitations of this CARPA guideline, are the lack of inclusion of photographs of skin infections. Other skin infection-specific clinical protocols designed for use in the remote Aboriginal primary care setting do nevertheless exist [218,219]. However, healthcare practitioners we interviewed in our study setting did not seem to be aware of them and use CARPA as their go-to reference for all types of presentations. This is understandable given the comprehensive and syndrome-based nature of the CARPA manual and that this is the guideline which provides the structure for nurse-prescribing to occur under Standing Orders. However, skin infection-specific protocols offer benefits, such as detailed photos of skin infections to aid diagnosis [218], or additional information about potential sequelae [219] to stress the importance of ensuring adequate treatment and follow up. Facilitating a wider availability of such guidelines, and ensuring healthcare practitioners are made aware of them by incorporating them into training activities or pointing them out during clinic inductions might increase their usage and familiarity amongst clinic staff.

6.2.4 There is a need for more acceptable and effective treatment options

The previous paragraph illustrates some of the limitations of the treatment options that are currently used by healthcare practitioners for the management of skin infections in remote Aboriginal settings. Carers and service providers also highlighted a range of barriers associated with currently available treatment options for skin infections, including the pain and fear that are associated with ‘the needle’ (benzathine penicillin G),

the complexity of oral antibiotic schedules and the need to remember to give them to the child, the size of tablets and the taste of the suspension, and the smell, texture and messiness of permethrin cream and its application.

Given these issues, innovation around skin infection treatment strategies is critically needed. Recently published studies have shown promising results in this area. One study has shown that a short course of oral antibiotics (co-trimoxazole; taken twice daily over three days OR once daily over five days) is non-inferior to a benzathine penicillin G injection [70], while a second study provided evidence for the safe and effective use of ivermectin (an oral drug; two tablets, 7-14 days apart) for the community control of scabies [62]. These are significant findings that offer potential benefits over the current first line treatment options outlined in the CARPA manual: a short-course, painless treatment option for skin sores, and an oral treatment option for scabies that could replace the need for permethrin cream in a large proportion of patients (noting that ivermectin is contra-indicated for treating children under 15 kg or <5 years old and pregnant or breast feeding women and is not currently listed as first line therapy for scabies in the PBS). Incorporating both treatment strategies in the CARPA manual has the potential to significantly improve treatment outcome and, in the case of co-trimoxazole for skin sores, to positively affect health service utilisation for skin infections given the prospect of reducing the need for painful benzathine penicillin G injections. However, monitoring for emerging antimicrobial resistance in the context of increasing use of co-trimoxazole for skin infections is needed [70].

One other avenue that requires further exploration is the potential beneficial effect that incorporating traditional knowledge and bush medicine in Aboriginal primary care settings may have on care seeking behaviour and health service utilisation [220]. Service providers and healthcare practitioners seemed generally aware of the practice of

traditional medicine in the Western Desert, but would often not be familiar with the specific characteristics of such practices and the types of “bush medicine” that may be used for the treatment of skin infections. The anecdotes relayed by carers about the effectiveness of bush medicine suggest that at least a portion of skin health issues are treated in this way, without presenting to a clinic. Comments about the strength of culture and the importance of recognising cultural knowledge in the region further hint at the potential for a concurrent approach to western and traditional medicine in the Pilbara to be beneficial to the overall health and wellbeing of the Aboriginal people living there. The embracing of this kind of ‘*medical pluralism*’ [220] is integral to improving health and wellbeing outcomes [143]. A recent review on ethnomedical practices of Aboriginal people provides an overview of previously documented traditional medicines and their indications, including skin infections [221]. This provides avenues for further exploration, although the authors do also indicate that there is a need to investigate possible interactions between bush medicine and pharmaceutical drugs [221].

6.2.5 The normalisation of skin infections in Western Desert communities is an important barrier to seeking care.

Our qualitative findings suggested that there is a substantial degree of normalisation around skin infections present in the four communities that were the focus of research. Chapter 4 described how normalisation, through its effect on ‘perceived need’, was described as an important factor that affected health service utilisation for skin infections in the Pilbara communities. While this was mostly reported as an issue from the perspective of service providers and healthcare practitioners, it was also highlighted by some of the interviewed parents/carers who added that this follows from a lack of health education in the communities around the importance of skin infections. However, what

might be perceived by healthcare practitioners and service providers as an issue of normalisation leading to non-presentation, could also be the result of carers avoiding contact with health services because of other factors, such as an adverse or negative previous experience with the clinic. This seemed to be particularly problematic in regards to accessing mainstream health services, although some carers did also express negative perceptions in regards to AMS clinics or certain staff members.

A recent study confirmed that health professionals working in regional hospital settings of Western Australia systematically underdiagnose scabies and skin sore infections [78]. This suggests either a lack of an ability to diagnose skin infections, a propensity to ignore such infections if they are not the main reason of the presentation, or a combination of both. It is possible that similar issues might be leading to the under-diagnosis of skin infections by healthcare practitioners in remote communities, possibly resulting in an under-representation of the true burden of skin infections reported in chapters 2 and 3.

6.2.6 There is a need for a more substantial patient-centred care approach that incorporates intercultural conceptualisations of health and disease.

Our qualitative findings underlined the importance of establishing a trusting patient-health provider relationship that lays the foundation for a patient-centred culturally responsive approach to primary care. One of the tenets of patient-centred care is the sharing of power and responsibility in the patient-health provider relationship, allowing patients to be actively involved in decision making around the management of their health conditions [222]. The carers we interviewed indicated that they generally considered a visit to the local community clinic to be a passive and disempowering experience,

sometimes fraught with judgement, inhibiting any opportunity for an equal and respectful exchange to take place.

Patient-centred care also implies that health providers incorporate the patient's worldview and perspectives on health into their clinical management practices. Healthcare practitioners in the remote Aboriginal setting therefore need to be aware that they are operating at the cultural interface between traditional and modern frameworks of health and that engaging with local cultural concepts and practices is critical to patient engagement [91,135,142,223,224]. Our qualitative findings showed that while some healthcare practitioners actively engage with such traditional conceptualisations of health, this is not a universal practice. Some of the experiences that were relayed by carers and service providers showed that some healthcare practitioners can be dismissive of Aboriginal conceptions of health, the differing cultural values and the adverse effects of their contemporary social circumstances. Although the importance of 'cultural competency' in Aboriginal health service delivery is widely acknowledged, the evidence base on how to effectively improve cultural competency in health services and healthcare practitioners remains limited [165]. However, it is clear that cultural awareness training in itself is not sufficient and that more comprehensive, systems-level approaches are necessary [165].

While acknowledging the challenges healthcare practitioners face when operating in the remote Aboriginal setting (we identified high workloads, high staff turnover rates, and the stress and isolation associated with working in a remote community as examples of this in chapter 4), structural efforts need to be made to enable the development of a culturally responsive, patient-health provider relationship that is conducive to putting the principles of patient-centred care into practice. Training and employing local Aboriginal Health Workers as well as community care workers or community support workers who

can fulfil the important role of cultural brokers between the health service and families is also an essential strategy in this regard. Our qualitative findings suggest that this was a challenge in our study area at the time of data collection. Innovative approaches could be explored to address this gap, including the establishment of intensive support mechanisms for the training of Aboriginal Health Workers, mentorship programs, active recruiting strategies and the use of peer support networks [161,225,226]

Nevertheless, ensuring that culturally responsive, patient-centred care is an integral part of the curriculum of any healthcare practitioner trained to work in the remote Aboriginal health setting is only a first step [165]. Public health applications of ecological models and social cognitive theories [227–230] illustrate how practices in healthcare are also a product of the immediate context as well as the wider system in which they take place; behavioural change can be stimulated by making changes to the social environment that align with the practices that want to be encouraged. Culturally responsive and patient-centred care could therefore be actively stimulated in healthcare practitioners by ensuring that these concepts permeate throughout the culture and setting of a health service, from how a clinic is set up (e.g. displaying culturally appropriate health education materials and making the clinic environment an extension of the community by -for example- exhibiting community images, drawings, photos), to the format and content of clinical guideline documents that are used (e.g. including prompts for healthcare practitioners and suggestions as how to encourage patient participation in consultations and the clinical management process) and to the policies and management practices of the health service (e.g. establish patient-centred care as an explicit and well defined goal of the organisation, include community-specific guidelines for patient-centred care in staff induction materials, reduce staff turnover rates, support the social integration of new staff in community life). In the absence of this kind of comprehensive approach that firmly embeds patient-centred care in the culture of a health service, the practice of patient-

centred care will depend mostly on the personal commitment and knowledge of the individual healthcare practitioner to apply such concepts in their clinical practice [173]. Ensuring the consistent practice of culturally secure, patient-centred care requires a more structural approach to ensure greater family and community engagement and ownership of the strategies to improve their health. The clear articulation of these principles in the WA Department of Health Aboriginal Health and Wellbeing Framework 2015 – 2030 [166], which is described as “*an agenda shared by all those concerned with the health of Aboriginal people and communities in WA*” [166], provides a useful policy instrument to make the case for continued investments in the cultural competency of the state’s healthcare provider workforce.

Box 6.2 – main findings and recommendations

Main findings

Skin infections are the **leading infectious cause for clinic presentations** among children living in remote Aboriginal communities in the Pilbara region of WA.

16% of all clinic presentations: skin sores 12%; scabies 2%; tinea 2%
[chapter 2]

Aboriginal children are **15 times more likely** to be admitted to hospital for skin infections compared to non-Aboriginal children

hospitalisation rates are highest amongst Aboriginal infants and children living in WA's most remote regions (Pilbara, Kimberley, Goldfields)
[chapter 3]

Health service utilisation for skin infections in remote Aboriginal communities in the Pilbara is likely impacted by:

*Parent/carer **hesitancy to access health services** because of bad previous experiences, experiencing prejudice, feeling a lack of engagement with the health care process, not having a relationship with healthcare practitioners.*
[chapter 4]

*Parent/carer **normalisation** of skin infections, caused at least in part by insufficient community awareness of the importance of skin health and a lack of health education provided on this topic.* [chapter 4]

*The association of skin infections with **painful BPG injections**, particularly for children and their parents/carers.* [chapter 4]

Well managed **community swimming pools** have the potential to lessen the burden of skin infections in remote Aboriginal communities and can contribute to the social and emotional wellbeing of the people living there. [chapter 6]

Main recommendations

Develop and implement **strategies for the screening and routine monitoring of skin infections**, including active case finding for crusted scabies.

Evaluate new treatment strategies and delivery methods that might be considered more acceptable alternatives to current first-line treatments for skin infections.

An increased focus on community, parent and carer **health education on skin infections** can contribute to the de-normalisation of skin infections and empower parents/carers in the healthcare of their child.

Encourage the practice of **patient-centered and culturally secure care** in health services and support the integration of newly arrived healthcare practitioners in the community.

Training of healthcare providers and development of appropriate resources to **support diagnosis and clinical management** of skin infections.

The effective and sustainable prevention and control of skin infections requires an **integrated approach** that is built on community engagement and collaboration between services.

6.3 Study Limitations

6.3.1 Clinic audits and hospitalisation data do not capture the full burden of skin infections

One of the main aims of this PhD project was to document the burden of skin infections in the Pilbara Western Desert communities in particular and across Western Australia in general. While we have provided new data on this topic, it is important to underline that our findings signify only an approximation of the true burden of skin infections in WA and most likely constitute an underestimation. Although we can assume that the community clinic and hospitalisation data we presented here adequately captures the more severe end of the skin infection burden spectrum (assuming that most children that are in considerable discomfort or are severely ill will present to the local clinic or will be admitted to a hospital), two themes that we discussed earlier suggest that our data most likely underestimate the true burden of skin infections in WA. First, as is illustrated by the findings of Yeoh *et al* [78], skin infections are possibly underdiagnosed by health providers. Second, the issue of normalisation and other previously described factors that affect health service utilisation, such as past negative experiences with health services, are also likely to lead to health service avoidance and delays in seeking medical care. Furthermore, as was suggested in our qualitative findings, some children might be treated by their carers at home, possibly by means of bush medicine. Finally, while the focus of this manuscript was mostly on the clinical burden of skin infections in Aboriginal children, we did not explore additional impacts such infections might have on their health and wellbeing. It is possible that children who frequently suffer from skin infections experience higher levels of malnutrition and an increased susceptibility to other infections [52,231]. Recurring skin infections may also contribute to increased antimicrobial

resistance through the repeated use of antibiotics [115,232] and can also impact on school participation and childhood development [30,31].

6.3.2 Our community clinic data cannot necessarily be extrapolated to other remote communities in WA

Some caution is advised in generalising the findings of the community clinic audit data to the larger WA setting. WA covers an area of roughly 2.5 million km², across which 278 small, remote Aboriginal communities are found [233]. Geographical, climate, socio-economic and cultural factors vary substantially throughout the state and its regions, a heterogeneity that is likely to translate in varying infectious disease burden profiles. However, while the findings of the clinic audit we performed in the Pilbara Western Desert communities are specific to the community clinics surveyed between 2007 and 2012, our findings are consistent with previous similar studies in the NT [14–16] and are backed up by the high burden of skin infections in Aboriginal children hospitalised across WA. Hence, our findings are likely to reflect the significant impact skin infection has on primary health care presentations in remote areas across the state.

6.3.3 Our qualitative findings are transferable, but not necessarily generalizable

Caution is also advised in generalising the outcomes of our qualitative work and making assumptions concerning the degree to which the various barriers that we described here are directly relevant to other remote community settings. However, the framework that we used to describe the factors that affect health service utilisation for skin infections in the Pilbara communities, and the concepts that emerged from our analysis, provide a

useful lens through which to do similar analysis in other remote Aboriginal communities. Nevertheless, similar barriers to health service utilisation for Aboriginal people have been identified elsewhere [142], providing further confidence that the key factors reported here reveal some of the issues that make it challenging to ‘close the gap’ in pervasive health outcomes. Therefore, while we cannot state that all of our qualitative findings are necessarily generalizable, we do believe that the concepts and types of barriers that we have elucidated in our analysis are consistent with established and evidence-based principles, recommendations and policy guidelines regarding Aboriginal health service provision [25,142,166]. The application of these principles can be applied in all communities to develop health services that are responsive and effective to local health and cultural issues.

6.4 Future Work and Recommendations

The findings presented in this manuscript provide valuable insights to inform skin infection prevention and control strategies in remote areas of WA in general, and the Pilbara in particular. Our qualitative findings suggest that immediate priorities should include tackling the normalisation of skin infections through community education and healthcare practitioner training activities, and supporting deeper cross-organisational collaboration between community service providers on child health issues. Furthermore, there is a need to create a strong evidence base for the implementation of novel skin infection treatment strategies that could simplify treatment and improve adherence and care seeking practices. Shorter courses of antibiotics for bacterial skin infections and the uptake of oral treatment options for simple scabies could be crucial ways forward in this respect. A trial led by our research team that aims to integrate all these aspects and utilise a ‘treatment as prevention’ strategy is currently underway in the Kimberley region of WA. If successful, this trial (discussed in more detail below) will provide a valuable proof of concept for the sustainable prevention and control of skin infections that could be expanded to other remote Aboriginal communities in WA.

6.4.1 De-normalising skin infections in remote communities: focus on health education

The research findings reported on in this work illustrate how normalisation of skin infections is an important issue that impacts on health service utilisation. Our findings suggest that health education and the provision of information (in plain language and in Martu) on the health impact of skin infections to parents/carers, children and other community members (e.g. Elders, community governance actors, school staff) is an

important step forwards in de-normalising skin infections and increasing awareness around the need to visit a clinic when such infections appear. To ensure the sustainability of health education activities and for health promotion messages to be provided in the context of trusted relationships, health promotion should ideally be incorporated in the routine activities of service providers that interact regularly with the parents/carers and their children. In the context of Aboriginal child health, this could include nurses, midwives, teachers and child and maternal health program workers. Engaging community members and respected elders in the development of strategies and resources to address skin infections is also crucial and recognises the knowledge that communities can bring in addressing their own health issues [73]. However, factors such as funding limitations, time restrictions or a lack of health promotion know-how and resources can impact on the potential for service providers to effectively provide health education and adequately engage with the community [234]. Support from external services can therefore be a crucial factor, as long as such collaboration is built on strong foundations and long-term commitments.

6.4.2 Driving integrated strategies for skin infection prevention and control

This thesis has illustrated how a range of demographic, cultural, socio-economic and clinical factors are associated with the burden of skin infections in remote Aboriginal communities. It substantiates the urgent need for public health action for the prevention and control of skin infections, and illustrates the need to address this complex issue by developing integrated strategies. New research projects are on the horizon in WA that acknowledge the complexity and multifaceted dimensions of skin infection prevention and control in remote Aboriginal settings. Later this year, a trial will commence in the

Kimberley that aims to address the issue of skin infections from three angles: the treatment perspective (evaluating the effectiveness of ivermectin treatment for scabies, a focus on crusted scabies and shortened 3-day oral antibiotic course for skin sores), the health education and environmental health perspective (health promotion activities in the community, developed in collaboration with the community), and the training of healthcare practitioners in the identification and management of skin infections. This multipronged approach is built on the premise that an intervention that addresses just one of these aspects is less likely to be successful at reducing the burden of skin infections in remote Aboriginal communities compared to a more comprehensive program of work that is owned by the community and aims for sustainability through partnership with regional and Aboriginal health services.

6.4.3 The need to document the hidden burden of skin infections in remote Aboriginal communities requires more proactive screening strategies

As indicated in the limitations above, our data sheds light on hospitalisations and community clinic presentations for skin infections, but falls short on providing data on the true prevalence of skin infections in WA. Chapter 2 indicates how clinic data can better inform our understanding of the burden of skin infections, despite the limitations noted. However, this manual extraction of data, especially from paper records, was extremely time intensive. Streamlined, automated data extractions to build dashboard reports are eminently feasible with the latest technology if an investment in this is made. This use of de-identified, routinely collected clinic data may be an important facilitator in highlighting disease burden and keeping it in the minds of clinical staff as they provide healthcare. If routinely collected data is not available or being used in this way, the most

effective way of measuring the true prevalence of skin infections would be by implementing prospective skin infection screening activities in communities, whether in the context of a study or more routine forms of data collection. However, it is costly and logistically challenging to implement such a study on a large scale and may not contribute to overall improved health – if it is not a core activity of a well supported, sustainable health workforce.

There might be potential to integrate skin infection screening with ongoing health screening programs that are being implemented across (or in certain regions of) WA. One such programme is the Australian Department of Health's annual trachoma screening programme, that screens many remote communities in WA on a regular basis. Collaborating with such an established screening program and integrating a basic skin check-up in their activities would signify a minimal amount of extra cost and effort, but would provide valuable data on the burden of skin infections in WA. This could also provide a baseline dataset to document temporal changes in skin infection prevalence and the impact of current and future prevention and control strategies. In addition, health services could perform regular data extractions of electronic health records to monitor skin infection related presentations and evaluate whether targeted screening and treatment interventions might be warranted. The Enhanced Aboriginal Child Health Schedule, which consists of a series of child health checks between birth and school entry [235], could also constitute an existing program from which data around skin infections could be extracted for monitoring purposes.

Crusted scabies has been shown in the NT to play a crucial role in the epidemiology of skin infections [52]. Although crusted scabies is uncommon, cases are hyper-infective and can drastically increase the prevalence of scabies in the community when left undiagnosed and untreated [74]. Our qualitative findings suggest that healthcare

practitioners operating in the Pilbara may not be aware of crusted scabies, its clinical presentation and epidemiological importance. The prevalence and potential impact of crusted scabies may therefore be hidden in WA. Drawing from the lessons learned in the NT [52], an active case finding program could be trialled in a region of WA where high rates of scabies have been reported. This could provide insights into the burden and epidemiological role of crusted scabies in WA.

6.5 Final Conclusions

The findings presented in this manuscript have underlined the importance of skin infections in Western Australia and have highlighted them as a significant public health issue. Aboriginal children living in remote communities are at a particularly high risk of skin infections and the severe sequelae that are associated with them. While the tools for the control of skin infections are available, there is an urgent need for public health stakeholders to use them more effectively and align prevention and control strategies to the realities of remote Aboriginal communities.

Our findings illustrate the wide range of factors that contribute to the burden of skin infections among children living in remote Aboriginal communities. The multidimensional determinants underpinning the high rates of skin infections documented in these settings underline the need for integrated ‘healthy skin’ strategies. This could be improved by strengthening the capacity of health services to work in partnership with communities to effectively develop and implement prevention and control measures for their communities. Research organisations with an interest in improving child health in remote communities of Western Australia can play an important role in this by forming partnerships with Aboriginal community controlled health services and other relevant government and non-government organisations. Such collaborations would ensure that research is community-led and need-driven and that the outcomes can be effectively implemented, evaluated and sustained.

Health education programs are urgently needed to address issues associated with normalisation, improve health service utilisation, and improve community awareness of skin infections and their health impact. This needs to be done in the context of a health service that provides culturally secure patient-centred care, which in turn requires adequately staffed and resourced health services that are well integrated in the community

and have functional working relationships with other service providers. Of particular importance in the context of Aboriginal child health is the need for community health services to establish health programs with child care centres, schools and other community organisations that engage with children on a daily basis. Well-funded, well-functioning AMS clinics that operate in harmony with the community and other service providers are the foundation on which strong, sustainable health programs can be built. If this prerequisite is fulfilled, it is likely to improve not just the state of skin infections and other infectious diseases in remote Aboriginal communities, but Aboriginal health and wellbeing in general.

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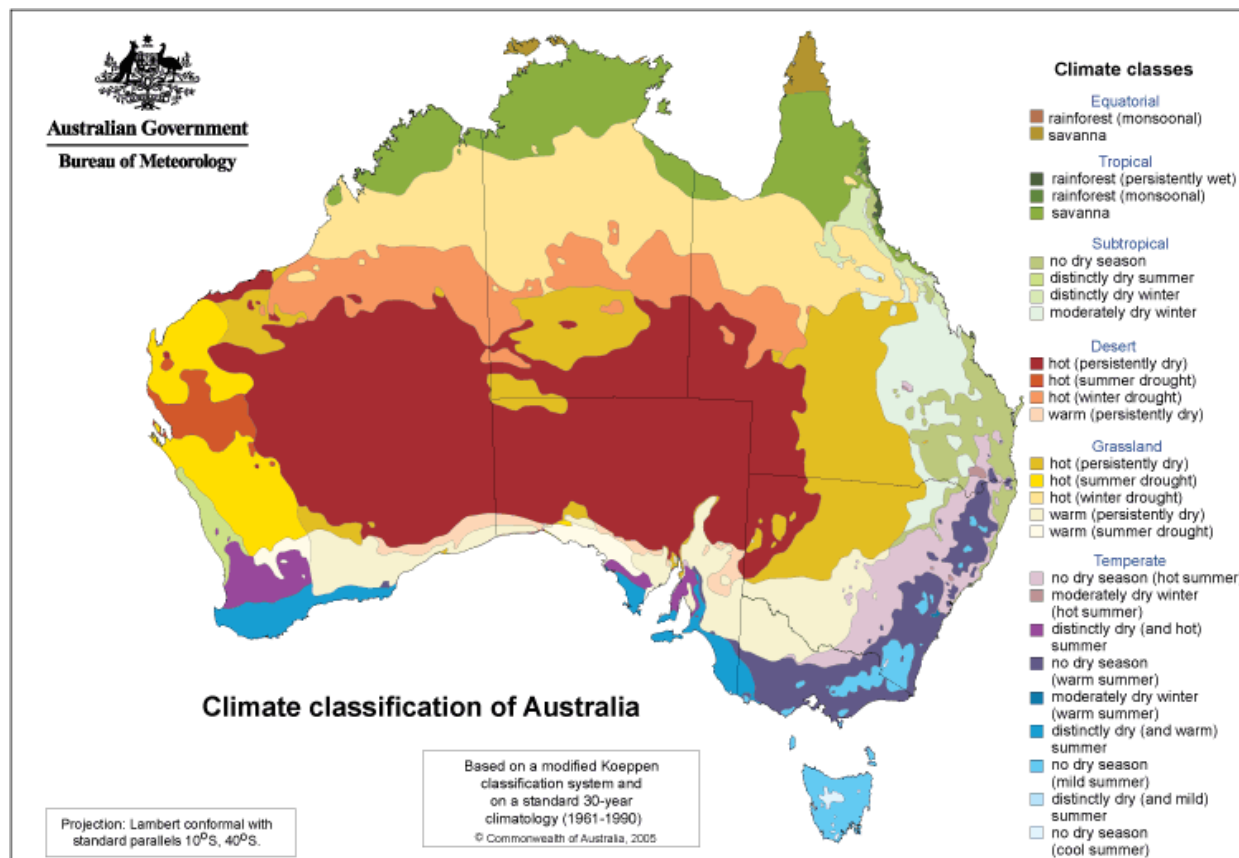


Figure App A.1 Climate classification map of Australia, showing the climatic diversity found across the country and within its states and territories.

(source: www.bom.gov.au, accessed 28-01-2017).

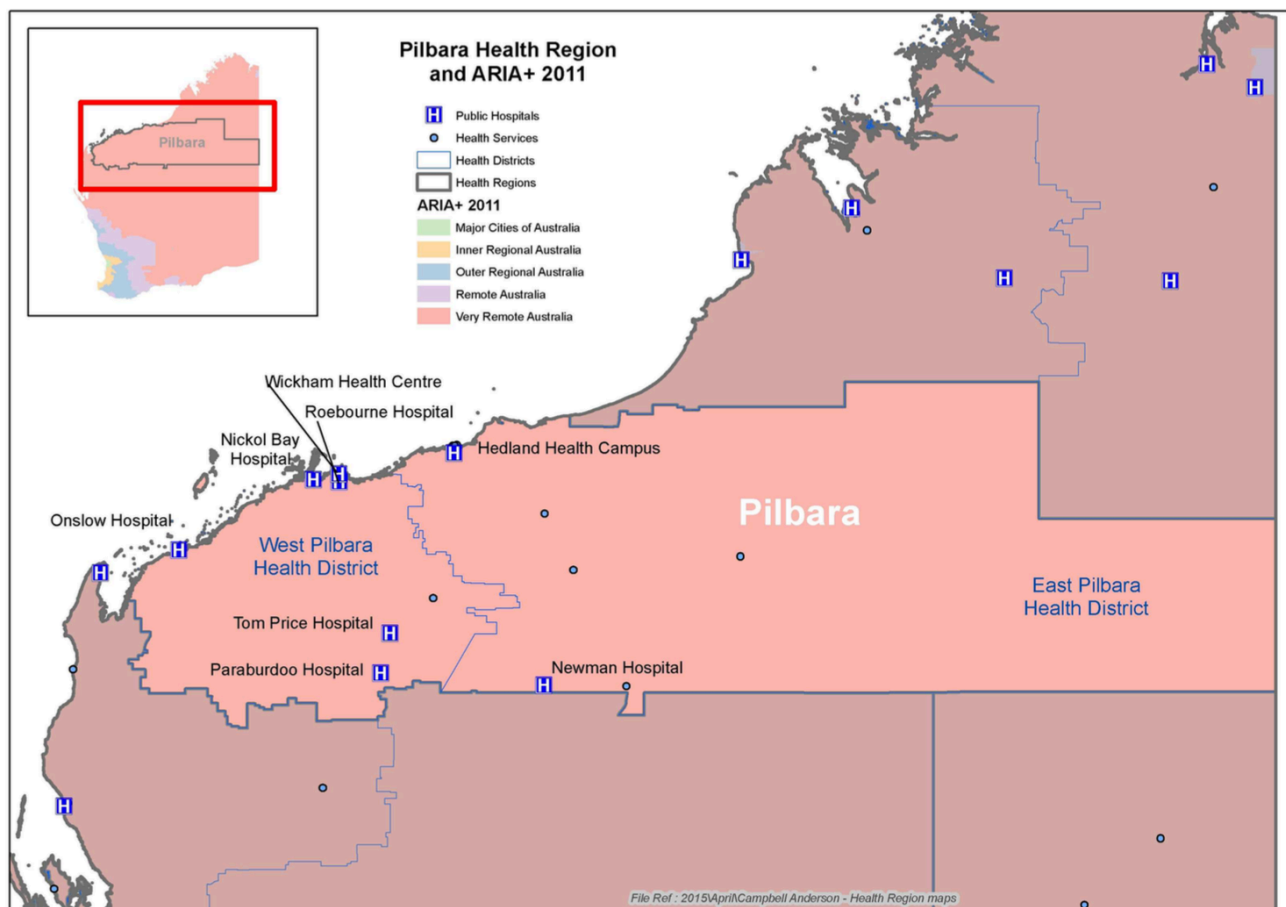


Figure App A.2 Map of the Pilbara showing health districts and relative remoteness (Accessibility/Remoteness Index of Australia) (source: WA Country Health Service. Pilbara Health Profile 2015. 2015. doi:ED-CO-15-5170

Table App B.1. IC-9-CM and ICD-10AM diagnosis codes used to identify hospital admission for skin infections

ICD Code	Classification
Scabies	
133.0	Scabies (Icd9)
B86	Scabies (ICD10)
133.8	Acariasis Nec (Icd9)
133.9	Acariasis Nos (Icd9)
B88.0	Other Acariasis (Icd10)
Impetigo & Pyoderma	
684	Impetigo (Icd9)
686.0	Pyoderma (End 1997) (Icd9)
686.00	Pyoderma Nos
686.09	Pyoderma Nec
686.8	Local Skin Infection Nec
686.9	Local Skin Infection Nos (Icd9)
L01.0	Impetigo [Any Organism] [Any Site] (Icd10)
L08.0	Pyoderma (ICD10)
L01.1	Impetiginization Of Other Dermatoses
L08.8	Other Specified Local Infections Of Skin And Subcutaneous Tissue
L08.9	Local Infection Of Skin And Subcutaneous Tissue, Unspecified
L30.3	Infective Dermatitis
L30.4	Erythema Intertrigo
L00	Staphylococcal Scalded Skin Syndrome
Fungal	
110.0	Dermatophyt Scalp/Beard
110.1	Dermatophytosis Of Nail
110.2	Dermatophytosis Of Hand
110.3	Dermatophytosis Of Groin
110.4	Dermatophytosis Of Foot
110.5	Dermatophytosis Of Body
110.6	Deep Dermatophytosis
110.8	Dermatophytosis Site Nec
110.9	Dermatophytosis Site Nos (Icd9)
111.1	Tinea Nigra
111.2	Tinea Blanca
111.3	Black Piedra
111.8	Dermatomycoses Nec
111.9	Dermatomycoses Nos
112.3	Cutaneous Candidiasis (Icd9)
B35.0	Tinea Barbae And Tinea Capitis
B35.1	Tinea Unguium

B35.2	Tinea Manuum
B35.3	Tinea Pedis
B35.4	Tinea Corporis
B35.5	Tinea Imbricate
B35.6	Tinea Cruris
B35.8	Other Dermatophytoses
B35.9	Dermatophytosis, Unspecified (ICD10)
B36.1	Tinea Nigra
B36.2	White Piedra
B36.3	Black Piedra
B36.8	Other Specified Superficial Mycoses
B37.2	Candidiasis Of Skin And Nail (ICD10)
111.0	PITYRIASIS VERSICOLOR
B36.0	Pityriasis Versicolour
L60.3	Nail Dystrophy

Abscess

680.0	Carbuncle Of Face (Icd9)
680.1	Carbuncle Of Neck (Icd9)
680.2	Carbuncle Of Trunk (Icd9)
680.3	Carbuncle Of Arm (Icd9)
680.4	Carbuncle Of Hand
680.5	Carbuncle Of Buttock (Icd9)
680.6	Carbuncle Of Leg (Icd9)
680.7	Carbuncle Of Furuncle Of Foot
680.8	Carbuncle- Site Nec (Icd9)
680.9	Carbuncle Nos (Icd9)
685.1	Pilonidal Cyst W Abscess
685.1	Pilonidal Cyst W/O Absc (Icd9)
681.01	Felon
681.02	Onychia Of Finger
681.11	Onychia Of Toe
L02.0	Cutaneous Abscess, Furuncle And Carbuncle Of Face (ICD10)
L02.1	Cutaneous Abscess, Furuncle And Carbuncle Of Neck (ICD10)
L02.2	Cutaneous Abscess, Furuncle And Carbuncle Of Trunk (ICD10)
L02.3	Cutaneous Abscess, Furuncle And Carbuncle Of Buttock (ICD10)
L02.4	Cutaneous Abscess, Furuncle And Carbuncle Of Limb (ICD10)
L02.8	Cutaneous Abscess, Furuncle And Carbuncle Of Other Sites (ICD10)
L02.9	Cutaneous Abscess, Furuncle And Carbuncle, Unspecified (ICD10)
L05.0	Pilonidal Cyst With Abscess
L05.9	Pilonidal Cyst Without Abscess (ICD10)
H60.0	Abscess of external ear
H60.00	Abscess of external ear
H60.01	Abscess of external ear
H60.02	Abscess of external ear
H60.03	Abscess of external ear

Cellulitis

681.00	Cellulitis- Finger Nos (Icd9)
681.10	Cellulitis- Toe Nos (Icd9)
681.9	Cellulitis Of Digit Nos
682.0	Cellulitis Of Face (Icd9)
682.1	Cellulitis Of Neck (Icd9)
682.2	Cellulitis Of Trunk (Icd9)
682.3	Cellulitis Of Arm (Icd9)
682.4	Cellulitis Of Hand (Icd9)
682.5	Cellulitis Of Buttock (Icd9)
682.6	Cellulitis Of Leg (Icd9)
682.7	Cellulitis Of Foot (Icd9)
682.8	Cellulitis- Site Nec (Icd9)
682.9	Cellulitis Nos (Icd9)
L03.01	Cellulitis Of Finger (ICD10)
L03.02	Cellulitis Of Toe (ICD10)
L03.10	Cellulitis Of Upper Limb (ICD10)
L03.11	Cellulitis Of Lower Limb (ICD10)
L03.2	Cellulitis Of Face (ICD10)
L03.3	Cellulitis Of Trunk (ICD10)
L03.8	Cellulitis Of Other Sites (ICD10)
L03.9	Cellulitis, Unspecified (ICD10)
035	Erysipelas (Icd9)
A46	Erysipelas (ICD10)
380.1	Infec Otitis Externa Nos (Icd9)
380.11	Acute Infection Of Pinna (Icd9)
H60.1	Cellulitis of external ear
H60.1	Cellulitis of external ear
H60.10	Cellulitis of external ear
H60.11	Cellulitis of external ear
H60.12	Cellulitis of external ear
H60.13	Cellulitis of external ear

Lice

132.0	Pediculus Capitis (Icd9)
132.1	Pediculus Corporis (Icd9)
132.2	Phthirus Pubis (Icd9)
132.3	Mixed Pedicul & Phthirus (Icd9)
132.9	Pediculosis Nos (Icd9)
B85.0	Pediculosis Due To Pediculus Humanus Capitis (ICD10)
B85.1	Pediculosis Due To Pediculus Humanus Corporis (ICD10)
B85.2	Pediculosis, Unspecified (ICD10)
B85.3	Phthiriasis (ICD10)
B85.4	Mixed Pediculosis And Phthiriasis (ICD10)

Other

134.1	Arthropod Infest Nec (Icd9)
134.8	Infestation Nec (Icd9)

134.9	Infestation Nos (Icd9)
	Infestation (Skin) Nos, Infestation By Mites Nos, Skin Parasites Nos
B88.9	(Icd10)

Table App B.2. Number and rate of hospital admissions for skin infections in WA-born Aboriginal and non-Aboriginal children aged<16 years, by region, 1996-2012

	Aboriginal			Non-Aboriginal		
	n	Rate/1000*	(95% CI)	n	Rate/1000*	(95% CI)
Metropolitan Areas						
<1 years	507	46.6	(42.7 - 50.9)	1176	3.6	(3.4 - 3.8)
1-4 years	779	21.6	(20.1 - 23.2)	2697	2.5	(2.4 - 2.6)
5-9 years	408	14.1	(12.8 - 15.6)	1225	1.4	(1.4 - 1.5)
10-15 years	170	12.1	(10.4 - 14.1)	624	1.5	(1.4 - 1.6)
<16 years	1864	20.8	(19.8 - 21.7)	5722	2.2	(2.1 - 2.2)
Kimberley						
<1 years	797	113.3	(105.6 - 121.4)	13	3.3	(1.8 - 5.6)
1-4 years	1189	49.5	(46.8 - 52.4)	41	3.1	(2.2 - 4.2)
5-9 years	587	28.9	(26.6 - 31.3)	27	2.5	(1.6 - 3.6)
10-15 years	208	20.8	(18.1 - 23.8)	9	1.7	(0.8 - 3.2)
<16 years	2781	45.3	(43.6 - 47.0)	90	2.7	(2.1 - 3.3)
Pilbara						
<1 years	373	129.8	(116.9 - 143.6)	39	4.2	(3.0 - 5.7)
1-4 years	508	53.7	(49.1 - 58.6)	88	2.8	(2.3 - 3.5)
5-9 years	184	23.2	(20.0 - 26.8)	35	1.3	(0.9 - 1.9)
10-15 years	71	17.9	(14.0 - 22.6)	17	1.2	(0.7 - 1.9)
<16 years	1136	46.9	(44.2 - 49.7)	179	2.2	(1.9 - 2.6)
Midwest-Murchison						
<1 years	273	73.6	(65.1 - 82.7)	44	3.5	(2.6 - 4.7)
1-4 years	422	33.7	(30.6 - 37.1)	107	2.5	(2.1 - 3.0)
5-9 years	209	21.1	(18.4 - 24.2)	63	1.7	(1.3 - 2.2)
10-15 years	59	12.3	(9.4 - 15.9)	41	2.0	(1.5 - 2.8)
<16 years	963	31.1	(29.2 - 33.2)	255	2.3	(2.0 - 2.6)
South West						
<1 years	25	21.9	(14.6 - 32.3)	85	2.9	(2.4 - 3.6)
1-4 years	42	11.1	(8.0 - 15.0)	204	2.1	(1.9 - 2.5)
5-9 years	22	7.1	(4.4 - 10.7)	97	1.3	(1.0 - 1.5)
10-15 years	11	7.1	(3.5 - 12.7)	45	1.2	(0.9 - 1.6)
<16 years	100	10.4	(8.5 - 12.7)	431	1.8	(1.6 - 2.0)
Goldfields						
<1 years	299	131.8	(117.3 - 147.6)	54	3.9	(2.9 - 5.1)
1-4 years	344	44.5	(39.9 - 49.5)	134	2.8	(2.4 - 3.3)
5-9 years	139	21.8	(18.3 - 25.7)	54	1.3	(1.0 - 1.7)
10-15 years	38	12.2	(8.6 - 16.8)	32	1.4	(1.0 - 2.0)
<16 years	820	42.1	(39.2 - 45.1)	270	2.8	(1.9 - 2.5)
Great Southern						
<1 years	37	41.9	(29.5 - 57.7)	30	2.6	(1.8 - 3.8)
1-4 years	45	15.1	(11.0 - 20.2)	62	1.6	(1.3 - 2.1)
5-9 years	32	12.9	(8.8 - 18.2)	41	1.3	(0.9 - 1.7)
10-15 years	13	11.0	(5.9 - 18.8)	19	1.1	(0.6 - 1.6)
<16 years	127	16.9	(14.1 - 20.1)	152	1.5	(1.3 - 1.8)
Wheatbelt						
<1 years	53	36.9	(27.7 - 48.3)	51	3.3	(2.4 - 4.3)

	Aboriginal			Non-Aboriginal		
	n	Rate/1000*	(95% CI)	n	Rate/1000*	(95% CI)
1-4 years	76	15.9	(12.5 - 19.9)	101	6.1	(1.4 - 2.2)
5-9 years	37	9.7	(6.8 - 13.4)	65	1.2	(1.1 - 1.8)
10-15 years	7	3.9	(1.6 - 8.0)	49	1.0	(1.4 - 2.5)
<16 years	173	14.6	(12.5 - 17.0)	266	1.9	(1.6 - 2.1)

† Any mention of skin infection in the principal and additional diagnoses fields.

*Rate of hospitalisations per 1000 child-years, WA, Western Australia

**Factors impacting on health service utilisation for skin infections
in a remote region of Western Australia.**

Supplementary material: a structured compilation of quotes

The quotes are organised according to the health service utilisation matrix and the various themes that were categorised in that matrix. The header included on each page shows which factor of the Andersen model (predisposing, enabling, need) and which level (client, provider, system) the quotes on the page are in relation to.

Within each theme, quotes are printed in the following order: parents/carers ('C'), healthcare practitioners ('HP'), other service provider ('OSP').

Names mentioned in quotes are aliases. Quotes are ascribed to one of the three participant groups (parents/carers, healthcare practitioners, other service providers) and not individuals for anonymity.

Quotes provide an overview of the range of attitudes and perceptions that were captured regarding the various themes documented in the health service utilisation matrix. They are reflections of an individual's opinion and do not represent the opinion of the authors. We have strived to provide a balanced and honest representation of the views expressed.

Unless specified otherwise at the start of the quote, quotes about health services are in reference to community AMS services and staff.

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

Shyness & shame

(discussed by C, HP, OSP)

"People get shame with the sores. You know they don't like to show anyone they have them." (carer)

"Some get shamed [going to the clinic]" (carer)

"[in reference to mainstream health services in town E] All the health staff have so much judgment when we go into the clinic. They judge us and wonder why we haven't taken them [our children] in earlier." (carer)

"[in reference to mainstream health services in town E] The main problem is the shame and judgment going to the clinic. [...] The staff at the clinic think that Aboriginal people carry disease. They think 'oh not that black disease-carrying person again'. That's why the Aboriginal people don't want to go to the clinic." (carer)

"Nevertheless, there's a shame factor involved, and that will probably contribute to people not coming and seeking out help. In communities where there's a good relationship between the nurse they'll come at an early stage for treatment, and again in communities where there is no good relationship then people will not come even if it's uncomfortable perhaps." (healthcare practitioner)

"Probably depends where the mother lives but if it's in the middle of the community some of them get shy to walk through the shops and come here to the clinic." (healthcare practitioner)

"But I still believe that just generally speaking, we may not... compared to-- Aboriginal people, there's a lot of shame factor about body image and body sexuality and stuff. They're quite modest [...] when it comes to showing their body or anything to do with their body, they are self-conscious. [...] Yeah, anything to do with illness and disease is shame. I hate that word, but it's a word that's often used. You can get that with people that you want to put on insulin. Not only is that shame, it's seen as a weakness. And sometimes people hide things and they won't come out because of that." (healthcare practitioner)

"People are very private, David. Some people, they won't walk up to you with a Webster-pak in their hand. You have to put it in a brown paper bag." (healthcare practitioner)

"[comment in relation to skin sores] Shame is a big thing here too I think. I have heard the mums say that before." (other service provider)

"[in reference to children going to school in town E] Some of the kids I see, they won't leave the house because of the embarrassment of it. The sores. When they're really visible, they have them on their feet and around their hands and that, they don't want to go to school because the shame, and kids make fun of them." (other service provider)

"But also there's special issues. There's men's business and women's business and then they're all shamed. [...] They're generally comfortable with the normal ear ache, that sort

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

of thing, anything personal - I suppose if I could put it - they are hesitant to come.” (other service provider)

“Because I think there’s a lot of shame, like that’s a really big part of their culture, Martu culture here is shame. So being embarrassed or... Or whatever the English word would be, because in their culture they don’t talk about pain and those sorts of things, so... You know, it’s gotta be something like, you’re almost dying to go to the clinic. [...] I don’t think they’re ashamed of the sore itself. They’re ashamed of feeling pain. Or maybe ‘shame’ isn’t quite the right word, but it’s not... You know, it’s not something to be open about. Like, if you’re a tough person, you don’t feel pain. More that kind of attitude.” (other service provider)

fear of judgement, incl. DCP&FS (Department for Child Protection and Family Services)
(discussed by C, OSP)

“[in reference to mainstream health services in town E] All the health staff have so much judgement when we go into the clinic. They judge us and wonder why we haven’t taken them [our children] in earlier.” (carer)

“[in reference to mainstream health services in town E] The main problem is the shame and judgement going to the clinic. [...] The staff at the clinic think that Aboriginal people carry disease. They think ‘oh not that black disease-carrying person again’. That’s why the Aboriginal people don’t want to go to the clinic.” (carer)

“[in reference to mainstream health services in town E] But you can’t stand up for yourself or tell the staff that they’re being rude cos they will just kick you out, not give you the treatment, and call the police.” (carer)

“[in reference to mainstream health services in town E] The judgment. Yeah, the judgment. He said when he went and got his head done one of the nurses was nice, but the other nurses were... you know sarcastic and throwing a few things around that he knew what she was trying to say in a roundabout way. And he thought, well, if I have to put up with that then why bother going back. I said “You could just be oversensitive” I was trying to get across to him, I said “You could be taking it all the wrong way, they’re not meaning anything by it”, but... yeah... we’ll have to wait and see.” (other service provider)

“And then of course there’s others that are still a bit weary because of the welfare issue. Just too scared to take their kids in because they are worried about the judgement and harshness from the doctors, welfare, things like that. [...] That’s their biggest fear. And I’ve tried to get across to them that if you take your child in when they are sick, they can see that you are trying to do the right thing by your kids. And so they would be going “well we don’t need to get involved, because you do all this regularly and are making sure your child is ok”. Instead of sitting back and waiting for the sore to get so bad. Some of the cases I’ve seen are just ridiculous. And I don’t have to explain to you that massive big sores -you know- their hands are covered in sores and I’d be soaking them in [unclear] and just scrape the skin off to get to the gross bit. I said “If you turn around and you get in early, you won’t have that problem, but if you get to that point then the kids get so sick you have to take them, it’s a welfare issue, because you’ve neglected them,

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

you haven't gotten them in soon.". I say the same thing to –and I was trying to explain to them- it's the same thing for me. I said "I got told off myself because my daughter's boil got so big", I said "I tried absolutely everything and then finally thought well, ok, I'll take her to the doctor's and the doctor told me off for letting it go for so long.". So it's a... I said "It's just the way it is." and I said... well, I guess up here it's just that bit more... they are very harsh with their speech. [...] I spoke to a lot of the mums there. They all talk about Stolen Generation happening all over again. You take your kid to the doctor and before you know it they'll be knocking on your door the next day. And it's like... It's very sad." (other service provider)

traditional remedies & self-treatment

(discussed by C, HP, OSP)

"[commenting on the use of bush medicine for treating skin sores] We use those gum tree leaves. And we boil it and then put it on the sores in the bath and it makes them dry and it goes away." (carer)

"We get normal leaves from the trees boil that up and get the leaves out and use what's there to wash it with. It works for sores and rash and boils." (carer)

"I treat the kids with dettol and dress the sores." (carer)

"...the betadine cream when you put it on it dries and gets healed." (carer)

"Mostly I buy stuff from the shops. Medicated soaps and medicated bubble bath to treat my kids." (carer)

"Sometimes when they [skin sores] get worse and worse I get them the medicine soap." (carer)

"They smoke the houses and they use bush medicine. I mean, I've seen some horrendous wounds and boils that have had bush medicine on them, and they come in, and they nearly lost a foot or... Because they've not been... they've not come to the clinic. While a course of antibiotics may have prevented it. I say 'may', don't know. It's one of those things, you don't know. But the... White man's medicine and black fella stuff can work in conjunction. But they... I don't know... Some of the older people believe that older medicine is the way. And you can still talk to them. The ladies will go out and come back with bush medicine and stuff. And it seems to be that they only come in to the clinic when it's not working." (healthcare practitioner)

"I think there is a real appetite in the community for traditional bush medicine here in [name of community], being quite a tribal community. Interestingly, our new health teacher made the suggestion of creating some traditional bush beauty products, and the Aboriginal staff were very interested. I'm sure I could see this being linked into traditional bush medicine, in addition to the western medicine." (other service provider)

"Yes. I do think that bush medicine is absolutely critical, and I think they should be working at tandem with the clinic to co-share, and that suggestion was also put in [name of town], because people were fearful of going off on the plane, and never coming back, and being taken off to hospital." (other service provider)

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

"They use bush medicine before going to the doctor. It's the same in New Zealand, the Maoris take 'Rongoa' - it's the New Zealand medicine, they take this before going to the doctor." (other service provider)

negative past experiences with clinic (discussed by C, HP, OSP)

"The clinic doesn't ask us if we want a choice- they only give the needle. They don't ever give us the syrup." (carer)

"[in reference to mainstream health service in town E] All the health staff have so much judgment when we go into the clinic. They judge us and wonder why we haven't taken them [our children] in earlier." (carer)

"Some just make a dressing and don't do anything eh. They just say come back tomorrow and don't do anything." (carer)

"[in reference to mainstream health service in town E] The staff just gave me Panadol for my sores. Then it got really, really bad." (carer)

"I mean, these kids, alright... If you stick a needle in them... There's one little girl who's terrified... Comes in the clinic, she sees a white face, she bursts into tears. You know? She's had LA Bicillin three times. It hurts. It's not a pleasant thing to do. To have, let alone do. And you know when this kid looks at you, the first thing she thinks is "You're going to stick a needle in me." You know? Straight away. So they're going to avoid coming. And as they get older, they're going "I'm not going there.", that's what's going to happen. So... yeah, LA Bicillin is a really good drug. Penicillin works wonders up here. You know... works wonders... Procaine... Wonderful drugs. But getting it into them... They know what you're going to do and... it's very difficult sometimes. And to hold a child down and inject a child... until you've done it, you don't understand... 'cause I've got kids... I've seen my children... Thankfully my kids have never had to have LA Bicillin or Procaine, you know. And I know how I would've felt... But... As these kids grow up, they only see themselves with these sores and they know a white fella is going to stick a needle in them because mum won't clean the sores and won't give them the medicine that she should." (healthcare practitioner)

"[in referring to mainstream health services in town E] I'm hoping she'll come back today for her boils, but... There was just no way of getting her any type of help. And she would not go to the hospital, because they give that... something bicillin injection, some sort of... you know what I'm talking about? "I don't want to go there, they give you a needle". We tried to get her in the car. She was ready to run even though she was sick as a dog. And I thought it's better for her to be here sick as a dog than running and something happening. So in the end I just... put her in bed and helped her through it. She was... She was really unwell. Seeing sick kids, but she was scary sick. If you saw her, it was ridiculous." (other service provider)

"Going to the clinic is a big thing, and if you get turned away, you're like, "Oh well, I might not come back."" (other service provider)

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

“[in reference to mainstream health services in town E] I’ve got a young bloke that’s coming over here at the moment, he’s 18. He burnt his leg on the exhaust of a motorbike. I finally talked him into going to the hospital. And when he unwrapped it, it stank to the high heavens, and they had to hold him down and do some sort of scrubbing. I wasn’t allowed in to watch, but they were -from what I can understand- scrubbing it off, cleaning it and then doing whatever they do for burns, and now he’s coming here and expecting me to keep the treatment going because he doesn’t want to be going to the hospital again.” (other service provider)

“[in reference to mainstream health services in town E] And I know, a couple of times if I’ve been there with a child, I haven’t always gotten the greatest reaction. [...] You know, where... I can give you an example. So one of the kids was playing on the oval and... Like just knowing the kids really well, you know when something’s serious. Otherwise you’re just like “Ok, alright, come on, you’ll be alright.”. So we took one of the kids to the clinic, and the nurse was just closing up and said “Oh no, he’ll have to wait until another day.”, didn’t even look at what we thought was something wrong with his ankle. And then it was the weekend. I can’t remember exactly how it happened, but basically it was a few days before he got it looked at. And then... when it was looked at, he was flown out... with a suspected broken ankle. It wasn’t in the end. It was... torn something, I can’t remember exactly. So it was obviously quiet serious, but I guess when you get that response you sort of start to lose trust.” (other service provider)

“I have brought a lady to the clinic before for a full body check-up. They wanted to do them, and they had-- I’d spoken to the nurse that I could round some people up and bring them in. That consisted of I spoke to the women and said what it involved, like hopping on the scales, measuring their waste, looking at eyes and ears, and asking some questions. I used my relationships with them to bring them to the clinic. We got there, and we were turned away. The nurse was busy. It was just wrong timing, and it wasn’t a good experience for the person.” (other service provider)

apathy & disempowerment (discussed by HP, OSP)

“I think that on a scale of priority, health comes at the bottom simply because it’s not anywhere different in any part of the world. If drug and alcohol issues, nutrition, family issues, domestic violence - all of those things - money issues, and grief, their position in the world, their place in our society, really that’s-- most people out here would be confronted with personal life traumas as stress factors that most of us really only maybe experience every ten years or five years. But they’ll do it in a year. A grandmother that has to look after four or five little kids, doesn’t get any financial aid, hardly can feed herself, her health is down there somewhere in the bottom [of priorities]. There’s a powerlessness there where I think that people are just-- there’s a kind of a, not giving up, but resigned.” (healthcare practitioner)

“We’ve had a couple of cases where these kids are really covered in stuff and they should be up at the clinic and they haven’t been. It isn’t really our responsibility to take them up there but do if we have to. If something happens at school like a cut or whatever, we fix that up and take them up there and that sort of stuff. Basically there’s a bit of apathy around in terms of health.” (other service provider)

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

“Apathy. I believe it goes hand in hand with the handout mentality. So, you don't have to do anything because someone will look after you somewhere, whether it's giving you a car, or giving you money, or giving you free medical, or coming to pick you up from your house because they've heard that you're sick. I believe it's the hand out mentality.” (other service provider)

“We want the black fellas to take responsibility for themselves, but we just keep doing it for them. You can't sit back and watch a kid hurting, or a kid you know that they've got to go to the clinic, and you can't sit back and expect parents to do it, because half the time they won't. You step in and do it for them, which takes away from the parents, “Oh, well. The white fellas will do it for you?”” (other service provider)

priorities, values & norms – health & child rearing

(discussed by HP, OSP)

“The parents don't seem to have the same... And I can't generalise here. Some parents are wonderful with the kids. It tends to be the grandmothers more so that tend to be looking after the young fellas and young girls. But, there are families where the kids are just left.” (healthcare practitioner)

“For them, it's priorities. This week there are 2 funerals and everyone is out of town. These are the barriers [...] They prioritise things like holidays and funerals.” (healthcare practitioner)

“I think it's partly because their parents-- it's partly back to that child-rearing stuff that children are so super-independent that their parents don't necessarily know what is going with them all of the time. To the outside world, that can look like neglect sometimes, and to an extent, it might be. But it is partly cultural that children are super-independent and that they be risk takers and they do things for themselves [...] that's a part of their learning process, it's a part of their spirituality.” (other service provider)

“Yeah, I can't articulate it as well as I'd like to, but it's that thing about that whole connection - the whole community raises the kids. To the outside world, that might sometimes look like neglect, but actually there is a notion, an instilled sort of thought, that the whole community will care for the kids regardless of who they are and where they're wandering. [...] Just that empowerment behind children being really independent and that's how they grow. And I guess, more than anything, is that spirituality. The Aboriginal way of being, that spirituality to their family, to their community, to themselves is quite special and that in an early childhood setting in a mainstream world, that gets missed” (other service provider)

“Because there's no word for tomorrow in Martu you can't explain what will happen. When you tell them that their runny nose and that the germ that does that is the germ that affects the kidneys and later on in life they'll be looking at kidney failure or renal dialysis's, they don't look that far ahead. It's today. It's for now.” (other service provider)

“The parents only think about trying to feed their children they don't think about their sores. [...] The structure of the family goes father then mother then children so treating children is the last priority.” (other service provider)

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“cos they’re lazy, cant get up, don’t want to go to the clinic. That mob! We tell them over and over again to ‘take your kids to the clinic’ but they just don’t wanna go. We say to the kids ‘get mum or pop to take you to the clinic’ and they say ‘no they won’t take us’ they always say that. So what can we do?” (other service provider)

“There is a child who is covered in sores who got flown out of [name of community]. It’s just neglect. The parents are non-compliant [...] I am really quite concerned about the health here because there is not enough to follow it up. And there is not enough interest by the parents.” (other service provider)

“So, I’m sure there are some parents and grandparents that would step up a bit more if they had that knowledge or if they were there with their children. Some of them are just busy because there’s so many other kids in the house, that one or two kids can be kind of overlooked or don’t get the necessary attention. I just know most of the children here have family units that have at least four up to ten kids in one house and that’s busy.” (other service provider)

“Even the young kids. Once they can walk and open the fridge door or open a cupboard door, they’re on their own. While they’re babies they’re very well looked after. Once they can toddle they’re on their own.[...] you’ll see certain babies are spotless. I don’t know how they keep them that way but as soon as they learn to toddle and they’re off and racing, they’re left to their own devices.” (other service provider)

“These kids are brought up to be independent from a very early age. I think, again, what surprises me - and I don’t see it as much in this community - but often the older ones [children] look out for the younger ones. So it’s the kids bringing up the kids in a way. I have one of the girls who’s just in my class, and she’s got a little one, a little niece, but because it’s her sister, she’s also classed as mother. So she can take the role of mother and look after this little one.” (other service provider)

cultural taboos

(discussed by HP, OSP)

“Also, understand from the cultural point of view how Aboriginal people think and do things. Mostly they are not... They feel ashamed to be outspoken, or to be heard, or anything to link something about them to anyone, because of... community and skin group and family connection. Sometimes an Aboriginal person will come to a clinic, they’ll find an in-law... and they will say “Oh, look, I’ll come back later.” – “No, no, no.” If you don’t understand [that reaction] and [insist]... “No, please, come in!”. No, no, no. Just let them go. And then they might realise “Oh, that’s an in-law in the other room. They knew he was in the clinic. So they wouldn’t be able to speak”. If you are not aware of that, you’ll be like “Oh, what’s wrong?”” (healthcare practitioner)

“I would see [name of female] come to the door at the clinic, look in and walk out. And then she would do it again and again. It wasn’t until I twigged, oh [name of male] is in the clinic and she’s not allowed to be in the same room as him. It’s their culture [...] The nurse can’t do certain things because her elderly uncle is too close to her. Because it’s disrespectful in their culture. That tradition is born in them, it will never go away.” (other service provider)

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"With the strength of the tradition of the culture here though, someone from this community being the nurse would be inappropriate, they wouldn't be able to treat probably three or four skin groups, and they wouldn't be able to-- Umaru, mother-in-law for example, so all these familial relationships and skin group relationships, that's a huge factor in coordinating anything." (other service provider)

"Mr Jones, who is a prominent figurehead, patriarch of the family, was heading to the clinic. and Margie was down there-- she's a really short elderly lady, she was inside the clinic, and Mr Jones opened the clinic door to see her about to walk out, and he literally - he's getting on a little bit, but he's still fairly fit - closed the door and ran from the clinic to the office and went around the corner, and it was hilarious, and I've sort of looked-- that was my first, I didn't know about Umaru, those kind of rules before that. So funny stories but in terms of health I think they just wait until they come out of the clinic, I don't think there's a-- I wouldn't say that's a detriment to health service or anything like that." (other service provider)

tolerance for discomfort & pain (discussed by HP, OSP)

"Because, you know, it's being a sook to report pain. It's being a... Suck it up. Be a man. A man should not cry." Or such things. So... being tough... That's why you find even health checks are very low on men, for a simple reason: men don't go easily, you know. Woman should go, 'whinge' and you know... But men, no. They should suck it up. They [boys] should not even cry. If they fall down and stuff like that, let them suck it up." (healthcare practitioner)

"They're extremely painful [referring to skin sores] but these kids never, ever complain. You can be damn sure if a Martu kid comes to you and say, "Miss, I'm paining" they're in agony because they just don't complain. But I've seen kids with boils in here and on their knuckles so they can't move their hands, they can't hold a pen, they can't write. Kids with boils on their bums. [...] You never get a Martu kid coming up and going, "Oh Miss, I've got a boil," like you do with the little white kids." (other service provider)

"And then the kids walked around here, and you say "Does that not hurt you?" No, it's all right. I thought, gee. What? You must either have a very high pain threshold or there is something very wrong. But for them it seems to be that's life." (other service provider)

"They don't, they really don't. They really don't notice the burden of it. We have kids with gaping sores and they don't notice it." (other service provider)

"I don't think they're ashamed of the sore itself. They're ashamed of feeling pain. Or maybe 'shame' isn't quite the right word, but it's not... You know, it's not something to be open about. Like, if you're a tough person, you don't feel pain. More that kind of attitude." (other service provider)

"And I've had children that are coming to school but not being able to sit down because the boils on their bottom is so severe, and whole armpits full of boils. It just puts tears in your eyes. It's like, "Oh my goodness, you need to be somewhere away from me that has pain relief," be resting. But their tolerance, their pain threshold is so phenomenal. [...] They'll have ear infections that I've seen that just have, not so much pus, but just like

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watery stuff. And I was like, "Is that sore?" "No, no miss." Me, I just get a paper cut and I'm in tears. Their pain threshold is phenomenal, and I don't know if that's because if they cry no one comforts them. It's a real put up and shut up type of thing, and that's not okay. But if they don't want to do their counting by hundreds, the whole world will fall in. It's kind of funny that if someone teases, the real tears come out; but if they need stitches, they're fine with it." (other service provider)

lacking (health) education (discussed by HP, OSP)

"Well... I mean... Lack of education, of school early on. But you can only teach a child so much." (healthcare practitioner)

"[in reference to the interviewee's experience of working in a location in rural Victoria] Oh my God, those people, no wonder they live long man, no wonder they live long. Because they follow what you tell them. These are the people that you do a care plan, and you give them a checklist "We've done your bloods and your parameters are like this. Please in March come, so that we check, we do the bloods again and check what has happened.", You know what? They'll come. You know? So they'll call you! "Oh [name of interviewee], it's that time again. I'm coming." [...] That's how much more advanced and better, you know, it is. I did all these things for a year, the second year they were calling me. Just give them, you know, reminders or checklists. They own their health and now you, you just facilitate it. But look these are people who are educated. So they know the importance of keeping their cholesterol in check, their weight in check, vitamin D issues, prostate check every year, pap smear, mammogram. They know, so they've embraced prevention, you know, as a way of life. But you know what? It took them years to... You know? Now, I enjoyed that, because I could see that what I was doing was bringing these results to people, right? And then they own it, ok?" (healthcare practitioner)

"And the education - even though the kids are here to get an education - but a lot of the families are uneducated" (other service provider)

"I think, again, it's education. It's not knowing that it's bad. I think many of them if they actually understood what it is and what it's all about will take far better care of their kids. But they just don't know. They're uninformed. So, that's the way it's always been." (other service provider)

language barrier (discussed by C, OSP)

"[in reference to mainstream health service in town E] They [healthcare practitioners] also expect us to know what they're saying, like they talk down to us you know. They use all this doctor talk and I don't have a clue." (carer)

"90% of the nurses over there they don't understand Martu. They have got no idea what they're saying. I took a girl over to see a doctor and the doctor had been here 15 years and I had to translate for them. There is a big major language barrier. The staff won't break it down to simple language [...] But the Martu people will say they understand."

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They will nod their head to the doctor and say they understand even though they don't."
(other service provider)

"I think language is a massive barrier for a lot of people. Just one example was one of the ladies from the communities was diagnosed with a brain tumor and they flew her to Perth pretty much straight away. I went to visit her when she was in hospital, and they were talking to her about all these things like chemo and operations. She's just going, "Yep, yep, yep." And then she'd have another person come in and tell her about five different things. She's going, "Yep, yep, yep." I'm going, "You guys have to explain to her what it is that you're doing. She's got no idea. She's terrified." Language, I think, particularly is a big issue with Aboriginal people accessing health services, clinic services, just because they're worried that they might not understand or that the language will be too difficult for them to cope with when they get there." (other service provider)

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Prejudice

(discussed by C)

"[in reference to mainstream health services in town E] All the health staff have so much judgment when we go into the clinic. They judge us and wonder why we haven't taken them [our children] in earlier." (carer)

"[in reference to mainstream health services in town E] The main problem is the shame and judgment going to the clinic. [...] The staff at the clinic think that Aboriginal people carry disease. They think 'oh not that black disease-carrying person again'. That's why the Aboriginal people don't want to go to the clinic." (carer)

"[in reference to mainstream health services in town E] The staff at the clinic are racist. The mums want an Aboriginal worker there not a white person." (carer)

Stressors associated with work environment

(discussed by HP, OSP)

"Challenging... not because of being busy, but because of remoteness, loneliness and isolation. The isolation there really is heavy because... basically you know the next doctor for your support is 900km away. The next community is [name of other community]. It's also in the middle of nowhere. So basically you are very far, you really feel it, you're very far, there's nothing, very few people to talk to. And during the festive season, like now, everyone goes over heat. It reaches up to 55 degrees there. They leave the community. So sometimes you are only two [people] in the community." (healthcare practitioner)

"There's a... The doctor that used to be there had this... He'd instilled in the people that they could come any time they want [to the clinic for medical attention]. Any time of day, or night, and they'd bypass the nurses and go straight to his house. What that's caused for the nurses that are there now is that people just rock up at any time. The clinic closes at 5pm, yet you'll have them wandering in at twenty past five expecting to be seen and saying "Well, [name of previous health worker] told us to come. We can do that.". That's a real issue. I tried to clamp down on that, saying "Nope. Emergencies only.", but I don't think they understand an emergency doesn't mean "I've got an ingrown toenail or headache." (healthcare practitioner)

"A lot of pressure on the nurses. On call. Long long hours. I did a... 11 o'clock in the morning, to 2:20am the following day shift. We're supposed to be paid... The remuneration we get is supposed to cover the hours that we do on call. No way, no way does it match up to the amount of hours that you obviously do for what we get. That causes a lot of consternation among the nurses, because... We've all got a life. I don't live there to work 24/7. I'm not... Albert Schweitzer. You know. I go out there for a reason. I have a partner, I have a mortgage." (healthcare practitioner)

"Yeah, of course, yeah, because there's a lack of exposure. I'm here on my own. That's my judgement only. Let's say it'd be two people working here. You'd more often go ahead, "What do you think of this?" [...] It's not that we need to be monitored and don't know what we're doing, but I do feel that the more remote you go, the less-- not accountability but you're are a bit removed sometimes, and sometimes it does-- it's even in hospitals and

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not even in remote communities. I've seen it in regional hospitals too where I was gobsmacked how sometimes things are diagnosed, and picked up or treated. More so when you're out here because there's different logistic issues here. You want to treat as much in the community as possible because trying to get people to hospitals-- or your clientele, you transport them to town to attend a cardiac appointment, and then you don't see them for two months because they get on to it. We're constantly having to weigh the benefits against the-- what's the opposite of benefits [laughter]?" (healthcare practitioner)

"Then again the upside or downside is that the mob think the nurse is there for 24 hours a day, and they'll knock on the door at 11:00 at night for a headache tablet, which they've had all day, and you can understand why nurses would get pretty pissed off. Yeah go away, come back tomorrow morning. I'm closed from 12:00 till 1:00, it's my lunchtime, come at 11:30 not 12:30. But the mob don't have any concept of time. I've got a problem then I have to go and fix it, now. Preferably yesterday. That's just the mob. We don't see that at the school, because we're not being hassled, if you want to call it hassling. But as a clinic, I suppose they have to make a call whether it's life threatening or not." (other service providers)

jadedness/frustration (discussed by HP)

"It's very difficult, because you try to educate people in diet, and smoking and grog. But they're all things that they just... do what the hell they want. They smoke, they drink. When they come into town, they binge, and they eat crap food really. They don't eat good food. And I... Sometimes when I... The amount of time and effort that I put into actually educating the people on what they should eat, it just seems to go straight over their head." (healthcare practitioner)

"It's very difficult, when you're... It's like, you start something, you get it right and then... A month later it's back again. It's just... They've not learnt the reasons behind why they're becoming ill. And I'm a big... You know... What's the word I'm looking for now? I... I believe in ownership. I won't spoon-feed these people. You can only do so much for them, and ownership of their illness is something they have to do. I couldn't go to my doctor and say "I want this, this and this.", and they'd go "Right.". They would say in the end to me: "Mr. [surname of interviewee], you can't come again. We're getting nowhere here. You have got to take ownership of what's wrong with you." (healthcare practitioner)

training/knowledge gaps (discussed by HP, OSP)

*"Yeah, yeah. Because none of us were really given that much cultural... sort of understanding, before... up until about a year, but I was given nothing... that was a huge, huge shock for me.
" (healthcare practitioner)*

"The health staff are learning as they go. It is not any disrespect to the doctors or nurses [...] It's a difficult injection to give [in reference to BPG] but it depends on the nurse

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giving it. It just depends on your technique and training. Some of them are pretty rough up there [...] The nurses don't do the 12 months additional training where you learn the culture, learn the ways. And that is important. This is going to become un-stuck soon because they don't know who is allowed in the clinic." (service provider)

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reconciling traditional and modern medicine

(discussed by HP, OSP)

"In some communities where there's a lot of strong elder people that still practise Maban, or bush medicine, I can almost guarantee you that they would've seen a Maban before they've seen me, or it's part and parcel. They coexist, and we don't acknowledge that enough. I know that in some other parts of Australia, it's starting to involve it more. But in these parts here, I find that almost unbelievable that as an Aboriginal health organisation we are not encouraging Aboriginal healing side by side in our practise. Because it's happening anyway. I know they're highly protective of it, so it's not just because we don't acknowledge it. [...] I think that there is another avenue for us to maintain their culture by encouraging that, so young people feel they want to go down that way. I mean, it happens irrespective of us, not that we're training people up for that. Maybe it's happening in a healthy way? I certainly worked with people on that level, and have let the people use the clinic for use of Maban, and I've seen it practised in front of me. And that again comes down to whether they trust you. Whether I believe in it or not is irrelevant. If you really want to be effective in your practises then you also have to acknowledge that that part also plays a part whether it's placebo or does have an effect."
(healthcare practitioner)

"One time I was called into a home. This woman was really sick, but not sick as an emergency, So... I go there. After reaching there, they say "Look, she's been bewitched. By so and so. In Jigalong, yeah. She's been bewitched. So we've brought our medicine man." Just doing stuff. "Once he's finished then you can do your stuff." Basically she had infection. So she had infection. She had all these sores which she did not treat, and then she got a fever and stuff. She was dehydrated. The first thing she needed was rehydration, put on a drip and stuff. From the medical point of view I'm like "Oh, look you guys." -sunken eyes and that- "I know what to do. But because you've said she's been bewitched, and you are doing something...". I thought "30 minutes of them doing that will not change anything really.", so I waited. I sat there. Waited. He was there, doing his stuff. I was like "OK. I will just sit here and wait, and once he's finished, then I'll take her to the clinic.". So I sat there. And then I went with the... You know, another nurse "Oh, that's bullshit, common man! Just tell them that's bullshit, then we...". I'm like "No no no no.". Respect their view and respect... You know. So look, it's that kind of respect which they really need and when you do it that way, you'll find that you'll gain their cooperation. Don't say "No, me I know it all.". You know from the scientific point of view, they know from the spiritual side, you can't argue with their spiritual issues. Those are entrenched beliefs of health from the time... So you are not there really to change that. And then after that we got the patient, rehydrated her, pumped her iv, she was ok. But, you know, the next day when I met them "You see, now she's ok. The JuJu man did it.". But me, clinically I know that, look... But "Yeah yeah yeah." You know?"
(healthcare practitioner)

"We had a young girl in clinic... psychotic, drug screwed, been smoking cannabis for a long time, took lots of different other... head-fuck pills... and she came in -she was obviously having a psychotic episode- but the mob brought this 'Nungkari' down from somewhere to take this... spirit... there was this spirit that was chasing her from somewhere. Olanzapine sorted it out. Diazepam and Olanzapine... stops the delusional state. They thought it was the Nungkari coming in, take away this spirit. So they still have their own ideas. They wouldn't... They couldn't accept that what was happening to her is in here (points to head). It wasn't a spirit thing that was coming to get her from

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Headland. It was in her mind. But... Yeah... I mean things like that... They smoke the houses and they use bush medicine.” (healthcare practitioner)

“It’s like... Feng Shui and acupuncture and all those things you don’t know about. Are they happening? Is it real? Or in somebody’s head? Are these things... I’m not an expert, I don’t know. I do believe the power of the mind is wonderful, wonderful thing. I’ve seen positivity work in cases of people with cancer. I’ve seen it happen. And I’ve also seen the other side happen, where they say “Oh, I’m fucked, I’m going.”. And they sure as shit will go. So I can’t say “That won’t work. That won’t work.”. The way I try to do it is say “Well, look, yeah we’ll do that, but in the meantime we need to try this as well.”. And then I won’t say to them afterwards, if they get better “Hahaha, yours is shit, ours worked.”, you don’t do that, because you’ll only ostracise yourself from the mob by doing that. You say “You see, it works. It both works. The Nungkari came, away went the spirits.”, when really it was the Diazepam and Olanzapine that did it. But you don’t say that to them. You let them believe that, because that’s their belief. I’ve got no right to say to them “No, that’s shite.”, because I can’t say that. In all honesty, because I’ve seen it work. I’ve seen Nungkaris come in, I’ve seen how it happens. I suppose it’s like therapeutic touch. A mother can get hold of a child that’s crying, kiss its knee... and it stops the pain. It’s gone. The child believes mum has taken it away, so it’s gone. So... that’s the same sort of thing that could be happening here. I don’t know. Greater minds than mine have tried to figure this out. You know? What... There is a place for it... As with everything, with all alternative... Well, we call it alternative, to them it’s just their medicine, you know...” (healthcare practitioner)

“We had a serious problem on one night - was it Friday - when one child came here and said “Oh no, there was the monster last night at this woman’s house and it attacked the old lady and--”. They are still very much into these spiritual and the supernatural and that stuff. She thought the old lady got attacked; there an attack. She actually came back here in the evening and she was like-- and we get her on the plane and so on and so. We still haven’t got the full information, but it was a medical condition, a stroke, or whatever the case may be.” (other service provider)

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low costs associated with medical care

(discussed by C, HP, OSP)

“I usually go to [name of community] [from town E] to get the cream because I can get it from the clinic for free.” (carer)

“[in reference to mainstream health services in town E] My son had 3 appointments in Perth but they didn’t want to pay for their trip and I can’t afford that much.” (carer)

“Thank God they don’t have to pay! If they had to pay to see a doctor here, by Christ, you’d have such a high mortality rate, or people losing limbs, if they had to go pay a doctor. You know. It just wouldn’t happen.” (healthcare practitioner)

“[in reference to mainstream health services in Town E] Free for children, under a certain age. I can’t remember how low it is, but it’s free for the children.” (other service provider)

“It’s all about money here. I know how much the creams are, I buy them myself, they are \$20 each, so the mums don’t spend that much to treat them.” (other service provider)

“[in reference to mainstream health services in town E] That’s the other problem, it is expensive to see a doctor in this town. It’s \$90 for adults, it’s free for children. [...] My husband’s Aboriginal, he still has to pay the \$90, unless he can present a healthcare card or something like that. And a lot of the Aboriginal people don’t carry their healthcare cards on them, so it’s pay up and then you get to see a doctor. And that’s why... ‘I don’t have the money’” (other service provider)

access to ‘Closing the Gap’ benefits

(discussed by C, HP)

“[in reference to mainstream health services in town E] They don’t put the ‘Closing the Gap’ anymore on the script. If you ask the doctor to write ‘CTG’ on the script, they will say ‘nah we don’t do that anymore.’ They just think all the black fellas are stupid and are trying to rob you.” (carer)

“[in reference to mainstream health services in town E] Even here they do this closing the gap scheme, but all of the black fellas they don’t know that they can go there and see the doctor for free. They need to tell us this stuff you know?” (carer)

“If they have ‘closing the gap’ benefits the consultations are free. But it’s up to the doctors to write ‘CTG’ on the script otherwise they have to pay full price. Many of the times the doctors don’t write it on there for them because they don’t even know.” (healthcare practitioner)

good perception of clinic staff

(discussed by C, HP, OSP)

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LEVEL:	client	provider	system

"[in reference to mainstream health services in town E] You can sit there for 3 hours before you even see a doctor. They don't even look like they're busy- they are pushing pens and just yarning. They're just lazy." (carer)

"He [the former doctor] would write it up and attach it to the bottle so I remember. But now they don't tell you anything." (carer)

"[in reference to mainstream health services in town E] They said 'oh nah the doctors not here' [...] But they wouldn't let me through the door. They just couldn't be bothered." (carer)

"[in reference to mainstream health services in town E] Even that nurse there, she's just an asshole too. And the nurses at the bloody hospital, they're even bad ass bitches too." (carer)

"[in reference to mainstream health services in town E] The doctors here can't wait to get rid of you quick enough." (carer)

"[in reference to mainstream health services in town E] We have one regular doctor here. The rest of them are FIFOs [fly-in fly-out] and they're dickheads." (carer)

"I used to go to [Name of former long-term health worker] everyday when he was here and he knew always what to do but the new staff there at the clinic don't know anything they just look it up in a book. I don't go to there anymore." (carer)

"[in reference to mainstream health services in town E] I actually went in yesterday for my son with sores to get the needle. But the nurse said 'oh the doctor wasn't here today so come back tomorrow.' But she's a nurse I know she knows how to do that needle." (carer)

"Another component to it, why things may not be as good, I think if there's a good relationship between nursing staff or medical staff in the community, parents are more likely to bring their children, or the children come themselves at an early stage. And then also depends on how school and the health centres work together. If there's a good working relationship and the community feels good about the health staff, they tend to come early. If they don't then it's left until the last moment." (healthcare practitioner)

"[in reference to AMS community clinic] I really can't speak for them because every time I go to the clinic I'm fixed up well and there's no hassle there. They're all pretty concerned and pretty on the ball, so I can't see that they wouldn't do the same thing for the community people that go up there. I've been up and sat there when people have been in the waiting room. They get shown through and given medicine and stuff so to me that works as well as it can. But I think it's a matter of getting to the care, is part of the problem. You know what I mean?" (other service provider)

"I find it's quite good [the community AMS clinic]. I think the clinic does a really good job. When kids go there and things I haven't had to wait too long with any of the kids I've taken in and they're usually pretty good going." (other service provider)

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“I had a skin outbreak and she said it was scabies, it wasn't scabies. It was just a bit of dry skin, we'd been walking in Tasmania, and my feet had been waterlogged for about ten days, bush walking and so I just got an infection in my foot. [...] So the nurse at the time, when I was over there [a different community] teaching for a few weeks, she sorted it out. I went and got another opinion.” (other service provider)

“Like I know one teacher went there at one point after being given antibiotics with... I'm not a nurse, but I'm fairly certain that it was hives, and she just started taking antibiotics and went back to the clinic and was told it was eczema. And you just sort of think “Oh God... I don't really know if you know what you're talking about.”. And there's nowhere to go for a second opinion here... So, you sort of want to be able to trust in their abilities as well.” (other service provider)

health status of carer (discussed by OSP)

“A lot of these people who are looking after these kids have early stage dementia or other major health problems themselves.” (service provider)

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

engaging & culturally secure staff & practices

(discussed by C, HP, OSP)

"[in reference to mainstream health services in town E] Even the old doctor here in [name of town E], he has been here for 30 years but he doesn't have a rapport with the community. He doesn't have a really good personality, it took nearly 3 years to get a smile off him!" (carer)

"...And me and this black fella man had to share the same toilet [at the hospital in town E]. But luckily an Aboriginal health worker was there visiting and she changed the room for me cos it's culturally inappropriate." (carer)

"[in reference to mainstream health services in town E] We should have Aboriginal health workers because they will make sure everything is right because they have had so much primary health care." (carer)

"[in reference to mainstream health services in town E] ...yeah but it's a shame, all the staff are pretty white. Or African. Hardly any Aboriginal." (carer)

"[in reference to mainstream health services in town E] The staff at the clinic are racist. The mums want an Aboriginal worker there not a white person." (carer)

"I think just being friendly [chuckles], and genuine, and actually as I've said make kids welcome. Make them feel like the clinic is a place where you come to get help. I find that here in particular, kids will come on their own and show me their sores. Often their sores or their cuts or whatever. And they engage. I engage them in how I interact with them, and I find that they're almost like happy to be coming and showing me their sore." (healthcare practitioner)

"How can we improve? Just make sure that your clinic is accessible and everybody's treated the same in the clinic. Nobody's treated any different. Everybody's the same. And that what you're told in the clinic is private and confidential and it's not going to get spread around. Because confidentiality is a huge issue in communities, a huge issue. Confidentiality with health workers is a huge issue. So they need to know that it's very private when they come here, but then nobody is going to be treated any different to anyone else." (healthcare practitioner)

"I think that's all the attitude from whoever is in the clinic makes all the difference. People need to feel comfortable to come to the clinic, and no issue is a small issue. They need to feel comfortable, they need to feel like you care about them. "We need you to take your tablets, because we don't want you to get sick. [...] and I tell people, the day the doctors and nurses care more about your health than you do yourself, then there's not much point. "You've got to care more than I care." They've got to feel comfortable coming to the clinic, and I mean we can be taken very much advantage of and you can get just absolutely totally worn out. There has to be some boundaries, but I want people to know that they can bring their kids up, and I don't care what time it is, if their kid's sick, I want them to bring their kid up to the clinic because I don't want to be flying that kid out because they've left it so long." (healthcare practitioner)

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

"The attitude of the people working in those areas. I know there's... Everyone's got different personalities... but there's certainly personalities that aren't forthcoming with people being... you know... Or wanting to go and visit those particular types of personalities... So I think that relationships is a big thing." (healthcare practitioner)

"I've never thought about that as a problem. I know one of the things that's more with adults is like females not supposed to show parts of their body to a male and the other way around - males are not supposed to show certain part of their body to a female - and by having clinics with either male or female nurse, there might be some issues around that. Like for me to give an IM injection of antibiotics into someone's bum, it's-- I have female clients refusing to have IM injections because I'm a male nurse." (healthcare practitioner)

"Yeah sometimes the staff just say 'I'm hungry I wanna go eat'. So they don't do anything. They don't even worry about it." (other service provider)

"Yes, I think it's really-- in terms of health service if you are going to have someone out here full-time they really have to be aware of the situation, and the culture, and that late at night people get sick and that's not a nine to five job." (other service provider)

"[in reference to mainstream health services in town E] The doctors that are there are... I... I've met up with a Jew doctor when I had to take one of my boys in. I had an African doctor that didn't have a damn clue what he was talking about. I don't know how a UTI can be an ear infection, but hey, he knew it all more than me! And I've come across a Muslim doctor that just, you know, think they're just dirty people and that it's pretty much their own fault that they are like that. Even though they don't put it that way, you can see it in how they carry on and the way they talk. And out in the community, when you see them walk around and how they... Yeah... So, it's very sad the doctors don't have it. And they... Some of them come straight from their country to here. One of the doctors that I got to know a little was Papa New Guinean. He was really getting the point across that in Papua New Guinea, there is no CentreLink. There is no... hand-out money, there is none of this, none of that. And he is "These people get more. There's money thrown at them and there's money they get off of the government every week and this money and that money. And look how they're living, it's their own fault that they are pretty much living like this. Back home we worked hard for our money, we worked hard to make sure our kids were well, we looked after our families.". And he just... that attitude of having a dig, you know." (other service provider)

established relationship between staff & client (discussed by C, HP, OSP)

"The nurses come and go all the time [in reference to community AMS]. I'm not gonna see someone I don't know." (carer)

"He [in reference to former longterm healthcare practitioner] has my own blood. He know my boys when they was baby. The ones now don't." (carer)

"[in reference to mainstream health services in town E] These FIFO doctors they come in, do their thing, don't care, and then leave." (carer)

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

"[in reference to mainstream health services in town E] This midwife once was really polite and wrapped my baby up. But you go back the next day later, and they're gone." (carer)

"I don't even know the staff up there now. They change all the time." (carer)

"[in reference to mainstream health services in town E] We have had a couple of good black fella doctors here, but yeah they haven't been back since. They all come and go. All the good ones go and we keep the bad ones!" (carer)

"He used to know what to treat you just by looking at it [in reference to a former long-term health worker in community AMS]. But there are too many new ones coming in." (carer)

"Nevertheless, there's a shame factor involved, and that will probably contribute to people not coming and seeking out help. In communities where there's a good relationship between the nurse they'll come at an early stage for treatment, and again in communities where there is no good relationship then people will not come even if it's uncomfortable perhaps." (healthcare practitioner)

"High turnover leads to the clients, the people in the community, always have to relate to someone new every time they come in. If the nurse that's here today starts a treatment or has been here for three weeks, four weeks, five weeks and started a treatment, the client is happy with that. They come back on a regular basis, and then there's a new nurse coming in that doesn't agree with what's done or think that there's no point doing it anymore because, "You're well enough now. Go home," then the people losing their confidence in the clinic and the nursing staff, and that's creating problems. They will be more reluctant to go back. And you also see that in clinics that have huge turnover of nursing staff but have a GP that comes on a regular basis, they will come to see the GP to get their treatment that the nursing staff hasn't given them, because they don't trust the nursing staff." (healthcare practitioner)

"Even from my perspective, people are more likely to come with something small. In communities where I have relieved, and the permanent nurse that's there hasn't had quite a good relationship, people don't present. They wait until there is a serious issue where they-- because they can't avoid it any longer. That's when you're going to see more blown out skin infections and people presenting at a point where it's more severe." (healthcare practitioner)

"I have to say in my previous experience, rarely [referring to a strong relationship between clinic staff and clients]. There's been a few times where I've seen it, but rarely just because the turn-over of staff is so high really in those posts. There's generally just one nurse out on their own and they have more than enough-- to be on call for 12 hours a day. The turn-over, I guess, has meant that it's been difficult for people to maintain those kinds of relationships with the community for an extended period of time." (healthcare practitioner)

"In my own experience, and previous experience, families won't engage with those sorts of services unless there are people that they recognize, or people that they've had a relationship with for a long time. That's why Aboriginal health workers are so important." (other service provider)

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

"[Name of former long-term health worker] has been a huge catalyst, ALL the community members loved him. I think because he stayed for a long time so they had a lot of trust in him and had strong relationships with him so they went to the clinic." (other service provider)

"[Q: Trust in the clinic staff is an important issue?] Very much. Especially with the women. If there's a male doctor there, very much. That's something that has been a huge loss. It will be a huge loss to the community in the health side of things because [name of past health worker] has been here for 20 odd years, so he knew everybody, knew their history, delivered probably most of them. All of that sort of stuff, known them from children. That's a huge loss." [other service provider]

"He [referring to a former long-term health worker] was good, he knew everybody and everybody's health and what tablets they have to take. And he knew people way back you know? Some people still ring him up today." (other service provider)

"We have a lot of turnover at the clinic it's just so hard for the community to trust whoever is in the clinic because they don't know who they are going to see next." (other service provider)

"People move around a lot and the staff probably don't know the context. I mean we have had people who have gone into the clinic and told the nurses they had their immunizations, and the staff look it up on the system and can't find it but it's because it was done in [name of community] and not in [name of other community]. The staff need to be more culturally aware I think." (other service provider)

"It was the only thing that threw me off and I didn't want to confront the nurse right then because she was a visiting nurse, because I find that's probably the biggest frustration for me and I think the community as well is how regularly the nurses switch over there. It's like one minute your calling, "Oh. Kimberley. Okay. Who are you? All right. You're a new nurse. Okay. You're permanent. Okay. Perfect." And then a month later, "Oh. Sarah? Hi Sarah? Is Kim-- ? Oh, Kimberley left. All right. So are you permanent? Oh, you're on a two month contract? Okay. Two month contract." And six months later Sarah is still there with her two month contract which they just kept extending. I think that's quite frustrating and I find the community it takes some of them quite a while to warm up to people. They'd rather just walk up and go, "Because you're a nurse I'm going to trust you?" And I think that's-- I don't know if that really creates barrier but I've heard people say before, "I don't know anyone at the clinic." And that can be I think a bit challenging. I know myself I wouldn't want to go see a stranger every time I was sick." [other service provider]

"Having said that, yeah the longer you can stay the more relationship you're going to have. And's that why [name of previous health worker] was so good, and I'm surprised they got rid of him but that's not for me to say, because he was brilliant. He's a good bloke and you could walk in and he'd know you and know the people and things would tick over. You could go in with any problem you like and there was no hassle." [other service provider]

clinic waiting time not too long

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

(discussed by C, HP, OSP)

"I think they only have 1 or 2 nurses there and you gotta wait a long time." (carer)

"You can wait an hour and a half, two hours here." (carer)

"...you got other families in front of us. And there are probably only 2 nurses." (carer)

"[in reference to mainstream health services in town E] There is a long wait at the hospital. One time I had a boil on my leg and I got up at 4 o'clock in the morning and went to the hospital and wait long time long time [and gave up] then I went home." (carer)

"I think a lot of parents don't come because they know sometimes there is a wait. Because there's only [name of nurse] and I at the moment." (healthcare practitioner)

"I think the waiting time, perhaps, puts a lot of people off. It puts me off [chuckles]. Oh, God. Hours. Even when it's quiet, it feels like you're there for hours at times." (service provider)

acceptability of treatment

(discussed by C, HP, OSP)

"My little one won't drink the medicine. She doesn't like it. They gave her the drink medicine but she won't take it." (parent/carers)

"Some don't got a fridge to put it in you know. At home." (parent/carers)

"Then I got antibiotics [for my sores] but they are too big, I sick all that up. And it's a funny taste for me so I vomit it up." (parent/carers)

"Sometimes the kids say after the needle that it's really sore and they can't walk. It makes them really sore. They walk funny." (parent/carers)

"Sometimes the parents get hurtful for that kid having the needle. They don't want to see that kid screaming there from that needle. And that needle is big it's not a little needle." (parent/carers)

"If the kids can hear the word needle they will take off from the clinic you know and never come back." (parent/carers)

"Sometimes parents get hurt for their kids from the needle- parents also get scared." (parent/carers)

"It's really sad [giving the injection]. Really emotional seeing the mums. One child had an injection today and the mother was tearing up like she was about to cry." (healthcare practitioner)

"I mean, these kids, alright... If you stick a needle in them... There's one little girl who's terrified... Comes in the clinic, she sees a white face, she bursts into tears. You know?"

FACTOR:	predisposing	enabling	need
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She's had LA Bicillin three times. It hurts. It's not a pleasant thing to do. To have, let alone do. And you know when this kid looks at you, the first thing she thinks is "You're going to stick a needle in me.". You know? Straight away. So they're going to avoid coming. And as they get older, they're going "I'm not going there.", that's what's going to happen. So... yeah, LA Bicillin is a really good drug. Penicillin works wonders up here. You know... works wonders... Procaine... Wonderful drugs. But getting it into them... They know what you're going to do and... it's very difficult sometimes. And to hold a child down and inject a child... until you've done it, you don't understand... 'cause I've got kids... I've seen my children... Thankfully my kids have never had to have LA Bicillin or Procaine, you know. And I know how I would've felt... But... As these kids grow up, they only see themselves with these sores and they know a white fella is going to stick a needle in them because mum won't clean the sores and won't give them the medicine that she should." (healthcare practitioner)

"Antibiotics are too hard. They forget or only take half the course." (healthcare practitioner)

" But if it's a single-dose injection, by all means I'll do that. But if it's a five-day one, you might only get two or three out of them before they disappear. And they're not necessarily that they-- because they're so mobile, they might have every intention of doing it, but then suddenly there's a car going to town so they jump in the car and head off without thinking, "Oh, actually I have two more doses of my penicillin before I go." So it's non-compliance to medication in many different ways. It's that, A, they don't come back, B, they lose the medications, V, something else more interesting happens so we're sort of forgetting that we are supposed to have two more doses. Then the question is, are we as healthcare providers responsible for chasing everyone that's on antibiotics, or should we say, "You're an adult, you're responsible for your own health," and then just treat them when they come back?" (healthcare practitioner)

"[Q: So adherence is an issue for oral antibiotics?] Yes, 100% yeah. You have better luck if it's administered in the school, but if they're smaller ones, you've got liquids, oral antibiotics, and they need to be kept in the fridge. Sometimes people don't have fridges so it becomes difficult." (health practitioner)

"Yeah. Amoxicillin, TDS, three times a day for ten days. Now, you and I probably wouldn't do that. [...] So that's why it's better to give the Bicillin, because that covers them then for 28 days.[...] Because I'm here by myself, and there is no way that I would be able to give that-- I would have had to have held that little fella down, and there's no way I could safely give that injection with just his mother and I here. No way. [...] With that case of that little fella today, there was no choice. He should've had the Bicillin, because I know the mother can't-- doesn't look after herself. And to let the child get to that stage—[...] if I had someone here to help me. If I had someone here to help me, I wouldn't hesitate, he would have had the Bicillin." (health practitioner)

"The pain. That drug [LA Bicillin] is really painful. So if you think it's too painful and that child is distressed, give procaine penicillin, which is not painful, but you have to give it for three days." (health practitioner)

"[discussing why not to use LA Bicillin on occasions] No, apart from distress, you don't want the child to hate the clinic. Because if they've got bad experiences about the clinic,

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

they are closing the children from immunisation, health checks... So you are basically creating an impression, "There they kill you. In the clinic they kill you.". So you don't want that. So go for the lesser evil and, you know, balance it all." (health practitioner)

"But for benzathine [LA Bicillin], it's very painful, but oh it's magical... But very sore. Very very sore." (health practitioner)

"The pain. That drug [LA Bicillin] is really painful. So if you think it's too painful and that child is distressed, give procaine penicillin, which is not painful, but you have to give it for three days." (health practitioner)

"Sometimes the kids complain about the pain of the needle- they can't walk. They walk funny, can't sit down. One boy today couldn't sit down because he was in too much pain from that needle. " (other service provider)

"Some of the families don't have fridge so they can't store the medicine." (other service provider).

"The kids after the needle they can't walk, they can't do anything." (other service provider)

"[Q: Do you think people overall are comfortable going to the clinic here, if they have any issues?] Well, the kids are afraid of getting a needle." (other service provider)

outreach activities (discussed by C, OSP)

"They used to have people drive around to your house to remind you of your appointment. It's a duty of care thing. And would drop all the old guys and the chronic guys off at their appointment. They should do that again." (carer)

"Two years ago there was a nurse called Danielle and she was my aid of gold, and she would come up to the school and she would make sure everyone was dewormed. Every day, three days in a row, you got a little medicine on a powder pop stick and all of the kids got dewormed, and that was good. That really sorted out bottoms. She also would give the school Yuvalin cream, little things like that. The kids would rub it on to their hands and face, and it would soothen their skin. She'd also come up-- we had a band on the oval-- pretty much the whole community was there. All the old people. All the parents. She walked around giving everyone flu injections. In those times I saw massive amounts of collaborations." (other service provider)

"Every now and then I think [name of AMS] will come out... I think they've only been out here once this year... Is that right? About nutrition." (other service provider)

"The other thing, too, is the limited health providers that come out to the school. In a mainstream school, you'd have a school nurse coming out into the school more regularly. You'd have access to dental care. You'd have occupational therapists, and psychologists, and all of that sort of thing." (other service provider)

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

"I have not seen them come over to the school. It's us going over to them. It's the school staff being proactive. In terms of-- at this stage I have not seen the clinic supporting the school with a range of health initiatives. [...] I would like to see it being two way. It's great that they're more than willing to see any of our students at any time, however in terms of promoting preventative health, it would be great to see a bit of interaction going on there." (other service provider)

"We had a great nurse there 12 months ago that started with a worming program at the school. She used to come every three months and worm all the kids, and check their general health and well-being, and that sort of stuff, and it was fabulous. And then, she left and nobody's done it since." (other service provider)

"I don't even bother, I just make sure they're in every day. In those days, we always did the insulins in the afternoon. One nurse went out at four in the afternoon and did all the insulins and if we had a couple of special ones, we had to scoop them up - like the skin infections and stuff like that - we'd take their meds as well, we'd give it to them. That's how we covered it. I know you're supposed to make them independent and all the rest of it, well, it doesn't work. In 16 years I've pelted my head against the wall, it doesn't work." (other service provider)

"They had an opportunity to have two nurses for a period of time and then one nurse was going to the school I think it was once or twice a week and just doing a look over of all the kids if they needed minor tests. She wasn't doing injections or anything like that at school but if they needed their hearing tested or eyesight tested or sores redressed, that sort of a thing. It was a great opportunity and it also helped them identify especially with the weepy ears and stuff, if a child's ears were starting to look bad she would get them to the clinic before it became a really big problem. And that I think make a huge improvement." (other service provider)

clear communication re visiting health services (discussed by C, OSP)

"The clinic staff don't let the mothers know when the baby doctors are coming." (carer)

"At least if the doctor comes, put pamphlets in everybody's mailbox. And just tell us 'she's coming', 'he's coming'" (carer)

"It would be good if they could notify the school or playgroup when they are coming so we can spread the word. [...] They just don't inform the mums when the doctors are coming into town, therefore they have no idea. We need to advertise it on the newsletter board." (other service provider)

"The other issues with hearing and immunizations and general health, one of our gripes is we often don't know what goes on at the clinic. There's little communication sometimes. We might know sometimes if the kiddie doctor's coming in, but to me if the nurse is at the school every two weeks, then we're talking all the time and they'll be some information that so and so's coming in, or an eye specialist, whereas people will just lob up out of the blue. An eye doctor will come, and we'll have no idea they're coming. [...] A classic example on Friday, Mental Health were here, no idea they were coming." (other service provider)

FACTOR:	predisposing	enabling	need
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"Not really. I don't go over there very often. We were supposed to have the ophthalmologist come out and check the kids' eyes, and then we got a call on the Friday, 'No, he's not coming.' So I said, 'Well, when's he coming next?' 'No idea.' Then the paediatrician came out, we didn't know the paediatrician was coming out. So what I really need to do, and this is my fault, I needed to, every Monday morning, ring up the clinic, or go over and say, 'What's your program for this week?'" (other service provider)

patient engagement (discussed by C, OSP)

"[in reference to mainstream health services in town E] Sometimes I go from population health, to the clinic, to the hospital and back again. I walk from one to the other cos they all say 'go next door, we don't do that'." (carer)

"[in reference to mainstream health services in town E] I actually went in yesterday for my son with sores to get the needle. But the nurse said 'oh the doctor wasn't here today so come back tomorrow.' But she's a nurse I know she knows how to do that needle." (carer)

"The clinic doesn't ask us if we want a choice- they only give the needle. They don't ever give us the syrup." (carer)

"We should have our own choice of treatment." (carer)

"Some just make a dressing and don't do anything eh. They just say come back tomorrow and don't do anything." (carer)

"[in reference to mainstream health services in town E] Even here they do this closing the gap scheme, but all of the black fellas they don't know that they can go there and see the doctor for free. They need to tell us this stuff you know?" (carer)

"[in reference to mainstream health services in town E] They also expect us to know what they're saying, like they talk down to us you know. They use all this doctor talk and I don't have a clue." (carer)

"[in reference to mainstream health services in town E] They don't even think about what they give, they just give something out without telling us what's wrong with us." (carer)

"The health clinic doesn't give them an option for treatment for their skin but it's whatever the nurse on at the time wants. They don't care. And that's the problem." (other service provider)

"I don't know if they have their own choice you know? They just go 'he needs a needle' and BANG! But they should 'would you like liquid or a needle?' [...] It's not a mothers choice, it's them over in the clinic. Because that's why mothers cry and are sorry for their kids. 'Those bloody nurses got my kid the needle.' [...] he [referring to a previous health worker] used to give tablets eh? The staff now just give needle, needle, needle." (other service provider)

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

“The staff don’t even tell them what to do with the medication or how to get rid of the sores. They need to educate them you know? [...] The health clinic doesn’t even give them soap or any stuff to rub on the sores they only give them medicine and no other treatment – no information on it either.” (other service provider)

“They have so many people going in [to the clinic] they actually don’t have the time to talk or impart knowledge- they just treat.” (other service provider)

comfortable clinic facility (discussed by C, OSP)

“[in reference to mainstream health services in town E] I hate the clinic. It’s so bad I don’t even like going there sometimes.” (carer)

“[in reference to mainstream health services in town E] Even the hospital here, it’s dirty and old. It needs to be burnt down and rebuilt.” (carer)

“What they love to see is heaps of photos of themselves [chuckles]. In the clinic. They love it, and they make it relevant to people here and what it means. [...] and that’s why I’ve always-- one of the things that I’ve put to my bosses is that I want computers here [in the clinic], and a better internet system so we can have adult literacy classes.” (healthcare practitioner)

“But then I’ve been to the clinic, as I said, when I had this four-day bug, I had to go a few times. They love-- the people just sit there. Whether it’s a community thing as well, you know, community meeting place that they can sit and they can get checked out, and they don’t mind the advice taking, the medications that are offered to them. They quite like, but as far as maybe teaching them, “Well, here’s some cloths and things; keep your sores clean,” and what have you, I don’t know how far it goes.” (other service provider)

“I think something needs to happen over that clinic. To get them a bit more organised. The place is filthy, it needs to be cleaned up. The likelihood is they don’t have a cleaner, because I know it’s very hard to get a cleaner in remote communities. So those are the two things that stand out, and inter-agency communication, absolutely.” (other service provider)

“Oh, yes, always at the clinic. Yes, it’s amazing. They are there all the time. They have their little tablets and potions and motions and things. They do. I’ve had the kids who, “Oh, I’ve got to go to the clinic. I’ve got a boil on my foot,” or, “I’ve got a cut that’s getting infected because I’ve trod on a prickly or something. I’ve got to go to the clinic.”” (other service provider)

“I actually think a lot of them really like going to the clinic. I always get that impression that they’re very comfortable sitting there, lounging all over the chairs and using the toilets.” (other service provider)

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

free or low-cost medical care

(discussed by HP, OSP)

“Thank God they don’t have to pay! If they had to pay to see a doctor here, by Christ, you’d have such a high mortality rate, or people losing limbs, if they had to go pay a doctor. You know. It just wouldn’t happen.” (healthcare practitioner)

“If they have ‘closing the gap’ benefits the consultations are free. But it’s up to the doctors to write ‘CTG’ on the script otherwise they have to pay full price. Many of the times the doctors don’t write it on there for them because they don’t even know.” (healthcare practitioner)

“[in reference to the utilisation of mainstream health services] Free for children, under a certain age. I can’t remember how low it is, but it’s free for the children.” (other service provider)

ensuring adequate medical supplies

(discussed by C, HP)

“[in reference to mainstream health service in town E] Back at that clinic they gave me a script to go buy my son his own shot [LA Bicillin needle] but I shouldn’t be buying my own because they should be provided from the hospital because every kid needs them.” (carer)

“Sometimes the clinic does run out of the liquid medications and then we give injection.” (healthcare practitioner)

“[Q: Do you find that there are any challenges there in terms of administering those treatments which are advised by the CARPA manual for various skin infections? For example, for skin sores?] They have to be in the medication room. [Q: So is that not always the case?] No. [Q: So is that a problem that you face regularly in remote clinics?] Yes, because whoever’s working-- the first thing that I do in the clinic is go through the treatment manual and make sure that whatever’s in the-- two things. Do people have any Webster Packs, and what’s the drugs that are in here. That’s the first thing that should be in your pharmacy. So then you can treat as per-- and your butt’s covered as well. [Q: But that’s not always the case?] No.” (healthcare practitioner)

“Clinics that has a huge turnover of staff often runs out of stuff on a regular basis because the relieving staff don’t know what to order. They don’t know the amount of things to order. If they order, they might order one or two or three and then the clinic uses five a week. So it’s a huge problem that the clinics aren’t well enough equipped to have everything they need at any given time, but on the other side we can’t have thousands of dollars in stock that we’re using once a year.” (healthcare practitioner)

adequate staff levels & low turnover

(discussed by HP, OSP)

“I think for the community it would be the consistency of the nurse. Like it’s good to have people long-term and that often doesn’t happen, you know.” (healthcare practitioner)

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

“Well, the nurses always say out here that they're run off their feet, and it'd be obviously always understaffed. Whether having an extra nurse, like point five, or I don't know, would make a difference, so they could treat-- so people weren't turned away. Going to the clinic is a big thing, and if you get turned away, you're like, "Oh well, I might not come back." Maybe by having more staff, but that's obviously a drain for every job. (other service provider)

“We have a lot of turnover at the clinic it's just so hard for the community to trust whoever is in the clinic because they don't know who they are going to see next.” (other service provider)

“They have so many people going in [to the clinic] they actually don't have the time to talk or impart knowledge- they just treat.” (other service provider)

“When they had permanent staff and health promotion workers, they had the capacity to go into the school and talk and do some health promotion and even sometimes treatments at school, but that's not the case anymore. They lost their staff.” (other service provider)

“I have to say in my previous experience, rarely [discussing practices of patient-centred care]. There's been a few times where I've seen it, but rarely just because the turn-over of staff is so high really in those posts. There's generally just one nurse out on their own and they have more than enough-- to be on call for 12 hours a day. The turn-over, I guess, has meant that it's been difficult for people to maintain those kinds of relationships with the community for an extended period of time.” (other service provider)

“I would hope so, and I think so, but it all depends on the nurse. There's been a high turnover in nurses in this community. Average stay is six to eight weeks. And to build up a rapport with someone takes a long time, let alone a Martu person. And you're talking about health. You're talking about your personal issues, and you don't really want to unload on anyone. But I do think they respect the nurse, and they do see it as a place.” (other service provider)

“Well I think the thing is... You can't expect too much of the clinic, because they are absolutely under siege. If you've got one full-time nurse there... They're saviours here now... So then... I mean all these other things that sort of appear to be extras, like making contact with the school, or coming and delivering health programs or whatever...” (other service provider)

AMS governance & stability (discussed by HP, OSP)

“I suppose when you look at a RAN [remote area nurse] point-of-view as well, you know, with their contractual basis and... I know [name of AMS] has been tumultuous, to say the least, over the last... you know... 10 years, by the sounds of it. As far as... you know... management coming and going.” (healthcare practitioner)

“Yeah, I mean, when [name of AMS] went into administration our major concern was we're going to lose our full-time nurse and it would be managed from [name of largest remote community in region], we put up a big hooah about that, but when the

FACTOR:	predisposing	enabling	need
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administrators came I need to be assured by the administrators that that's not going to happen, and they understand we need one for the number of people, I guess, with issues. So our full-time nurse is fantastic.” (other service provider)

“So [name of AMS] have had a few issues as well the last few years. I wouldn't say they're the most stable organisation, and that's probably impacted on their services as well. But I don't-- I can't really comment on that, I can only make observations. I don't really know the nitty gritty. But you can imagine if the organisation's in turmoil that would impact on their services.” (other service provider)

“I think something needs to happen over that clinic. To get them a bit more organised. I know they've had all the hoo-ha with [names of two previous health workers] going, and they've had a huge re-organisation. But I think all of that stuff has impacts on the quality of care they can provide.” (other service provider)

efficient use of resources

(discussed by HP, OSP)

“What I find is that things are more successful when the health practitioner lives in the community. I find that even from my perspective, fly in, fly out - I call it the roadshow. Balloons and colouring stuff, and here's a hand, and here's this, and here's a chart, and blah blah, and disappear don't work. I just can't see how a lot of the health promotion stuff that is regurgitated has any effect whatsoever. With all that money, I do believe again that our main thrust should be in the more mental and emotional sphere. That is one of the biggest barriers why people are disillusioned, people are depressed, people are suffering.” (healthcare practitioner)

“All the ambulances have to be state-of-the-art... And how many are going to... When you look at statistics... Three per year, cardiac arrests. And you spend so much money to make this investment and then only have three patients per year? And even if you do that anyway, where we are here, it's so far, if it's a major cardiac infarction, the patient will die anyway. So how about the downstream philosophy where you try to put a lot of resources there.” (healthcare practitioner)

“Well, one thing I think it doesn't need is, you just throw money at things. And throwing money at it doesn't work. It has to be put in the right places. The money has to be made to work.” (other service providers)

“A classic example on Friday, Mental Health were here, no idea they were coming. \$10,000 for the plane and we've come to say hello. To me, give us \$10,000, that is just a waste-- you feel like writing to the newspaper because that is criminal. How can you spend \$10,000 to come and tell us who you are, and the people you want to see are not even here. So what's wrong with a phone call? But because we have this thing called tick a box, where they have to say they've visited a community, regardless of whether they do anything or not, they say we visited.” (other service provider)

“But I guess the real frustration for us is when you see a \$10,000 plane and five or six people's wages, they come for one day, and you just think “That money could be so much better spent.” (other service provider)

FACTOR:	predisposing	enabling	need
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"Like... I mean... I don't know what her name is, but the 'no-smoking lady', she comes in quite often, and she sets up a little store... And I just think "Not that many people smoke here!" She's a lovely lady. But I always see that and think like... well there's not that many people that smoke here. I wouldn't say smoking is a big issue in [name of community]. And she's here probably the most often out of... most. And then... You know, like, the foot doctor comes... and everyone's got infected toes and infected feet... and they come what? Once every three months or something? And it's just like... like, priorities... what we see is really frustrating. You know, that you can... The way the money goes, it could be so much better spent." [other service provider]

"I think yeah, who you get's really-- a good saying - it's not my own, but it's one I've stuck to - is that, "People cure people's problems, money doesn't cure people's problems." And it's a case example Australia-wide, of mountains of money being thrown on the wrong people on the ground, the wrong understanding, the wrong direction." (other service provider)

trained Aboriginal health workers (discussed by C, HP, OSP)

"[in reference to mainstream health services in town E] We should have Aboriginal health workers because they will make sure everything is right because they have had so much primary health care." (carer)

"[in reference to mainstream health services in town E] ...yeah but it's a shame, all the staff are pretty white. Or African. Hardly any Aboriginal." (carer)

"[in reference to mainstream health services in town E] The staff at the clinic are racist. The mums want an Aboriginal worker there not a white person." (carer)

"Clinics with Aboriginal health workers are often easier to get people back because you can send the health worker out to remind people. But in clinics without the health worker, you're sort of missing the link between the white person in the clinic and the indigenous people outside the clinic. I've been to clinics with no health worker and it's a lot harder to chase people to get them to come to the clinic for continuing treatment. But if you have a health worker, it's easier because they can go out and find the person and explain in their way that you need to come back and have your medicine. [...] Local knowledge. They know who the people are. They know who to chase. They will also be able to tell me if people are here or not, if there's someone I need to catch for one reason or another. And it's a nice link, and they will tell you what's culturally appropriate and not appropriate. So having a good health worker is important for the nurses, and I think if you have a clinic with high turnover of nursing staff, having a health worker as your local resource is fantastic." (healthcare practitioner)

"And of course the problem with that... we experience with our Aboriginal health workers, is that... They do their training and everything like that... confidentiality is always an issue, because family is family and everything... So that's a new concept, that you don't share everything, but they never get away from work... my experience from working here is that, yeah, they do the work that -say WACHS- [Western Australian Country Health Service] expects them to tick off, and then they go home and they still

FACTOR:	predisposing	enabling	need
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work, especially when everyone knows that they have skills that are meant to only be for them. So, that's why we appear not to keep our health workers, because it's just this thing, 24 hours a day, and they end up leaving.

But that's what I'm saying, you know, ideally, they all have this idealism that... can make these changes from within, and then when they've got the pressure of what the organisation's expectations are of them, and then what their family's expectations are, it's really hard to do that education with family feuds and family connections and things like that. And so it breaks down all those good intentions of... coming from within, kind of dissipate and it's just a matter of survival.” (healthcare practitioner)

“Do I see Aboriginal health workers? Yes. Do I see long-term Aboriginal health workers? No. And that's for various reasons, particularly because they're put in a position of authority where they have to necessarily say no to their family sometimes which is culturally a big thing to be able to do.” (other service provider)

“With the strength of the tradition of the culture here though, someone from this community being the nurse would be inappropriate, they wouldn't be able to treat probably three or four skin groups, and they wouldn't be able to-- for instance, mother-in-law, so all these familial relationships and skin group relationships, that's a huge factor in coordinating anything.” (other service provider)

good collaboration with other services

(discussed by HP, OSP)

“I know for some people it's not important, but I think it's very very important. Creating a positive environment between [name of AMS] and the community. Improving communication. Ok? Because where communication is poor, the community doesn't know what is happening, the thing is more stability. The community has got... a propensity to fight an organisation... and you'll be gone in seconds. You need cooperation. All these things we're talking about is cooperation. Without cooperation, you're wasting your time.” (healthcare practitioner)

“The other thing is... I know things like nutrition, you know... failure to thrive, issues with children... Is a challenge for the clinic really, we can't give them food and stuff like that, but you know, we can, you know... give a bit of education and work with partners like, Worldvision and stuff like that to, you know. Chip in. So, there's a lot actually to do with the kid's issues, which can be done, but the beginning, I think, is, apart from the collaboration with partners, is the school health program, the deworming stuff, and you know, things like that.” (healthcare practitioner)

“The clinic hasn't been involved with the school for some time. There are only two nurses here.” (healthcare practitioner)

“And also if it's a good working relationship between the teachers and the nurses. Sometimes it doesn't always work well, and then there's reluctance to actually go and engage with each other because of communication issues, then I believe that only the community members suffer.” (healthcare practitioner)

“The problem is, I think, the clinic doesn't talk that much with [name of community coordinator], the clinic doesn't talk that much with us. So they're very much isolated. [...]

FACTOR:	predisposing	enabling	need
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But you can probably gather that communication is the key, and that's what's lacking."
(other service provider)

"Also just the communication thing being improved, so that we know who's coming, we know what they're going to do." (other service provider)

community engagement & outreach policies (discussed by HP, OSP)

"The clinic hasn't been involved with the school for some time. There are only two nurses here." (healthcare practitioner)

"They no longer have any health staff coming to the school which they used to- they used to do health checks and stuff at school." (healthcare practitioner)

"One, approaching the community before you actually start, and finding out things that are appropriate and things that aren't appropriate. Have a practice run with the delivery, with appropriate people, and get feedback from that. Not just develop something and do it. It's got to be really well-thought out. It's building relationships with the community."
(other service providers)

"They no longer have any health staff coming to the school which they used to- they used to do eye checks and stuff at school but they don't anymore so we have to take them down." (other service provider)

"I think what would make the greatest difference here is if we had a nurse on once a week, every week, and saw all of the kids. Even if the Department [considered?] having a nurse on site, but yeah, I think that would make the biggest difference, because all the kids would be monitored on an ongoing basis, and things would be picked up much more quickly." (other service provider)

"There has been collaboration with the clinic, but my sense is that the clinic is so overwhelmed that they're not proactive in outreach. Any of the outreach has been instigated from the school." (other service provider)

"When they had permanent staff and health promotion workers, they had the capacity to go into the school and talk and do some health promotion and even sometimes treatments at school, but that's not the case anymore. They lost their staff." (other service provider)

"Yeah, I have. It's just I feel sometimes we could probably do a bit more for these kids than what's going. And maybe that's a [name of AMS] directive, I don't know. [name of AMS] have maybe said to nurses staying at clinics to let the problems come to you rather than go out and look for problems. And you can understand it from a nurse that they always seem to be overworked, why go looking for more work? But my argument is that sometimes kids don't know they've got a problem." (other service provider)

"The other issues with hearing and immunizations and general health, one of our gripes is we often don't know what goes on at the clinic. There's little communication sometimes. We might know sometimes if the kiddie doctor's coming in, but to me if the nurse is at the school every two weeks, then we're talking all the time and they'll be some information

FACTOR:	predisposing	enabling	need
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that so and so's coming in, or an eye specialist, whereas people will just lob up out of the blue. An eye doctor will come, and we'll have no idea they're coming." (other service provider)

"I know that they are understaffed, and I know that they're stressed about their workload but there used to be a lot more collaboration than there is now. I supposed that if you got children that are getting dewormed and getting flu shots while they're here, they get a lot more people than the ones that come to the clinic." (other service provider)

"Here in [name of community], a high degree of consultation with the [name of community] council. For example, making them aware of visits, making them aware of services, getting their support is number one. Then, once you've got the support, using a range of opportunities to present these health messages. Here in [name of community], because of the community office, everyone goes there, making messages pictorial and visual and accessible would go a long way I think. There's limited print in the homes, so maybe promoting opportunities for getting print out there." [other service provider]

"But just assistance with screening, assisting teachers with preventative health programmes, adding to our expertise as educators with specific health programmes. We're very fortunate here that we've got a specialist health teacher, so I would expect that the health teacher have significant collaborations with the health workers in the community, working together on a range of programmes relating to mental health, physical health, sexual health, that kind of thing." [other service provider]

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

lacking awareness re skin infections

(discussed by C, HP, OSP)

"... she [her daughter] had a sore on her arm so I took her on a plane to Hedland [...] It looked like a blister it was black. I didn't know it was any problem. The baby doctor said I had to go." (carer)

"A lot of black fellas leave it until the end stages cos they aren't educated." (carer)

"They also normalise it. They think 'oh it will get better' they will only take the kids to the clinic if it's really, really bad" (carer)

"The mothers don't think it's an issue. Sometimes they will think 'oh that will be fine tomorrow', But they don't know what will develop behind this. In the blood stream you know?" (healthcare practitioner)

"I think it's a combination of lack of knowledge and it's, "Why do we have to do something with it now?" But lack of knowledge is probably one of the things." (healthcare practitioner)

"It's not neglect, it's not laziness, it's just too vague. No one knows what it [the skin conditions] is." (other service provider)

"I think they need to educate and understand skin infections more, otherwise they become normalised and people don't bother to go until it's really bad." (other service provider)

"Maybe lack knowledge. Everyone, not the health professionals. There's white fellows out there that have no idea. But definitely lack of knowledge and education." (other service provider)

delayed presentations & self-treatment

(discussed by C, HP, OSP)

"A lot of black fellas leave it until the end stages cos they aren't educated." (carer)

"Most people leave them until they get really, really bad and worse." (carer)

"I don't go to the doctor unless it's serious [in reference to skin sores]" (carer)

"Mostly I buy stuff from the shops. Medicated soaps and medicated bubble bath to treat my kids." (carer)

"Sometimes when they get worse and worse I get them the medicine soap." (carer)

"We use those gum tree leaves. And we boil it and then put it on the sores in the bath and it makes them dry and it goes away." (carer)

"We get normal leaves from the trees boil that up and get the leaves out and use what's there to wash it with. It works for sores and rash and boils." (carer)

FACTOR:	predisposing	enabling	need
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"I don't think they care before it starts being a problem. So when it starts being painful, when the kid starts to lose sleep over it, that's when they come, when things are past the initial stage of just being an easy fix with a small dressing. They wait till it's a big problem and there's more work involved in cleaning it up, preventing more, starting medication. It's sort of a vicious circle. They wait too long and then the treatment is bigger and more time-consuming. A lot of things could have started earlier and are preventable." (healthcare practitioner)

"The little boy today, obviously, has scabies because he's got the sores here, and he wasn't brought to the clinic because of the sores. He was brought to the clinic because his arm was sore, because they said he hurt it playing football. But there's a big sore on the arm and that's where the pain's coming from, not from the football. [...] And then they didn't wait for the antibiotics. So tomorrow I'll have to chase them. They didn't come back for the antibiotics. [...] They don't come until they're so bad. And in that time, they've just spread them around to everyone else. So the school has to play a part in that as well." (healthcare practitioner)

"Even from my perspective, people are more likely to come with something small. In communities where I have relieved, and the permanent nurse that's there hasn't had quite a good relationship, people don't present. They wait until there is a serious issue where they-- because they can't avoid it any longer. That's when you're going to see more blown out skin infections and people presenting at a point where it's more severe." (healthcare practitioner)

"They don't go get it fixed until it hurts them or until it causes problem. I knew a child a few years ago who had a skin infection that was left too long and then he lost his leg." (other service provider)

"I think they need to educate and understand skin infections more, otherwise they become normalised and people don't bother to go until it's really bad." (other service provider)

"Well I think because it's so common the mothers think 'oh it will go away'. They don't go in until it's very, very bad." (other service provider)

"They use bush medicine before going to the doctor. It's the same in New Zealand, the Maoris take 'Rongoa' - it's the New Zealand medicine, they take this before going to the doctor." (other service provider)

"I don't think it's an issue that people would necessarily go to the clinic for unless it was causing severe itching, irritation or something like that. I don't think I've seen anyone go to the clinic because a child's got a ringworm, that's for sure." (other service provider)

normalisation of skin infections (discussed by C, HP, OSP)

"They also normalise it. They think 'oh it will get better' they will only take the kids to the clinic if it's really, really bad" (carer)

FACTOR:	predisposing	enabling	need
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"I don't know what they see as a normal part of life in their skin problems. I know that most likely they're used to it. They're used to, "Mom had heaps of boils when she was young, so why should I start running to the clinic with my child when they have them, because they're just there anyway?" (healthcare practitioner)

"It's not seen as being different. It's not seen as if there is anything wrong with it because all of the kids got sores. What's different between my kids having sores and everybody else?" (healthcare practitioner)

"Well I think because it's so common the mothers think 'oh it will go away'. They don't go in until its very, very bad." (other service provider)

"I think they need to educate and understand skin infections more, otherwise they become normalised and people don't bother to go until it's really bad." (other service provider)

"I guess it's a cultural thing where... You know, like, for me, if I've got a sore, I'll complain about it "Oh my God, that's really sore!", and I'll show someone "What do you reckon that is?", I'll go to the clinic... Whereas for these guys, they don't talk about the pain unless it's really really bad and they feel sick, like... You know... One of these kids was in my class last year and was literally passing out. A boil. The boil had gotten just so... big and infected. He hadn't told me because it was under his clothes. So I took him to the clinic and "Oh, its just a boil.", but obviously you get so unwell from it." (other service provider)

"I think they are very well trained and groomed and whatever, if we want to say, not to give the appearance that it affects them. Because it affects nobody else so why should it affect me. But I do think these things do bother them and it does for a good measure make them not concentrating or not performing to the level that they should [referring to school] They might be feeling uncomfortable." (other service provider)

"They do [think skin sores are normal]. Sometimes I think, "Ooh, that's gross." I think I have more qualms about it than they do. Sometimes they want to hold your hand, and then you're, "Nng [chuckles]." And it's not because it could be infectious, but just because I think the culture, if you've got anything like that, you've got to do something about it. But they're quite happy. They have no qualms about it. No, I don't think it bothers them at all." (other service provider)

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

clinic not providing sufficient health education

(discussed by C, HP, OSP)

“The healthcare in these communities is really poor because they don’t teach us.” (carer)

“If they don’t educate they will all end up with that kidney and heart stuff.” (carer)

“The nurses should be out there educating people on the skin stuff, not just treating.” (carer)

“There needs to be... You know more treatment [education]. Say ‘bathe him in this’ or ‘wipe him with this.’ They don’t, they just give medicine.” (carer)

“I think we need to push to the AMS for more health promotion. And probably need someone to go visit the communities with pictures and the creams and what to do.” (carer)

“So it's different ways of looking at it, but I think education towards the kids about their health needs to be developed and maintained in a different way. And I think the health care professions needs to step in and do it, and not rely on the teachers to do it, because the teachers have enough other things they need to educate the things in. I think by getting a new face in, explaining, showing, and then it might be one or two things the kids remember later on that might prevent one kid to have boils or scabies or something like that.” (healthcare practitioner)

“The staff don’t even tell them what to do with the medication or how to get rid of the sores. They need to educate them you know? [...] The health clinic doesn’t even give them soap or any stuff to rub on the sores they only give them medicine and no other treatment – no information on it either.” (service provider)

“We're finding it hard pressed to get people to go to the clinic when their kids have gastro, just because they don't realize it's gastro. They just think they're having a runny-- Skin conditions, that whole thing about keeping dressings on sores and stuff, there needs to be education around it because as soon as kids go to the clinic, and their families are told they have to keep this on for a certain amount of time, it comes off straight away. [...] And all that kind of stuff, they're just like, "Yeah. But what else?" That's normal sort of. It's not fair for me to say that, but there definitely needs to be some awareness or education around it because people don't really see it as being anything different.” (other service provider)

actively encourage child/carers to go to clinic

(discussed by OSP)

“If there's something that I don't like the look of, I just get the mom to take them to the clinic, or I do. The clinic's literally next door to us, so it's not an issue. It's not hard taking them. It's not a long trip or anything.” (other service provider)

“We often tell them. “You need to get so and so and go to the clinic.”. Or yeah, in extreme cases we take them, but I know that’s not ideal because we’re not guardians.” (other service provider)

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

“We try and call the carer or the parent and say, “come and pick them up and take them”. And nine times out of ten they’ll come and take them. Whether they take them to the clinic or take them home is a moot point. If it’s really, really bad and we can’t find anybody, then we make a decision to take them up or whatever. Sometimes you just can’t get hold of the carer. You don’t know where they are. Typically, we try and get the parent or the carer to take responsibility.” (other service provider)

FACTOR:	predisposing	enabling	need
LEVEL:	client	provider	system

No quotes.

Table App D.1. Supplementary file 1: Prisma 2009 checklist

Section/topic	#	Checklist item	Report on pag #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	p1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number. Author comment: The abstract included in the manuscript was prepared in accordance with the ANZJPH guidelines.	p2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	p3
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	p3
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number. Author comment: The review procedures are provided in the methods section of the manuscript. No separate review protocol was prepared.	NA
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale. Author comment: This information is provided in the 'Search strategy' section of the manuscript.	p4
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	p4

Section/topic	#	Checklist item	Report on pag #
Search	8	<p>Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.</p> <p>Author comment: The broad key word search string provided in the 'Search strategy' section was used verbatim for searching all databases.</p>	NA
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	p4
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	p4
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	p4
Risk of bias in individual studies	12	<p>Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.</p> <p>Author comment: Given the wide range of study types we included in our review, we did not consider it possible to provide a standardised evaluation of bias in each of the studies. Instead we simply aimed to list a (non-exhaustive) list of methodological considerations for each included study to help the reader to critically reflect on the limitations of each study. These are highlighted in table 2 and expanded upon in the discussion section.</p>	p4 and table 2
Summary measures	13	<p>State the principal summary measures (e.g., risk ratio, difference in means).</p> <p>Author comment: Given the wide variety of study types, outcome measures and statistical methods encountered in the studies included in this review it was not feasible to identify principal summary measures. No form of meta-analysis was therefore undertaken. The focus of the review instead was on presenting each study's respective outcomes in a succinct manner.</p>	NA
Synthesis of results	14	<p>Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.</p> <p>Author comment: Considering the wide variety of study types and outcome measures employed throughout the studies included in this review, we did not perform any kind of meta-analysis. Methodological differences between the studies rendered it impossible to meaningfully directly compare outcomes of any two studies.</p>	NA
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	NA

Section/topic	#	Checklist item	Report on pag #
		Author comment: The risk of bias across studies has not been addressed in the current review, with exception of the methodological considerations highlighted in table 2 and the discussion section of the paper.	
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	NA
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	p5
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	p5-9, table 2
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12). Author comment: Considering the variety of study types included in our review and the lack of true randomised control trials we did not consider it feasible to provide a standardised evaluation of the studies in terms of a set of pre-defined markers of validity. Instead we have opted to highlight some of the methodological challenges we encountered in the included studies in the discussion section of our paper and table 2.	table 2
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot. Author comment: Study outcomes are reported in the results section with more detailed information provided in table 2. No standardised way of presenting study outcomes was feasible given the heterogeneity of the included studies.	p5-9
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	NA
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	NA
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	NA
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	p9

Section/topic	#	Checklist item	Report on pag #
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	p9-10
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	p9-10
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	p10

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: www.prisma-statement.org.

Publication details	Evidence level Study description Study area	#study site(s) sample size retention research staff	Reported findings relevant to health & wellbeing outcomes	Considerations
Carapetis JR et al. (1995) <i>Skin sores in Aboriginal children</i> peer-reviewed journal article	C1/B2 Observational; skin sore screening 1 month pre and 2 months post the opening of a swimming pool - recorded skin sore type, severity & distribution NT - Australia	1 community (unnamed) 109 schoolchildren (no age range provided) t0 = 81; t1 = 54 (26 seen at both surveys) Skin sore screening performed by Aboriginal health workers.	<9 year olds were most at risk of skin sores; Skin sore infections were found to be less severe post-pool; Severity of skin infections was overall lower in those children that reported swimming more than once per week (30% vs 57%, $\chi^2=3.38$, $p=0.05$), a difference that was most notable for <9 year olds (22% vs 56%, $\chi^2=4.15$, $p<0.05$); No difference found in skin sore prevalence, type or distribution overall.	Observational study Variations in pre/post pool study population; Self-reported swimming pool use Only 1 post-pool screening performed; Small sample size.
Peart A & Szoek C (1998) <i>Recreational water use in remote Indigenous communities</i> study report	D2 Cross-sectional audit via telephone administered surveys with community key informants NT, WA, QLD - Australia	39 communities: 13 with pool, 26 without 1 key informant per community Research staff details not provided	7/13 communities reported reduced infection rates since opening of pool (mostly skin, but also eye [2 communities] and ear [2 communities]) 4/13 communities reported social and wellbeing benefits 2/13 communities reported improved standard of hygiene 1/13 community reported the benefit of children no longer swimming in dangerous, polluted or unhygienic swimming areas, such as dams and sewage treatment ponds.	Outcomes purely anecdotal, no data provided to substantiate listed benefits
Lehmann D et al. (2003) <i>Benefits of swimming pools in two remote Aboriginal communities in Western Australia</i> peer-reviewed journal article	C1 + Q2 Observational; screening for skin sores (recorded severity & type) and ear infections (recorded tympanic membrane colour & position, presence of wax, cholesteatoma, perforations, otorrhoea); 4 visits over approximately 2 years (1 pre-pool, 3 post-pool) WA - Australia <i>See also: TICHR 2006, Lehmann et al 2010</i>	2 communities (Burringurrah & Jigalong) 162 under 17 year olds Community A: 61% seen twice, 43% seen three times, 14% seen four times Community B: 61% seen twice, 38% seen three times, 29% seen four times Screenings performed by team of paediatricians and ENT specialists	Burringurrah Skin sores: strong overall reduction in prevalence (62% to 18% - $p<0.0001$; $\chi^2 = 24.88$) and severity (except for t3: increase in severe pyoderma) The prevalences of any skin infection (sores, scabies, abscesses, fungal) at the four consecutive surveys were 64%, 51%, 43%, and 18% ($p<0.0001$; $\chi^2 =17.32$). Tympanic membrane perforations prevalence: gradual decline (32% to 13% - $p=0.04$; $\chi^2 = 4.32$). Decline was more rapid in resident children compared to those who were mobile. School attendance: proportion of children with attendance rates of at least 70% rose from 42% (t0) to 51% (t1), 65% (t2) and 67% (t3) Other benefits cited in interviews: social and emotional wellbeing, kids looked healthier and learnt to swim, positive feedback on no-school-no-pool policy, decline in petty crime noted No significant change in prevalence of otorrhoea Jigalong Skin sores: strong -although fluctuating- reduction in prevalence (70% to 20% - $p<0.0001$; $\chi^2 = 17.03$) and severity The prevalences of any skin infection (sores, scabies, abscesses, fungal) at the four consecutive surveys were 78%, 43%, 69%, and 20% ($p<0.0001$; $\chi^2 =25.16$). Tympanic membrane perforations prevalence: gradual decline from t1 onwards, although non-significant (40% to 18% - $p=0.14$; $\chi^2 = 2.18$) School attendance: proportion of children with attendance rates of at least 70% varied from 52% (t0) to 40% (t1), 33% (t2) and 54% (t3)	Observational study Limited control over environmental & socio-contextual factors No control communities included No measure of swimming pool use; Swimming pool closure in Jigalong might have affected study outcomes; Poor follow-up of individual children due to population mobility; Possible confounding effects due to the periodic field visits (which included paediatric consultation training of health and education staff and dissemination of best practice guidelines; 'Other benefits' mentioned are anecdotal, no data provided to support them.

Publication details	Evidence level Study description Study area	#study site(s) sample size retention research staff	Reported findings relevant to health & wellbeing outcomes	Considerations
			<p>No disease outbreaks reported in any community, 2 reports of faecal contamination, 2 reports of pool related trauma (broken arm in one community, mild concussion in the other)</p> <p>No other benefits cited, as this community was not interviewed.</p> <p>No significant change in prevalence of otorrhoea</p>	
<p>Telethon Institute for Child Health Research (2006)</p> <p><i>The swimming pool study</i></p> <p>research report</p>	<p>C1 +Q2</p> <p>Component 1 <i>See Lehmann et al 2003</i> This report adds 3 additional screening points (2003 to 2005)</p> <p>Component 2 <i>See Silva et al 2008</i> WA - Australia</p>	<p>Component 1 2 communities (Burringurrah & Jigalong)</p> <p>Component 2 2 communities (Jigalong & Mugarinya) No further details provided regarding study population and retention in this report, but some info provided in Lehmann et al 2003 and Silva et al 2008 Screenings and audit performed by paediatricians and ENT specialists</p>	<p>Component 1 <u>Burringurrah:</u> Skin sores: strong gradual reduction in general prevalence (62% @ t0 [pre-pool]; 10% @ t6) and prevalence of severe sores (30% @ t0 [pre-pool]; 2% @ t6) Tympanic membrane perforations prevalence: gradual decline, with some fluctuation (33% @ t0 to 15% @ t6); wet perforations also down but fluctuated (11% @ t0 to 5% @ t6) Other benefits cited (anecdotal): social and emotional wellbeing, kids looked healthier and learnt to swim, positive feedback on no-school-no-pool policy, decline in petty crime noted</p> <p><u>Jigalong:</u> Skin sores: strong fluctuations in prevalence and severity over study period Tympanic membrane perforations prevalence: wet and dry perforations fluctuated greatly throughout study period.</p> <p>Component 2 <u>Jigalong:</u> Clinical records indicate reduction in antibiotics prescriptions and diagnoses of skin, ear and respiratory diseases (no details provided in this report). <u>Mugarinya:</u> No outcomes presented for this community in this report.</p>	<p><i>See Lehmann et al 2003</i> <i>See Silva et al 2008</i> No statistical measures provided in this particular report to establish the significance of the study outcomes.</p>
<p>Silva et al. (2008)</p> <p><i>Effects of swimming pools on antibiotic use and clinical attendance for infections in two Aboriginal communities in Western Australia</i></p> <p>peer-reviewed journal article</p>	<p>C1</p> <p>Retrospective review of patient records, comparing annual morbidity and antibiotic prescription rates before and after the construction of a pool (1999 to 2005) WA - Australia</p>	<p>2 communities (Jigalong & Mugarinya) 259 under 17 year olds (131 in Jigalong, 128 Mugarinya) Audit performed by paediatricians</p>	<p>Jigalong Rates of infectious diseases declined from the pre-pool year to 2005 (ear infections -61% (annual decline = 15% - p<0.05; 95%CI -21% to -8%); skin infections -68% (annual decline = 15% - p<0.05; 95%CI -20% to -10%); respiratory infections -52% (annual decline = 10% - p<0.05; 95%CI -16% to -3%). Prescription rate decreased by 45% from pre-pool year to 2005 (annual decline = 11% - p<0.05; 95%CI -15% to -7%).</p>	<p>Observational study Limited control over environmental & socio-contextual factors No control communities included No measure of swimming pool use;</p>

Publication details	Evidence level Study description Study area	#study site(s) sample size retention research staff	Reported findings relevant to health & wellbeing outcomes	Considerations
			Mugarinya Trend analysis showed a decline in skin infections (annual decline = 11% - $p < 0.05$; 95%CI -20% to -1%). No significant changes in rates of other infections and antibiotic prescriptions.	Differences in available health services in both communities and population mobility might have affected outcomes
Sullivan et al. (2008) <i>Swim for life Nuiyu - aquatic recreation project</i> conference paper	C1 + Q2 Observational mixed methods evaluation of a program to promote use of the community swimming pool. Prospective pre/post program (1 year interval) comparison of health outcomes and other associated benefits. NT - Australia	1 community (Nuiyu Nambiyu) For health outcomes: 92 school age children screened pre-program, 72 post-program - no details provided about retention Screenings performed by local clinic staff (unspecified)	Health outcomes: trachoma follicles -55.1%; skin sores -57.2%; ENT referrals -100%; failed audiometry -100%; anaemia +595.4%; heart abnormalities (0 at both screenings), eye test failures (0 at both screenings) Physical activity: significant increase (anecdotal) School attendance: attendance improved (anecdotal) Social and community benefits of the program: professional development opportunities, employment opportunities, the swimming pool as a hub for social activities (anecdotal)	Observational study Limited control over environmental & socio-contextual factors No control community included No measure of swimming pool use; No statistical measures provided to establish the significance of reported outcomes; No details provided about how anecdotal benefits were documented; Only 1 post-program screening performed.
Rubin et al. (2008) <i>No School No Pool: Maximising the benefits of the community pool for remote Aboriginal and Torres Strait Islander communities</i> conference paper	Q2 Anecdotal qualitative study consisting of semi-structured telephone interviews with school staff members regarding perceptions and attitudes towards 'no school no pool' policies NT - Australia	11 communities 13 interviews, divided over 12 schools (school principals, deputy principals and teaching staff) Research staff details not provided	Schools running a 'no school no pool' program at the time of the study reported it to be effective in improving school attendance rates. Other reported benefits of the community swimming pool and the 'no school no pool' policy included improved classroom behaviour, swimming, fitness and water safety competence, improved self-esteem and improved hygiene and skin health.	Confounding likely since all schools ran other attendance schemes in parallel with 'no-school no-pool' policies All outcomes are purely anecdotal, no data provided to substantiate listed benefits.
Mathew et al. (2009) <i>Effects of swimming pools on antibiotic use and clinical attendance for infections in two Aboriginal communities in Western Australia</i> Letter in peer-reviewed journal	C1 + Q2 Observational; prospective screening for trachoma; retrospective review of clinical records for antibiotic prescriptions, ear and skin infections; key informant survey to document other benefits. SA - Australia	1 community (unspecified) 3 trachoma screening visits performed (pre-pool, pool + 6 months, pool +18 months): n0=45, n1=46, n2=59 ; 26 children were seen at all three visits (age range = 1 to 10) 166 children reviewed in audit of clinical files (age range = 1 to 15) 5 key informant interviews to document other potential benefits/barriers	Anecdotal - pool benefited the community in other ways (more exercise and recreation options, incentive to attend school). Proportion of children with follicular trachomatous inflammation remained low and unchanged (7% at t0, 7% at t1, 8% at t2) Trend of increasing rates of infection and prescriptions (unspecified)	Observational study No control community included No measure of swimming pool use; Hypo-endemic rates of trachoma Small sample size Population mobility might have affected outcomes Possible reporting bias in patient files

Publication details	Evidence level Study description Study area	#study site(s) sample size retention research staff	Reported findings relevant to health & wellbeing outcomes	Considerations
		All screenings performed by same person (doctor with ophthalmology experience) study details not provided in original publication, based on personal communication		High turnover rate of clinic staff may have affected outcomes of clinical audit
Lehmann et al. (2010) <i>Impact of swimming pools in remote Aboriginal communities in Western Australia</i> peer-reviewed journal article	C1 +Q2 <i>See Lehmann et al 2003; TICHR 2006; Silva et al 2008</i> WA - Australia	<i>See Lehmann et al 2003; TICHR 2006; Silva et al 2008</i>	<i>See Lehmann et al 2003; TICHR 2006; Silva et al 2008</i>	<i>See Lehmann et al 2003; TICHR 2006; Silva et al 2008</i>
Healthcare Planning and Evaluation (2010) <i>Evaluation of the sustainability and benefits of swimming pools in the Anangu Pitjantjatjara Yankunytjatjara landa (APY lands) in South Australia</i> research report	C1/C2 + D2 Observational study; prospective screening for ear (perforation, otorrhoea, tympanic membrane condition) and skin infections (prevalence, severity) over 2 years (2007 to 2009); oral survey to record community attitudes and practices regarding the swimming pools. SA - Australia	4 communities (3 with pool, 1 without) 262 children (<1 to 19 year olds) for health screening 4 6-monthly screenings performed in communities with pool; 3 in communities without pool 55% of children seen once, 31% seen twice, 10% seen three times, 4% seen four times Screenings performed by team of doctors.	Overall decline of prevalence and severity of skin sores throughout study period. In the two communities with pre-pool data reductions in prevalence (32% no sores pre-pool; 78% no sores one year after opening pool; $Z=3.362$, $p<0.001$) and severity (25% with severe skin sores pre-pool; 6% with severe skin sores one year after opening pool) of skin infections were recorded after the opening of pools. Other benefits of pools reported on: children more active, alternative to other hazardous/unsafe/polluted swimming areas, skin health seemed to improve when pools open, no school no pool seen as a positive encouragement for kids to go to school, way of building skills in young people by engaging them in supervisory and teaching tasks, provides employment opportunities, provides safe and healthy atmosphere for young people to interact, may potentially lead to reduced criminal activities by youth. No evidence for improved school attendance rates due to no-school-no-pool policies No decline in prevalence of wet and dry tympanic membrane perforations throughout study period.	Observational study Limited control of environment & socio-contextual factors Annual school attendance rates provide little insight in terms of potential pool benefits (only open in summer); No measure of swimming pool use; No data provided to support other (anecdotal) benefits; Population mobility a limitation to the study; Unforeseen swimming pool closures might have affected study outcomes; Annual ear disease data is aggregated over all 4 communities (3 with pool, 1 without); No pre/post pool comparison for ear disease data; Composition of team of doctors changed after 1st screening visit

Publication details	Evidence level Study description Study area	#study site(s) sample size retention research staff	Reported findings relevant to health & wellbeing outcomes	Considerations
Sanchez et al (2012) <i>An evaluation of the benefits of swimming pools for the hearing and ear health of young Indigenous Australians: A whole-of-population study across multiple remote Indigenous communities</i> research report	B2 Retrospective intervention cohort study (2009 to 2011); regular screening of schoolchildren for ear health outcomes (acuity, perforations, middle ear function). SA - Australia	11 communities (4 with pool, 7 without) 813 schoolchildren (5 to 18 year olds) seen for screening 8 largest communities visited 6 times (twice annually) 2 smaller communities visited once annually 1 community not visited, inhabitants expected to come to screening in nearby community 45,8% of children seen on more than two occasions Audiologists and ENT specialists performed screenings (same core research team for all visits)	No statistical difference observed between pool and non-pool communities in the percentage of children failing audiometric tests. No evidence of a differing risk for closed ear disease as seen in Type B tympanograms associated with pool and non-pool communities. No difference between children in pool and non-pool communities in the frequency with which perforations with active or inactive ear disease were present. No difference found in median school attendance between pool and non-pool communities.	Observational study Limited control of environment & socio-contextual factors analyses limited to aggregated pool vs non-pool communities Swimming pool use only measured indirectly, using school attendance as a proxy; Possibility of children of the control communities having had access to pools in intervention communities. Study population does not include pre-school children.
Stephen et al (2013) <i>A randomised controlled trial to examine the impact of swimming on Aboriginal children with chronic suppurative otitis media.</i> peer-reviewed journal article	B1 Randomised control trial comparing two groups of children with tympanic membrane perforations over a 1 month period (otorrhea, microbiology of nasopharynx & middle ear): Group 1 was provided with daily swimming lessons, Group 2 was not allowed to swim and was offered other daily activities. swimming directly observed NT - Australia	2 communities 89 schoolchildren (5 to 12 year olds); 41 swimmers; 48 non-swimmers 92% of participants were screened both at baseline and post-intervention examinations performed by nurses & doctors, trained to ensure standardisation of assessments	After 4 weeks, 24/41 swimmers had signs of ear discharge compared to 32/48 non-swimmers, [RD: -8% (95% CI: -29 to 12)]. There were no significant changes in the microbiology of the nasopharynx or middle ear in swimmers or non swimmers. <i>S. pneumoniae</i> and <i>H. influenzae</i> were the dominant organisms cultured from the nasopharynx. <i>H. influenzae</i> , <i>S. aureus</i> and <i>P. aeruginosa</i> were the dominant organisms in the middle ear.	Study was underpowered; Possibility of children in the control group having swam during course of study; lack of objective measures for study outcomes (inter-observer discrepancies possible) Outcomes might differ with exposure greater than 1 month.

Table App D.2. Supplementary file 2: Detailed version of Table 2 (Summary of health and wellbeing benefits reported in studies included in this review)

Figure App D.1 Supplementary file 3: Swimming pools literature review - study information sheet

Publication details

Title:

Authors:

Year:

Type:

Study details	
Study period	
Study area	
Study description	
No. of included communities with and without pools	
Use of control groups or communities?	
Total sample size	
Age range	
Number of research visits	
Retention rate of sample across visits	
Was there dosage measure of pool use?	
What was assessed?	
How was it assessed?	
Description of research staff	
What outcomes were reported?	
Considerations and comments offered by authors?	