Evaluation of the One Disease Crusted Scabies Elimination Project

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List of Abbreviations

ACCHS	Aboriginal Community Controlled Health Service
AHW	Aboriginal Health Worker
AHP	Aboriginal Health Practitioner
CARPA	Central Australian Rural Practitioners. Association Inc Standard Treatment Manual (7th Edition)
CDC	Centre for Disease Control
CIS	Clinical Information Systems
CS	Crusted Scabies
CQI	Continuous Quality Improvement
GP	General Practitioner
IC	Integrated Care
KPI	Key Performance Indicator
KWHB	Katherine West Health Board
NfP	Not-for-profit
NT	Northern Territory
OD	One Disease
PCIS	Primary Care Information System
PHN	Primary Health Network
QoL	Quality of Life

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Executive Summary

Evaluation

The evaluation is addressing four key questions:

- Area 1: How and to what extent has the program been implemented and what are the barriers and enablers to implementation in different settings and for different client groups?
- Area 2: What are the impacts on patient and service outcomes including the numbers of new cases, the number of recurrences in primary health care and hospital activity?
- Area 3: What are the impacts on patient experience and patient-reported quality of life outcomes?
- Area 4: What is the cost-of-illness in the Northern Territory?

Methods

This is a mixed methods evaluation drawing on qualitative and quantitative data from key reports and documents, interviews and focus groups with key stakeholders and program staff and an audit of patient records. A total of 27 stakeholders participated in interviews or a focus group between March and July 2018. Patients were included in the audit if they had an episode between 1st of July 2016 and 1st March 2018 and had records on the Northern Territory's shared electronic health record. The audit period extended from date of the first episode of CS after the 1st of July 2016 until 1st May 2018 and for an equivalent number of months before this initial episode. Detailed methods are provided for each area of evaluation.

The CS Elimination model

One Disease is a non-government, not-for-profit, philanthropically funded organisation that has a long-term goal to eliminate Crusted Scabies from Remote Australia by 2022. It has been working with health services in the NT since 2010 and began implementing a structured approach to eliminating crusted scabies from communities in the NT in 2016. This culminated in the development of an Elimination Plan and coincided with the introduction of a mandatory notification system for crusted scabies in the Northern Territory. The elimination plan articulates the following key objectives:

Goal 1: To improve detection and diagnosis of Crusted Scabies
Goal 2: To prevent reoccurrence and ensure treated clients live in a "Scabies-Free Zone"
Goal 3: To explore and destigmatise CS so that clients and families feel comfortable seeking care from health professionals
Goal 4: To develop a sustainable model of coordinated care that can be replicated in other diseases in remote Indigenous communities

Key Evaluation Findings

A well regarded strategy

The OD program is a well-regarded strategy that fits within the health service context and is acceptable to participating providers. Implementation of the program is well established in Top End services and providers have invested significant time and commitment into working together with OD staff to implement it.

A variety of strategies that support diagnosis, treatment and management

The program has strategies to improve knowledge, influence attitudes and change procedures through which providers deliver services and work with communities to achieve improved outcomes. Education, support and coordination help people to access and complete treatment, establish a scabies free home environment and assist treated patients to engage in ongoing self-management and routine screening to prevent recurrences, in the context of overcrowded housing and poor living conditions. These services have not routinely been available for CS patients in the Top End.

A dedicated focus, flexible approach and respectful relationships are highly valued

Stakeholders value the dedicated resources and focus on CS, provision of staff development, training and technical expert advice and the capacity for timely, practical support and education. The partnership approach, familiarity and knowledge of OD staff with the NT health service and remote community context, as well as the focus on building respectful relationships through two-way learning with clients and communities were deemed as important to the perceived success of the program as the work itself.

Treatment is improving in hospital and the community

Audit data shows that the program is improving treatment completion and trends in recurrences are positive. The most significant impact of the program on care processes is the increased length of hospital treatment which has more than doubled in the period following July 2016 compared with the period prior, suggesting that patients are more often completing treatment in hospital. The length of treatment also generally matched the grade of disease and most patients had a clear skin scraping on discharge. This is a remarkable achievement for a NfP organisation which has had to establish relationships and work across multiple organisational boundaries to influence care pathways and support clients.

Other processes of care in the community also improved. Data showed that following the completion of hospital treatment, more frequent contact was provided in the community. This is a positive result, particularly as the patient cohort have high levels of disadvantage that pose a challenge to delivering recommended treatment in the community. Half were homeless, and all of those who were homeless also had a chronic condition that could impair immune function, in particular end-stage renal disease. The duration of treatment was shortest among patients with alcohol dependence, especially when the patient was also homeless. Substance abuse was a common factor in the majority of patients with frequent recurrences of CS and these individuals had poor contact with health services after discharge.

Recurrences are reducing

Overall trends in recurrence were positive. The majority of patients with an initial episode of CS after July 2016 did not have a recurrence during follow-up. Only 4 of 26 patients with an initial episode after July 2016 had a recurrence and it appears these were acquired in the community. Of 16 individuals with a recurrence prior to July 2016, only 5 had a recurrence after July 2016. None of these new recurrences had more than 2 episodes during the follow- up period. In all but one case the grade of disease was less at the recurrence. Duration between episodes is six months or more, before which the disease is seen as a recrudescence of incomplete initial treatment. The hypothesis that the disease was reacquired in the community is supported by the long length of initial treatment and the presence of a clear scraping in 4 of the 5 cases.

Scabies free zone is the hardest to implement

In the context of endemic scabies, maintaining a scabies free zone is challenging as it requires coordination of contact tracing and treatment of all household members, and is dependent on good relationships and the active involvement of communities and individuals. Many stakeholders stressed that Aboriginal leadership is critical for building relationships and working with communities and households to provide education and support for a scabies free environment. This may be challenging in the context of difficulties recruiting and retaining the Aboriginal health workforce, particularly in remote communities.

Elimination

Together these results highlight the major challenge in moving towards elimination of crusted scabies. While there have been marked improvements in initial hospital treatment, these disadvantaged patients are then returning to scabies endemic environments. In this context, there is always a risk of re-infection and without measures to markedly decrease scabies prevalence, it may be that what can be achieved is control of crusted scabies, with detection of the disease at an early stage and high quality initial treatment, rather than elimination.

While potential for elimination is as yet uncertain, progress towards establishing elements of an elimination approach have been made. The OD program has worked closely with the NT Government Centre for Disease Control and service providers to improve accurate diagnosis through applying the CS case description, support implementation of standardized treatment protocols (CARPA), and work towards effective recording and reporting systems. The program has well defined objectives with identified timeframes for elimination and includes coordination strategies to improve vertical integration of care across primary and secondary care as well as horizontal strategies to strengthen primary care systems and provide support to clients in the community. Mentoring, support and training of an Aboriginal health workforce to lead community development and education is needed

The cost of illness

The expected health care cost per patient diagnosed with CS is $31,209.20 resulting in an overall cost of $1,373,204.87 for managing all patients diagnosed in the Northern Territory in a given year. This includes the costs associated with diagnosing, treating patients in hospital, and follow-up care relating to the patient and members of their family and household. By far the biggest component of the health care costs falls on the public hospital system. The COI results show that for every episode of CS prevented the health care system can expected to save $31,209.20.

Scalability

The NT context of notification for CS, together with long standing involvement of PHC services in community based scabies control programs provides a unique context for implementation of the OD program that may not be in place in sites in WA and QLD where roll-out of the program is planned. Notification of CS in the NT has arguably provided a mandate for a focus on CS and a rationale for developing coordination strategies that promote vertical integration of care pathways and data collection systems that are needed in elimination programs.

Scaling up requires an assessment of need and the alignment of policy context, as well as an assessment of the likely acceptability among stakeholders and the organizational, technical, human and financial resources required to deliver the program effectively. Lessons from the NT experience suggest a strong policy fit, identified need, and widespread adoption among stakeholders. Factors that appear to be important to the success of the program, as outlined above, include having a mandate to address crusted scabies; a partnership approach with strong leadership from people with a deep knowledge of the local context and ways of working, as well as respectful two-way learning which fosters trust and good relationships with communities and individuals. Engaging the Aboriginal health workforce early and providing mentored support for a leadership role in community development for scabies-free zones could be expected to assist with filling what is a perceived gap in service at the household level.

1. Introduction

Purpose of the report

This report presents the findings of the evaluation of the One Disease Crusted Scabies Elimination project. The evaluation was undertaken through a partnership between One Disease and a consortium from the Public Service Research Group at the University of New South Wales Canberra, the ANU Medical School, Australian National University and The Centre for Health Economics Research and Evaluation (CHERE), University of Technology Sydney.

Evaluation aims

The evaluation covers the period from 1 July 2016 to the present. The start date represents the time when the project entered into a structured implementation phase and adopted a formal approach to eliminating crusted scabies from communities in the Top End of the Northern Territory (NT).

The aim of the evaluation is to assess the extent to which the program has been implemented and to determine whether it has met its key objectives for improving the detection, management and follow-up of CS, reduced the number of new cases and recurrences and to determine the cost-of-illness for crusted scabies in the NT. Lessons from the evaluation will inform a planned roll-out of the program to Western Australia and Queensland services beginning in 2019.

Evaluation questions

The key overarching evaluation questions are:

> Area 1: How and to what extent has the program been implemented and what are the barriers and enablers to implementation in different settings and for different client groups?
>
> Area 2: What are the impacts on patient and service outcomes including the numbers of new cases, the number of recurrences in primary health care and hospital activity?
>
> Area 3: What are the impacts on patient experience and patient-reported quality of life outcomes?
>
> Area 4: What is the cost of illness of crusted scabies in the Northern Territory?

As agreed with One Disease, Area 3 of the evaluation consists of a pilot to adapt, develop and apply a QoL instrument for Aboriginal people that is appropriate to assess their patient-reported quality of life outcomes. The data for this component of the evaluation are currently being collected by One Disease staff and on the basis of current recruitment projections, it is anticipated sufficient data may be available to the evaluation team for analysis in early 2019.

It is expected that this component of the evaluation (Area 3) together with the cost of illness study (Area 4) will provide a foundation upon which further work can be commissioned by OD to conduct a full cost effectiveness study of the program as its expands into Western Australia and Queensland.

Methods

This is a mixed methods evaluation drawing on qualitative and quantitative data from key reports and documents, interviews and focus groups with key stakeholders and program staff and an audit of patient records. Interviews with clinicians and other stakeholders associated with the program were held between March and July 2018, either face-to- face in Darwin and remote health centres or via phone. Interviews took anywhere between 20 minutes and one hour to complete. Two focus groups were also held; one with staff in a remote health clinic and another focus group with One Disease staff. With the permission of the stakeholders interviews were digitally recorded and transcribed verbatim then uploaded into QSR International's NVivo 11 Software to assist with data management, including coding and analysis.

OD staff conducted the audit of patient's electronic health records. Patients were included in the audit if they had an episode between 1st of July 2016 and 1st March 2018 and had records on the Northern Territory's shared electronic health record. The audit period extended from date of the first episode of CS after the 1st of July 2016 until 1st May 2018 and for an equivalent number of months before this initial episode. Data were manually extracted from the shared electronic health record by the OD team into an excel spreadsheet. The data extraction template was developed by a member of the evaluation team (JA) with input from OD. The variables for the data extraction were determined from reviewing the CARPA guidelines for treatment of CS and developing a program logic for the OD program of work and a patient's expected treatment journey.

Detailed descriptions of the methods employed to answer each of the evaluation questions are provided in each of the relevant sections.

Ethics

Ethics approval for the evaluation was obtained from the Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research and the Aboriginal Ethics Sub-Committee (AESC) of NT (Ref: 2017-2940) on 2 March 2018. Approvals were obtained from NT Department of Health for participation of primary care and hospital services; from the NT Centre for Disease Control (CDC) for access to CDC data; and from three Aboriginal Community Controlled Health Service Boards who agreed to participate in the evaluation. Two other Community Controlled Health Organisations that were approached did not respond.

Following this introduction, the report is set out across 7 sections. A background and context section draws on literature and relevant reports to provide a description of the prevalence of CS, interventions to address it and the NT health context into which the program was introduced. Section 3 describes the One Disease model, its history and current strategies employed. Section 4 provides an assessment of service and patient outcomes. Section 5 presents the Cost-of-Illness study. Section 6 draws on interview data to describe barriers and enablers to implementation and provider perceptions of key success factors. Section 7 outlines the Quality of Life Pilot and early findings. Key findings and conclusions are discussed in the final Section 8.

2. Background and context

Crusted Scabies

Scabies is one of the most common dermatological conditions in the world (Swe, Christian, Lu, Sriprakash, & Fischer, 2017), affecting more than 130 million people at any one time (World Health Organisation (WHO, 2017). It is also the most prevalent and neglected ectoparasitic infestation (S.S. Wong et al., 2015) responsible for 0.07% of the total burden of disease (Karimkhani et al., 2017). Caused by the mite *Sarcoptes scabiei*, scabies often results in severe itching, and in patients with compromised immunity it may progress to "crusted scabies" (CS). Crusted scabies (or Norwegian scabies) is a severe variant of scabies caused by a hyperinfestation of the same mite that causes ordinary scabies (Strong & Johnstone, 2007). While scabies infestations typically involve 5 to15 scabies mites (Huekelbach & Feldmeier, 2006), individuals with crusted scabies (CS) can have in the range of thousands to millions of mites, making them significantly more contagious and easily able to cause significant outbreaks. CS varies in severity from mild to severe (Bouvresse & Chosidow, 2010; Huekelbach & Feldmeier, 2006; Strong & Johnstone, 2007). However the fissures associated with CS provide a portal of entry for bacteria, potentially resulting in secondary infections, glomerulonephritis, rheumatic heart disease, sepsis and death (Thornley et al., 2018). Worldwide CS most commonly affects people with immunodeficiencies, developmental delay and malnutrition (Roberts, Huffam, Walton, & Currie, 2005)

In Australia, scabies is uncommon in urban areas and regional towns, but is endemic in remote Aboriginal communities in the Northern Territory, which have among the highest reported rates of the condition in the world (Romani et al., 2015a). An average monthly prevalence of 13.4% has been reported in some communities and children carry the major burden of disease with a higher average monthly prevalence of 22.7% for under 3 year olds (Andrews, McCarthy, Carapetis & Currie, 2009). It is estimated that up to one third of all Aboriginal and Torres Strait Islander children who live in remote communities have been affected by scabies, and that in some communities the point prevalence of scabies has been measured at as high as 50% (Romani, 2015a; Currie, Connors, & Krause, 1994). Sixty three percent of children had sought treatment at local medical clinics by 12 months of age in a study conducted by Clucas et al. (2008). In 2016, the CS burden in remote Aboriginal communities of the Northern Territory was estimated as 2.4 per 1000 population, however there is a significant gap in research to accurately describe this burden outside of these communities (May et al., 2016). Risk factors for transmission of scabies and crusted scabies in the NT include overcrowding, a high burden of chronic disease and high levels of mobility within and between communities.

Transmission is most common through skin-to-skin contact, fomite spreading, and contaminated environments (May et al., 2016). Mites can live off the body for 3-5 days in optimum conditions (warm temperature and high humidity). People with CS are core transmitters of scabies mites, as shedding skin can result in the spread of thousands of scabies mites to members of the household and community (Heesterbeek et al., 2015). In addition, they often have other chronic conditions that may impair immune function, making them highly susceptible to reinfection from people with simple scabies and leading to recurrences. This cycle of reinfection between people with CS and simple scabies, underpins the proposition that the elimination of CS is a crucial first step to addressing scabies (Engelman & Steer, 2018; Feldmeier & Heukelbach, 2009; Worth et al., 2012).

Various countries and organisations have identified scabies control as a public health priority Tropical Diseases recently recommended that scabies be included in the Neglected Tropical

Disease profile in category A (International Alliance for the Control of Scabies (IACS), 2018; WHO, 2012, 2017, 2018). In Australia CS was listed as a notifiable disease on 2nd March 2016 in the NT. It is hoped this will provide the opportunity into the future for more accurate estimates of disease burden and facilitate a sustainable treatment system (Quilty, Kaye, & Currie, 2017).

Interventions addressing Scabies and Crusted Scabies

Treatment strategies for scabies and CS range from treating individuals and their contacts, to mass drug administration (MDA) strategies, treating whole communities at once (Abedin et al., 2007, Haar et al., 2014, Heukelbach et al., 2004, Kearns et al., 2015, Lawrence et al., 2005, Mohammed et al., 2012, Pruksachatkunakorn et al., 2003, Romani et al., 2015b). Drugs include oral ivermectin as well as a range of topical treatment options such as permethrin (Lyclear) and benzyl benzoate lotion. Elimination of scabies and CS is difficult as cured patients often get re-infected.

Community based scabies and healthy skin programs have been conducted in remote Indigenous communities in the NT since the late 1990s (Carapetis et al., 1997; Dowden 1999; L.C. Wong et al., 2002) with variable results. Programs include those that have focused solely on the mass community administration of drugs, for example, ivermectin or benzyl benzoate lotion, without implementing a community based program or education to complement this (Kearns et al., 2015) as well as programs that have combined active screening regimes and annual treatment days with health education initiatives and environmental interventions (L.C. Wong et al., 2001, 2002). Whilst mass drugs administrations (MDAs) initially result in decreased prevalence of scabies and crusted scabies, decreases are rarely sustained. The impact of MDA of ivermectin in a remote Australian Aboriginal community in 2015 for example found that scabies prevalence fell from 4% at baseline to 1% after six months, however after 12 months of MDA, prevalence rose to 9% and there was a sustained association with an identified exposure to crusted scabies case, that saw an increase in prevalence to 14% and a number of new infections (Kearns et al., 2015).

A Healthy Skin project that combined active screening regimens and annual treatment days with health education initiatives and environmental interventions was shown to successfully reduce and maintain a lower rate of community scabies for more than 15 months post-intervention and at a fraction of the cost of the tertiary health care required for scabies (L.C. Wong et al., 2001, 2002). L.C. Wong et al. (2002) therefore argued that sustainable programs need to integrate community-wide treatment with education and community involvement, both in the design and implementation of the program, stressing the importance of personal relationships between team members. Such programs have been successfully replicated in a number of Australian Indigenous communities to address scabies, however the extension to application in crusted scabies has yet to be observed in literature (Carapetis et al.,1997; Custodio et al., 2016; Estrada, Chavez-Lopez, Estrada-Chavez, & Paredes-Solis, 2012; L.C. Wong et al., 2001, 2002)

In remote Aboriginal communities in the Northern Territory, poor housing, overcrowding, high burden of chronic disease, and movement between communities are key factors that increase likelihood of transmission. Addressing any of these factors may increase the impact of programs on reducing transmissions, yet there is a paucity of research on program design and implementation and we know little about the combination of strategies that might improve program sustainability.

Multi-sectoral and interactive programs and models of care for the detection, management, treatment, recurrence prevention, and elimination of crusted scabies are needed to address the high prevalence of scabies and its relationship with poor housing and overcrowding, and the disproportionately high burden of crusted scabies on Indigenous populations in remote communities. There is widespread agreement that the priority in the control (and by extension elimination) prospects for scabies and crusted scabies are dependent on accurate definitions of target and priority populations, appropriate community-based control measures that not only treat the disease but also address the underlying social determinants of poverty associated with scabies and crusted scabies (WHO, 2012). Moreover, government and community buy-in to these programs in the form of resources and expertise is needed (Engelman et al., 2013; Hay et al., 2012, 2014).

Elimination

Elimination is a key long term goal for One Disease whose aim is to eliminate crusted scabies from Australia by 2022. Eradication and elimination have been subject to much debate regarding their definitions, the effective public health initiatives needed to undertake them, and the many complexities involved in achieving them (Dowdle, 1999). Eradication has been defined in a number of ways, with a hierarchy of interventions involved in public health efforts for dealing with infectious diseases. The most well-known hierarchy was developed in 1999 by the CDC (Dowdle, 1999):

- "Control: The reduction of disease incidence, prevalence, morbidity or mortality to a locally acceptable level as a result of deliberate efforts; continued intervention measures are required to maintain the reduction. Example: diarrhoeal diseases.
- Elimination of disease: Reduction to zero of the incidence of a specified disease in a defined geographical area as a result of deliberate efforts; continued intervention measures are required. Example: neonatal tetanus.
- Elimination of infections: Reduction to zero of the incidence of infection caused by a specific agent in a defined geographical area as a result of deliberate efforts; continued measures to prevent re-establishment of transmission are required. Example: measles, poliomyelitis.
- Eradication: Permanent reduction to zero of the worldwide incidence of infection caused by a specific agent as a result of deliberate efforts; intervention measures are no longer needed. Example: smallpox. Extinction: The specific infectious agent no longer exists in nature or in the laboratory. Example: none."

There are four key criteria or principle indicators for whether a disease would be eradicable: biological, economic, social and political (Dowdle, 1999). The biological criteria require that an effective intervention is available to interrupt transmission of the agent; practical diagnostic tools with sufficient sensitivity and specificity are available to detect levels of infection that can lead to transmission; and humans are essential for the life-cycle of the agent, which has no other vertebrate reservoir and does not amplify in the environment (WHO, 2018; Dowdle, 1999). The economic criteria require the determination of whether elimination or eradication programs are economically sustainable, or whether there are alternative health interventions that are more effective (as the result of an evaluation of the cost and benefits of eradication programs versus health interventions, whilst considering the direct and consequent effects of both of these interventions) (Baguelin et al., 2012; Dowdle, 1999; Jit, Choi & Edmunds, 2008; Klepac et al., 2015

The social and political criteria carry with them a number of related factors that are necessary for their satisfaction. The success of disease eradication initiatives is almost entirely dependent on sustained societal and political commitment through its design and implementation (Dowdle, 1999). As these initiatives generally bring with them considerable economic and resource/infrastructure burden, they are generally given more scrutiny and less commitment from governments (especially considering their long term goals and impacts, compared to short term outputs). There needs to be perceived social appeal and interest in the disease that recognises it as an issue of public health importance and that there are clear reasons for eradication that will maintain support (Dowdle, 1999). The interventions must be feasible and developed by technical experts as well as in consultation with affected communities. Finally, it is important that these programs have "a well-defined scope with a clear objective and endpoint, and the duration is limited. Successful eradication programmes produce sustainable improvement in health and provide a high benefit cost ratio" and also "must address the issues of equity and be supportive of broader goals that have a positive impact on the health infrastructure to provide a legacy in addition to eradication of the disease' (Dowdle, 1999).

In reflecting on the success of the eradication of smallpox, Henderson described the strength of the small pox eradication program as related to it being embedded within existing health service structures and using local resources such as teachers and village elders. He highlighted the importance of setting measurable goals and not simply relying on a medical model when considering future approaches to eradication and /or elimination of disease. Klepac et al. (2015) argued that eradication and elimination programs require a targeted vertical approach in addition to what control programs offer which are usually integrated in horizontal programs focused on strengthening primary care, improving surveillance and training personnel.

Ultimately elimination or eradication programs require extensive surveillance and continuation of control interventions, as well as ongoing social and political support to be effective (Dowdle, 1998). They demand high standards of performance and dedicated services (Klepac et al., 2015). Considering the potential cost, resources and social and political will required to drive eradication and elimination programs, coupled with the fact that few diseases have been eliminated globally and in view of the minimal research and measurement of burden conducted on CS, it might be expected that the elimination of crusted scabies in the Australian Indigenous population will be difficult.

While this evaluation does not address the issue of elimination, it aims to contribute insights into program implementation, impact and cost in order to inform future efforts in the roll-out of the program to WA and QLD, and these could be expected to underpin future work that will be required to inform potential for elimination.

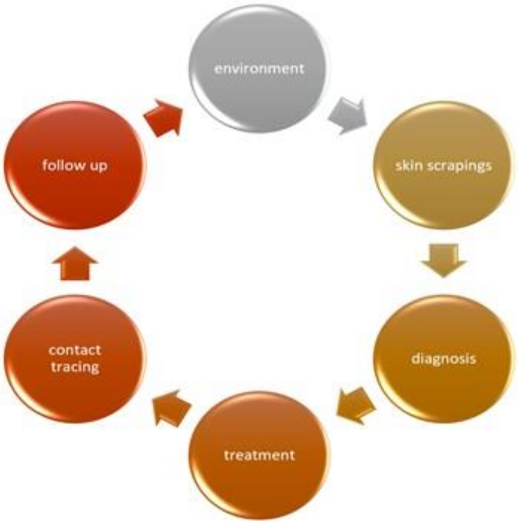
Northern Territory health service delivery context

The NT primary health service sector consists of 25 Aboriginal Community Controlled health clinics and over 30 NT Government primary care clinics across regions in the Top End of the NT. Major hospitals are in Darwin, Katherine and Gove and key infectious disease and skin specialists oversee diagnoses and treatment regimens for CS patients. Various aspects of diagnosis and treatment for individual CS patients in the NT are complex. Stigma and shame associated with having CS can make patients reluctant to seek care. Extended treatment periods of 3-4 weeks in a hospital isolation ward away from community is also difficult for many patients and it is common for patients not to complete hospital treatment. Studies have shown that limited opportunities for privacy in overcrowded households (Hay et al., 2012; Currie et al., 1994) and poor housing hardware (Bailie et al., 2005) are major barriers to ongoing prevention and treatment.

The Central Australian Rural Practitioners Association (CARPA) Standard Treatment Manual has recently been updated to include new guidelines for scabies and crusted scabies treatment processes and grading scales, based on work undertaken by the East Arnhem Scabies Control Program Medical Working Group. These changes together with the inclusion of CS as a notifiable disease in the NT change the way CS is diagnosed, managed and followed up in the NT.

Under the new guidelines, diagnosis and treatment are carried out in the following steps (Davis et al., 2013).

- Skin scrapings with laboratory testing and clinical confirmation from an Infectious Disease Specialist confirms a diagnosis of CS
- Diagnosis is graded into one of three categories, based on clinical assessment in four key areas: the distribution and extent of crusting; the depth of crusting; the degree of skin cracking and pyoderma; and the number of previous episodes
- A treatment phase is almost always provided in hospital for confirmed CS cases,
- Contact tracing and treatment for all household contacts, involving an initial application of cream to the whole body, followed by an additional treatment 7 days later,
- The creation of a scabies-free home for patients returning home from hospital, and
- Lifelong follow up including regular skin checks for people who have had CS



This new emphasis on accurate diagnosis and comprehensive treatment in the context of notifiability makes the need for a coordinated health response essential. Achieving a coordinated response involves working together to establish accurate data on the numbers of cases under the new case definition, as well as working vertically between specialists, hospitals and PHC clinics to improve access to services and promote continuity of care for clients across the treatment spectrum, and horizontally between clinics, public health environmental and community services and households to support scabies-free households and follow-up screening for treated clients.

In PHC clinics, clinical information systems are well set up to manage chronic conditions through recalls and electronic care planning. PHC services also work together with environmental health programs to improve housing hygiene through spraying, rubbish removal and healthy skin days in the community. Achieving and maintaining a scabies free home environment depends on clinics having good relationships with communities and is difficult in overcrowded houses in communities with high prevalence of scabies where travel between households and communities is common and weather conditions favour mite replication. In addition, the high prevalence of scabies in Indigenous communities is said to have led to a culture of acceptance of scabies and skin sores both in health clinics and in communities (Thomas et al., 2017) and this may have resulted in a less aggressive approach to treatment than the new guidelines for CS promote. Shifting attitudes among health service providers and in the community is therefore a key requirement for implementation of the new guidelines.

Workforce turnover is also a significant barrier to implementation of the guidelines. Nursing staff are often recruited on short term contracts, as new graduates from major cities with limited knowledge of remote Aboriginal communities. Ongoing education on the management of CS is therefore essential. There are also difficulties in maintaining the Aboriginal health practitioner workforce and this is particularly problematic given how important this workforce is in facilitating linkages with communities and promoting the personal approach to engaging communities as partners in managing ongoing CS prevention (L.C. Wong et al., 2002). The most recent Australian Institute of Health and Welfare Online Services Report for Aboriginal and Torres Strait Islander health organisations 2016-17 found that two- thirds of services reported significant challenges in recruiting, training and supporting Aboriginal and Torres Strait Islander staff and staffing levels, and over half (57%) reported staff retention and turnover as a challenge. Very remote services were more likely to report staff retention and turnover as a key challenge and experienced difficulties with recruitment, training and support of Aboriginal and Torres Strait Islander staff (75% compared with 67% overall) (AIHW 2018).

A high burden of disease in the community also means PHC services can be overwhelmed by demands for acute and chronic care and time to coordinate care across hospital, PHC and household boundaries can be difficult. The growing burden of chronic disease in communities is likely to place continued pressure on services. The need for care coordination is critical and may increasingly be recognised in policy, such as through funding provided to Primary Health Care Networks (PHN) for integrated team care. This funding is to improve the health outcomes for Aboriginal and Torres Strait Islander peoples with chronic health conditions through better access to coordinated and multidisciplinary care and to close the gap in life expectancy by improving access to culturally appropriate mainstream primary care services. A number of ACCHS in the Top End have received funding for care coordinator positions.

Summary

The NT context for implementation has elements that are both supportive and challenging for embedding OD program elements and achieving key objectives. First, the program is addressing a recognised health priority. Scabies and crusted scabies are identified public health issues in Indigenous communities in the NT that carry a significant (though not yet fully quantified) burden of disease. Previous experience in implementing scabies control programs in the Top End has contributed to an accumulating evidence base that has highlighted risk factors for transmission in the NT (overcrowding, poor living conditions and mobility between communities), identified partnerships with communities as critical to the implementation of successful programs and emphasised the difficulties of sustaining strategies over time. The cycle of reinfection between people with CS and simple scabies underpins the proposition that the elimination of CS is a crucial step in addressing scabies and provides a rationale for the OD approach.

The recent inclusion in 2016 of CS as a notifiable disease in the NT creates an imperative for addressing CS and the coalescence in timing with implementation of the OD program allows the development of the kinds of vertical and horizontal strategies that international evidence shows are key components of elimination programs and necessary for embedding system changes. Accurate case description, standardized treatment and effective recording and reporting systems underpin elimination programs.

In the NT, recently updated CARPA guidelines for identifying and managing CS together with a PHC context that is well set up for managing chronic disease through electronic recall and care planning systems are important facilitators for accurate diagnosis, treatment and ongoing monitoring for patient with CS in primary care. Other factors such as stigma that may prevent affected people from seeking treatment and the high prevalence of skin sores that has reportedly led to a culture of acceptance among providers and communities suggest a need for supporting attitudinal change. Also challenging are difficulties in recruiting and retaining an Aboriginal and Torres Strait Islander health staff workforce who are critical to elimination programs. Coordination roles that enable integration across the whole trajectory of care appear to be a gap in service in healthcare, only recently being recognised in policy.

Prospects for elimination are as yet unclear given the current state of knowledge and the multidimensional commitments and resources required to achieve it. This evaluation does not directly address the issue of elimination but aims to contribute insights into program implementation, impact and cost in order to inform future efforts in the roll-out of the program to WA and QLD, and these could be expected to underpin future work that will be required to inform potential for elimination.

3. One Disease Project Model Description

One Disease is a non-government, not-for-profit (NfP), philanthropically funded organisation that has a long-term goal to eliminate Crusted Scabies from Remote Australia by 2022. NfP organisations have long played a role in helping to eliminate diseases and promote wellbeing in many countries around the world (Cochi and Dowdle, 2011, Stepan, 2011). The provision of philanthropic funding and/or specialist equipment, professionals and other resources can be a helpful way to focus attention on a particular issue. However, concerns have also been raised about the degree to which organisations external to the health system can work to influence change, and the sustainability of any changes once the program has finished or the NfP organisation has left the sector.

One Disease began working to establish relationships with East Arnhem land communities and health services in the NT in 2010, at that time as a healthy skin project addressing simple as well as crusted scabies. Much of the early focus was on establishing relationships, through community engagement projects such as "Listening" and through support for community wide Healthy Skin days in which education for households with scabies was provided. This work emphasised a "health literacy two ways" focus and culminated in the presentation of a message stick (a form of communication traditionally used by Aboriginal and Torres Strait Islander people, usually an etched solid piece of wood) to symbolize partnership with Yolgnu people in East Arnhem Land in 2012. In 2013, a washing machine program "Spin" increased the number of households with fully functioning washing machines to assist families to reduce bacterial load associated with infected scabies.

From 2011, a pilot project was established as a joint initiative of One Disease, Miwatj Health Aboriginal Corporation and the NT Government Department of Health, known as the East Arnhem Scabies Control Program (EASCP), to enhance regional efforts to reduce the impact of scabies as a public health problem in remote communities of Arnhem Land (Lokuge et al., 2014). The program was integrated into existing health services and sought to reduce the burden of CS on affected individuals and households in participating East Arnhem communities. A medical working group was established to update Scabies and CS guidelines in the Central Australian Rural Practitioners Association (CARPA) Standard treatment manual, and a protocol to prevent recurrences of CS was developed and trialled.

One of the first activities was an audit of health service records to identify people with recurring CS and to find their household contacts. Case management guidelines and health centre registers were then used to support follow-up of people living in scabies-endemic areas who were at risk of developing recurrent CS. The initial goal was to provide treatment to individuals, creams to household contacts and to eventually support self-management. Data over the period from 2011-2013 demonstrated that this preventive long-term case management approach was associated with significant reductions in episodes of recurrent CS in the seven cases identified, accompanied by a reduction in days spent in hospital and a significant reduction in scabies-related presentations for the household contacts (Lokuge et al., 2014). The program demonstrated that usual follow-up surveillance and chemoprophylaxis was inadequate for patients returning from hospital to endemic areas and recommended active surveillance and wider adoption of the preventive case management approach.

Scaling up the approach 2014- 2016

The success of this initial ground work led to a new phase of work from 2014, which focused on implementing a case management model of care into health clinics across NT top end communities, with expansion into Central Australia planned in 2019. In this phase, One Disease staff worked closely with individuals, families, communities and health centres to refine and promote uptake of the model as well as supporting healthy skin days and collecting community level data on scabies and CS.

A structured approach to eliminating Crusted Scabies - 2016 ongoing

From 2016 a more structured approach to eliminating crusted scabies from communities in the NT culminated in the development of an Elimination Plan and coincided with the introduction of a mandatory notification system for crusted scabies in the Northern Territory. The elimination plan articulates the following key objectives:

Goal 1: To improve detection and diagnosis of Crusted Scabies
Goal 2: To prevent reoccurrence and ensure treated clients live in a "Scabies-Free Zone”
Goal 3: To explore and destigmatise CS so that clients and families feel comfortable seeking care from health professionals
Goal 4: To develop a sustainable model of coordinated care that can be replicated in other diseases in remote Indigenous communities

One Disease works in partnership with existing health services and uses evidence based medical and public health approaches and community development principles to deliver strategies that:

- Promote a care coordination approach to improve access to services and continuity of care for patients with CS between primary and secondary care services
- Conduct audits of PHC clinics against CS case definition to improve detection
- Embed integration of CS management into PHC clinics and hospitals
- Support timely and comprehensive treatments including providing individual case management
- Follow-up treated CS clients in PHC centres to ensure ongoing prevention and management
- Maintain a focus on household level strategies that address the health of the household by treating all members and supporting the achievement and maintenance of a “scabies-free zone”

The Elimination Plan endorses a partnership approach to working with health services and aims to facilitate better coordination among services for the detection and management of CS. As stated earlier, this includes conducting audits to improve diagnosis against the case definition, working vertically between specialists, hospitals and PHC clinics to improve access to services and continuity of care for clients across the treatment spectrum, and horizontally between clinics, community and environmental health and households to support scabies free households and improve management and life-long follow-up in PHC.

Competencies for One Disease staff, outlined in the Elimination Plan, therefore span program planning, partnership building and planning evidence based strategies. These emphasise the involvement of community members and other stakeholders in all aspects of the program design and implementation, together with building partnerships and applying culturally relevant and appropriate approaches that include health promotion and education strategies, mass media strategies, community development and community engagement, advocacy, lobbying and social marketing.

Program adoption

All primary health care (PHC) NT Government clinics, 4 of 5 ACCHS in the Top End, and hospitals are participating in the current phase of the program (2016 onwards). Participation is facilitated via a Memorandum of Understanding (MOU) between One Disease and the Department of Health and via Partnership agreements between One Disease and Community Controlled organisations.

The OD/NT Health MOU commits the parties to work together in partnership to eliminate crusted scabies from the NT and sets out the principles and agreed actions for doing so. These include a commitment to:

- jointly implement, monitor and evaluate the program
- implement the relevant guidelines for community control of scabies, skin sores, tinea and crusted scabies in the NT, the Central Australian Rural Practitioners Association Inc (CARPA) Standard Treatment Manual (7th Edition), Managing Crusted Scabies in Remote Aboriginal Communities guide, Managing households with recurrent scabies guide
- hold quarterly meetings of a Steering Committee which provides expert opinion, guidance and feedback on the program
- funding to be provided by One Disease for program operations
- a coordinated team approach to elimination and management
- work with NT Health staff to embed sustainable systems for managing crusted scabies
- develop and implement electronic care plan protocols for improving systematic and coordinated management of CS
- assist implementation of care plans in Clinical Information Systems (CIS)
- assist clinicians in NT PHC Clinics and hospitals to effectively manage individuals with CS including providing in-service education and dissemination of resources and education
- implement an evaluation framework with agreed sharing of data from NT CIS
- OD provides annual reports on progress to NT Health
- NT Health provides support and access to clinical records and NT Health information technology structures that support clinical records and care plans
- NT Health provides access for OD staff to work with NT staff in hospitals, PHC centres and community health centres.
- NT Health provides access for OD staff to attend appropriate professional development

Partnership agreements between One Disease and Community Controlled Health Services, Miwatj, Wurli-Wurlinjang, Sunrise, and Katherine West Health Board WHB were also signed during 2016/17, setting out an agreement that allowed One Disease staff to:

- have de-identified access to Communicare Information Systems
- work with key personnel in community controlled services

- conduct audits of Communicare to determine if Crusted Scabies has been documented in client files against criteria in CARPA 7th Edition and the new case definition and to provide feedback to services;
- assess systems supporting Crusted Scabies in service delivery
- include an agreed Care plan for management of Crusted Scabies into the Communicare System; and
- provide education sessions for staff on Crusted Scabies

A letter of support for the project was issued by Dr Simon Quilty, General and Acute Care Physician, on behalf of the Katherine Hospital on 22 January 2016.

Program implementation

Implementation of the program is via a small team consisting of a program director, community nursing positions and administrative support staff. Two community nurses are employed directly by One Disease to deliver the program in Darwin and West Arnhem regions, and two positions are funded by OD under contract to the Centre for Disease Control (CDC) NT Government which employs two public health nurses to deliver services in Katherine and East Arnhem regions. Discussions had also been held with the ACCHS sector in these regions regarding the potential for the public health nurse roles to be managed by them but this had been rejected due to perceived underfunding.

Funding agreements are in place between OD and the CDC NT Government to support implementation of the program into health services (as set out in the OD/NT Health MOU), facilitate payment arrangements and set out issues related to privacy, confidentiality etc. Under the funding agreement, CDC public health nurses provide:

- support and resources for CS elimination and management by maintaining a focus on the scabies free zone for confirmed diagnosed CS patients;
- education sessions to clinicians, community members and households
- investigation of children under 5 years with three or more presentations of scabies in a 2 month period.

CDC also maintains a representative on the steering committee and provides quarterly reports to OD which include data on the number of people with confirmed CS in the quarter; the percentage of those with a care plan in place and who have received education about the scabies-free zone; numbers of people with evidence of recurrence; details about the education sessions delivered and funding expenditure information.

Strategies implemented

The One Disease elimination plan has guided the implementation of a broad range of strategies in the period July 2016 to present. Specifically staff have worked to

- Conduct clinical audits of primary health care clinical records to establish accurate numbers of cases against the new criteria for CS
- Provide education to staff, community members and individuals to improve knowledge of CS and its appropriate treatment
- Embed electronic care plans in PHC centres to improve recall and ongoing management of CS and reduce likelihood of recurrence
- Provide support to individuals and households to increase completion of hospital and community based treatments and prepare and maintain scabies free zones

- Take a coordinating approach to bringing services to together for smooth transition and patient journey
- Takes a respectful client-centred two-way learning approach

The program aims to provide the opportunity for reform in health care and also to build the evidence base for a system-wide approach to the detection, management and elimination of CS. Like many complex interventions, the OD model contains different strategies for changing behaviours, expertise and procedures. Strategies include

- community nursing roles (actors) that seek to change behaviours and attitudes of staff and clients to deliver specific outcomes
- decision support tools and guidelines such as the hospital care pathway (objects) that aim to change expertise and actions of those delivering care, and
- electronic careplans and recall (context) to change the procedures through which crusted scabies is managed and clinical management goals are achieved.

The different types of activities staff report they undertake are listed in the box below.

ONE DISEASE STRATEGIES

Changing expertise & actions of those delivering care

Audits of primary health care clinical records

Audits of healthcare records in CIS across all Top End health clinics against the new case definition for CS to establish accurate numbers of cases with a confirmed case of CS. There has previously been both under and over-reporting. Under-reporting may be associated with stigma whereby individuals do not want to access clinic health services or go to hospital, or if they do, skin problems may not be recognized as CS. Over-reporting in cases where individuals are thought to have CS but actually have a different skin condition has also occurred. One Disease staff are working with clinic staff to refine audit processes and feedback data to services to encourage accurate data collection and promote an improvement approach. Further feedback on audits and the CS Elimination program is to be presented to the NT CQI workshop in October 2018.

A hospital clinical pathway for the treatment of CS in hospital also promotes discharge planning links to PHC services for patients leaving hospital. This promotes a coordinated approach to ensure patients return to a scabies-free household and receive follow-up community based preventive care. The pathway contains practical information and prompts to ensure staff liaise with family to organise discharge at a time when a scabies free household can be achieved and to avoid discharge at busy times when funeral or sporting events increases numbers in households. Hospital discharge planners have engaged with the program and are working with One Disease staff to develop better care pathways and discharge processes.

Changing attitudes and behaviours of staff and clients

Education

Program staff have played a significant role in educating health professionals about CS detection, diagnosis & management. Both in hospital and in PHC services, staff turnover reportedly results in continual demand for training. Many nursing staff on the isolation ward at Darwin hospital and in PHC clinics have participated in professional education and training provided by OD. OD staff are also supporting Aboriginal Health Practitioners (AHPs) to develop a special focus on skin where this is possible and have developed a healthy skin module for Aboriginal Health Practitioner Certificate 4. AHPs will be able to conduct follow-ups, administer second round treatments for scabies and provide community education and support when they have completed training. Education aims to play a role in shifting attitudes among staff and individuals away from an acceptance of scabies as ‘normal’ to promoting active treatment.

Education is also provided to individuals, households and communities, such as in schools, playgroups, mums and bubs groups is ongoing and aims to educate people about scabies and crusted scabies transmission, promote self-management and empower households to obtain and maintain a scabies free environment. Working with communities also aims to reduce stigma and encourage clients to seek treatment. To this end, a consumer reference group was established and trialled but other ideas have centred on setting up a new CS client advocacy groups to destigmatise/educate about CS and provide support to both patients and health care professionals.

Support, advice and problem solving for individuals

Additional supports to individuals with crusted scabies to assist them to complete treatments, secure and maintain a scabies-free zone are an important component of the work undertaken. Activities include liaising with hospital staff to facilitate admission, visiting people in hospital and providing assistance that enable family life to continue while the person remains in hospital. Example include coordinating banking, shopping, obtaining food and problem solving to explore options to problems that might otherwise cause a person to discharge themselves. In the community, OD staff help to coordinate cleaning of houses

Changing procedures through which CS is managed and clinical goals are achieved

Electronic Careplans

At the time of interview (March 2018), electronic care plans had been installed in both Communicare (ACCHS) and PCIS (NT Health clinics) CIS. It was anticipated that inclusion of electronic prompts and care plans within Clinical Information Systems would assist health service staff to provide appropriate, comprehensive and timely care, in the same way a disease register is able to maintain records of a specific disease or condition for a population.

Summary

The OD program has been widely adopted in the Top End by both government and Aboriginal community controlled PHC services and two hospitals. Formal agreements commit the parties to working together in partnership to eliminate CS from the NT and set out the principles and agreed actions for doing so. Expert advice is provided through a steering committee. The model builds on lessons learned from earlier scabies control programs conducted across Top End services and from a case management approach to CS piloted by OD prior to the current elimination phase. Like many complex interventions, the OD model has strategies that aim to improve knowledge and expertise, change behaviours and attitudes and embed new procedures into care processes. Specifically these include strategies for building partnerships with community controlled health services and government; auditing PHC records to improve case detection; providing education and support to increase knowledge, standardize the new approach to treatment and reduce stigma; and support for achieving continuity of care, treatment completion and targeting of reinfection through scabies free zone.

4. Impact on patient and health service outcomes

This section addresses the following questions

- What are the impacts on patient outcomes and hospital activity?
- To what extent has care followed best practice guidelines?
- What has been the reach of the program?
- Did the CS strategy reduce recurrences of CS among individuals?

Methods

To answer these questions the OD staff conducted an audit of patient's electronic health records. Patients were included in the audit if they had an episode between 1st of July 2016 and 1st March 2018 and had records on the Northern Territory's shared electronic health record. The 1st of July 2016 was decided as the start date for the current OD program after discussions with the OD team. Whilst there have been OD activities prior to this date, the OD staff felt this date best reflected the date that the current 'intervention' began.

Records were audited from the date of the first episode of CS after the 1st of July 2016 until 1st May 2018 and for an equivalent number of months before this initial episode

Data were manually extracted from the shared electronic health record by the OD team into an excel spreadsheet. The data extraction template was developed by a member of the evaluation team (JA) with input from OD. Where there was ambiguity regarding a variable, this was discussed between the OD team and JA prior to data extraction. The variables for the data extraction were determined from reviewing the CARPA guidelines for treatment of CS and developing a program logic for the OD program of work and a patient's expected treatment journey.

Definitions

The patient's primary clinic was defined as the service with the highest number of primary health care services for the patient in the 12 months following the most recent CS diagnosis. Definitions for grading of CS were taken from the CARPA guidelines. The definition of homelessness aligned with the definition used by the Australian Bureau of Statistics.

Data linkage and analysis

The shared electronic health record data were supplemented with data on CS notifications from the NT CDC. Records across the two datasets were matched using probabilistic matching based on patient's age, sex and date of notification.

Data were analysed in Stata version 15. Chi-square tests were used to compare proportions between groups, Mann-Whitney test was used to compare unpaired medians and Wilcoxon test for paired medians.

Results

Sampling

There were 76 individuals who had an episode of CS reported to the CDC during the audit period. During the same time there were 42 individuals with an episode of CS who had a shared electronic record and were included in the OD audit. Data matching between the databases was incomplete with one record in the audit unable to be matched and a recurrent episode in the OD audit but recorded as a new, separate case in the CDC database.

Table 2 compares the demographics of the individuals in the OD audit to those in the CDC dataset without a matching record. The median age was similar but there were a higher proportion of women within the OD audit. The audit captured a higher number of recurrences during the follow-up period and captured the grading of a significantly higher proportion of episodes. This was due to the OD team grading based on information in the health record, even if a grading had not been documented.

Table 2: Characteristics of individuals with episode of crusted scabies between July 2016 - May 2018, Top End Northern Territory

	One Disease audit	Notifications to Centres for Disease Control not in One Disease Audit
Individuals	42	36
Median age	47	45
Age range	21 – 71	0 – 87
Sex • Female • Male	 28 (67%) 14 (33%)	 17 (47%) 19 (53%)
Recurrences	9	3
Total episodes	51	39
Grade 1 Grade 2 Grade 3 Not graded	19 (37%) 18 (35%) 11 (22%) 3 (6%)	7 (18%) 5 (13%) 0 (0%) 27 (69%)

Patient characteristics

The vast majority of individuals with CS had a chronic condition that may impair immune function identified via testing recommended by the CARPA guidelines. *Table 3* breaks down the proportion with an identified chronic condition. Overall 81% (34/42) had one or more chronic condition that may impair immune function. This included 10 individuals with stage 5 chronic kidney disease and 2 recipients of a renal transplant.

Table 3: Testing and results for possible causes of impaired immune function. One Disease audit of crusted scabies notifications, July 2016 – May 2018, Top End Northern Territory

Condition	**Testing documented**		**Positive result ***	
	n	**%**	**n**	**%**
Type II diabetes mellitus	39	93	20	51
Chronic kidney disease	42	100	16	38
Systemic Lupus Erythematosus	23	55	2	7
Alcohol dependence	35	83	14	40
Other substance dependence	18	43	4	22
Human T-lymphotropic virus 1	32	76	2	6

* Totals more than 100% as a patient may have more than one chronic condition identified

Table 4 shows that 50% (21/42) individuals were homeless. ‘Living in a boarding house’ was the most common reason for being classified as homeless and most of these individuals had end-stage renal disease. Every individual who was homeless also had a documented chronic condition that may impair their immune function as listed in *Table 3*. There were 8 individuals who were not homeless and for whom no chronic condition was documented in the OD audit.

Table 4: Categories of homelessness. One Disease audit of crusted scabies notifications, July 2016 - May 2018, Top End Northern Territory

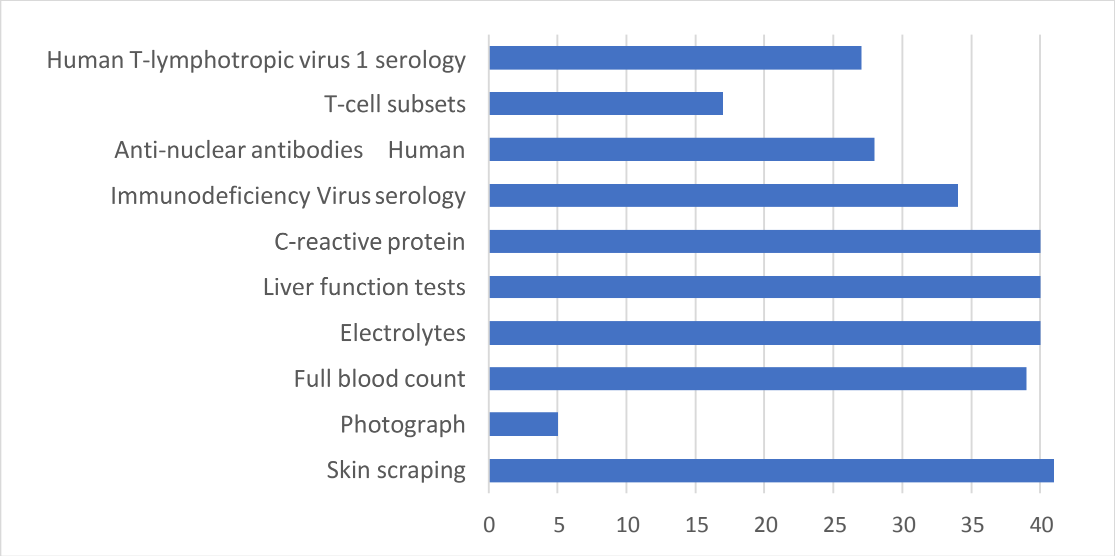
Category of homelessness	**n**	**%**
Not homeless	21	50
Improvised dwelling	6	14
Temporary with others	5	12
Boarding house	7	17
Other temporary lodging	3	7

Processes of care

Initial work-up

The OD team audited ten investigations recommended in the CARPA guidelines as part of the work up for suspected CS. To a large extent, these guidelines were followed with 60% (25/42) having 8 or more of the investigations documented and 7% (3/42) having less than 4 investigations documented. Only one case did not have a skin scraping documented (*Table 5*).

Table 5: Number of patients tested as per Central Australian Rural Practitioners Association guidelines. One Disease audit of crusted scabies notifications, July 2016 - May 2018, Top End Northern Territory



Hospital processes of care

Location and length of treatment

Following the initial diagnosis in the audit period all but one patient was hospitalised for some of their care and 25 patients (60%) received all of their care in hospital. The length of hospital treatment ranged from 1 – 82 days with the median 13 days (inter-quartile range (IQR) 9 – 20). *Table 6* details the length of treatment by grade and the proportion with a documented clear scraping. There was a significant increase in the median length of treatment after July 2016. For the patients with recurrences before July 2016 captured by the OD audit, the median length of initial treatment more than doubled (13 vs. 5 days, p=0.01)

Table 6: Grade of disease, duration of treatment and clear skin scraping prior to discharge for initial episode of crusted scabies after July 2016. One Disease audit of crusted scabies notifications, July 2016 - May 2018, Top End Northern Territory

Grade	Median length of treatment	Range	Clear scraping	
	Days	**Days**	**n**	**%**
Grade 1 (n=15)	8	1 – 38	5	33
Grade 2 (n=15)	14	4 - 82	12	80
Grade 3 (n=11)	28	4 - 33	7	64
No grade (n=1)	1	1	0	0

For the 17 patients who had community treatment median length of treatment was 15 days (range 7 – 28) of which a median of 3 days were community based treatment (range 1 – 15).

The group with the shortest length of treatment were those living in improvised dwellings (median 5.5 days, range 1 – 12). All of these individuals also have documented alcohol dependence. Two individuals had only four days initial treatment, no documented clear scraping and had grade 2 or 3 disease.

The length of treatment for the other subgroups classified as homeless was similar to those who were not homeless. When comparing homeless as a binomial variable to length of hospital treatment there was no significant difference between the groups (12 vs. 15 days, p=0.2). Similarly, there was no significant difference between those with alcohol dependence and those without (13.5 vs. 12 days, p=0.4) and the distribution of grade was similar between the groups.

The proportion with a clear scraping documented varied with grade. There was no significant difference in the proportion with a clear scraping among those who were homeless or had alcohol dependence and those who were not.

Treating home before discharge

There was documentation of 18 households (43%) being treated prior to discharge from hospital. Unsurprisingly, there was a lower proportion with evidence of household treatment among those who were homeless and those who were not that (24% vs 62%, p = 0.1).

Community processes of care

Care planning

A CS care plan was documented in the records of 20 patients and 13 had structured recall for CS care with 7 patients having both. This remaining 16 individuals had no evidence of either in their record.

Episodes of care

There was a median of 31 episodes of care in the follow-up period (IQR 12 – 90). This equated to 3.4 episodes of care per person per month or almost a patient contact each week. This was a significant increase with twice the rate of patient contact in the matched time period before the first episode of CS after June 2016 (3.4 vs. 1.7 episodes per person per month, p<0.01).

There was a lower median rate of episodes of care among people with alcohol dependence (1.4 vs 4.6 episodes of care per month, p=0.2)

There was a higher median rate of episodes of care per month among homeless patients, however, this is confounded by the fact that all patients on renal replacement therapy are classified as homeless.

Medication dispensing

There was patchy evidence of medication prescribing or dispensing for CS medications in the shared health record. *Table 7* shows the number of patients prescribed one of the recommended medications. The data quality was deemed too poor to make any further analyses.

Table 7: Number of patients with a prescription and rate of prescriptions per year. One Disease audit of crusted scabies notifications, July 2016 - May 2018, Top End Northern Territory

	Patients with a prescription recorded	**Median scripts per year**	**Range**
Lactic acid	15	5.1	1.5 - 65.5
Permethrin	21	4.7	1.3 - 49.5
Ivermectin	20	2.5	0.7 - 13.3

Community management by CDC staff

One disease has begun funding positions within the Northern Territory Centres for Disease Control (CDC). The audit identified 8 patients whose care is primarily coordinated by CDC staff. These patients were similar to the rest of the cohort with 50% homeless and 88% with an identifiable chronic condition that may impair immune function. There were 3 patients who were not classified as either CDC or OD care.

There were differences in process of care between the two groups but the sample size was too small to detect any significant differences (*Table 8*)

Table 8: Community process of care by co-ordinating organisation. One Disease audit of crusted scabies notifications, July 2016 - May 2018, Top End Northern Territory

	Centres for Disease Control (n = 8)		**One Disease (n = 31)**	
	median	**IQR**	**median**	**IQR**
Episodes of care per month	5.5	2.2 – 8.7	1.9	0.8 - 10
	n	**%**	**n**	**%**
CS care plan	3	38	15	48
CS recall	4	50	7	23

Recurrences

Among the 42 patients in the audit

- 22 (52%) had a single episode of CS
- 11 (26%) had previous recurrences of CS (one or more episodes of CS prior to July 2016 but only one episode during the audit period)
- 4 (10%) had a new recurrence of CS (no episodes of CS identified before July 2016 but 2 episodes during the audit period)

- 5 (12%) had multiple recurrences of CS (multiple episodes of CS before and after June 2016)

Of the 9 patients who had a recurrence since June 2016, *Table 9* lists their key demographics. The distribution of age and sex was similar to that of the larger cohort. Most had an identified chronic condition that may impair their immune function and all three people identified in the OD audit as having substance abuse were among the multiple recurrences group.

Table 9: Characteristics of patients with a recurrence of crusted scabies after July 2016. One Disease audit of crusted scabies notifications, July 2016 - May 2018, Top End Northern Territory

New recurrences			
Age	**Sex**	**Homeless**	**Chronic condition that may impair immune function**
44	F	Temporary lodging	Diabetes and CKD
26	F	Not homeless	Diabetes
42	F	Improvised dwelling	Alcohol dependence
46	F	Not homeless	No cause identified
Frequent recurrences			
Age	**Sex**	**Homeless**	**Chronic condition that may impair immune function**
52	F	Not homeless	Diabetes
49	M	Other temporary lodging	Multiple causes incl. substance abuse
37	M	Other temporary lodging	Diabetes and CKD
52	M	Not homeless	Substance abuse
50	F	Not homeless	Substance abuse

The duration of treatment was generally consistent with what was recommended by the grade of disease and all had the vast majority of treatment in hospital. Many did not have evidence of a clear scraping, however, in all but one case there were over six months until the first recurrence was detected (*Table 10*)

Table 10: Grade, treatment and time to recurrence of patients with a recurrence of crusted scabies after July 2016. One Disease audit of crusted scabies notifications, July 2016 - May 2018, Top End Northern Territory

New recurrences				
Grade	**Duration of initial treatment**	**Clear scraping**	**Days until first recurrence**	**Grade at recurrence**
2	13	No	373	1
1	7	No	509	2
2	12	Yes	436	2
3	17	No	561	.
Frequent recurrences				
Grade	**Duration of initial treatment**	**Clear scraping**	**Days until first recurrence**	
3	28	No	219	2
2	17	Yes	215	1
2	82	Yes	151	.

2	25	Yes	396	1
3	28	Yes	298	1

Table 11 details the characteristics of community-based treatment for patients with recurrences during the audit period. All but two patients had at least one episode of care per month and most recurrences were detected as incidental findings following a presentation to a health service for another reason.

Table 11: Community based treatment of patients with a recurrence of crusted scabies after July 2016. One Disease audit of crusted scabies notifications, July 2016 - May 2018, Top End Northern Territory

New recurrences				
Episodes of care per month	**Crusted scabies (CS) recall in place**	**Structured CS assessment in place**	**Detected on active recall**	**Organisation co-ordinating CS management**
3.4	No	Yes	No	CDC
8.8	No	No	No	CDC
1.9	Yes	No	No	OD
1.6	Yes	Yes	No	Not documented
Frequent recurrences				
Episodes of care per month	**Crusted scabies (CS) recall in place**	**Structured CS assessment in place**	**Detected on active recall**	**Organisation co-ordinating CS management**
6	Yes	Yes	Yes	CDC
14.7	No	Yes	No	OD
>15	No	Yes	No	OD
0.9	Yes	Yes	No	OD
0.8	Yes	Yes	Yes	OD

Discussion

The audit revealed improvements in important process of care that are required to eliminate CS but also highlighted the challenges posed in providing care to the complex, highly disadvantaged patients that are susceptible to the disease. The process of the audit also highlighted difficulties in data collection that should be addressed to improve monitoring of future elimination efforts.

What are the characteristics of the cohort? What has been the reach of the program?

The audit highlighted high levels of disadvantage that pose a challenge to recommended treatment. Half the cohort were homeless, and all these individuals had an identified chronic condition that may impair immune function, in particular end-stage renal disease.

The program continues to frequently identify new patients with CS across the Top End including a number of hard to reach patients. There were a high proportion of patients with alcohol dependence and a small number with an identified addiction to another substance. These patients continued to have poor initial treatment and follow-up. The duration of treatment was shortest among patients with alcohol dependence, especially when the patient was also homeless. Substance abuse was a common factor in the majority of patients with frequent recurrences with CS and these individuals often had poor contact with health services after discharge.

To what extent has care followed best practice guidelines?

Two key processes of care showed improvements following July 2016 – length of initial treatment and episodes of care in the community. While sample sizes are small, the median value following the OD intervention was more than twice that in the period preceding July 2016. Length of treatment generally matched grade of disease and the vast majority of treatment was delivered while the patient was an inpatient. This was followed by frequent contact in the community, with the average episodes of care approaching one per week.

In general testing followed protocols and these identified that more than 80% of CS patients had a chronic condition that may impair immune function. This highlighted that treatment for CS most often occurs in the context of complex multi-morbidity with a high proportion having end-stage renal disease and diabetes.

Implementation of recalls and structured assessments in the community was patchy as was treatment of the home prior to discharge. The data were of insufficient quality to comment on medication prescribing in the community.

Did the CS strategy reduce recurrences of CS among individuals?

The number within the sample and the duration of the audit were insufficient to conclusively answer this question but the trends were positive. Among the 16 individuals with a recurrence prior to July 2016, only 5 had a recurrence after July 2016.

The data suggest that in each of these cases the patient re-acquired scabies in the community with the duration between episodes six months or more, before which the disease is seen as a recrudescence of incomplete initial treatment. The hypothesis that the disease was reacquired in the community is supported by the long length of initial treatment and the presence of a clear scraping in 4 of the 5 cases.

This highlights the challenges of CS elimination. Each of the 5 recurrences had a chronic condition that may impair immune function and there is an inherent risk that within a scabies endemic environment that they would reacquire the disease. Reassuringly, in all but one case the grade of disease was less at the recurrence.

In a similar positive trend, the majority of patients with an initial episode of CS after July 2016 did not have a recurrence during follow-up. Only 4 of 26 patients with an initial episode after July 2016 had a recurrence and again it appears this was acquired in the community. In contrast with the frequent recurrence group, none of these new recurrences had more than 2 episodes during the follow-up period.

Data limitations

There were a number of limitations in the data collection that prevented the evaluation team from answering all the proposed questions for the evaluation. While previous research has identified recurrent scabies in children as a possible ‘sentinel’ event for CS within the community, there is no widely used data extraction to identify children with recurrent scabies. However, this is being developed and will shortly be available to support monitoring of the impact of CS treatment on scabies prevalence.

While ethics approval was provided to obtain health services data on workforce and capacity from the Online Services Report, both community controlled and government health organisations were reluctant to share this information. These data are routinely collected each year and contain potentially valuable information on workforce which may help identify issues with capacity that impact upon CS elimination efforts.

Medication data extracted from the shared electronic health record were incomplete with less than 50% of patients having evidence of a prescription for recommended outpatient therapy and this prevented analysis of this important process of care.

The CDC database contained incomplete information with a mismatch between cases in the OD audit, limited patient information and incomplete data on grade. To understand the complexities of treatment required for patients with crusted scabies a time extensive audit conducted by the OD team was required. There is a need to develop systems to prospectively collect data that will inform CS elimination efforts.

5. Cost-of-illness

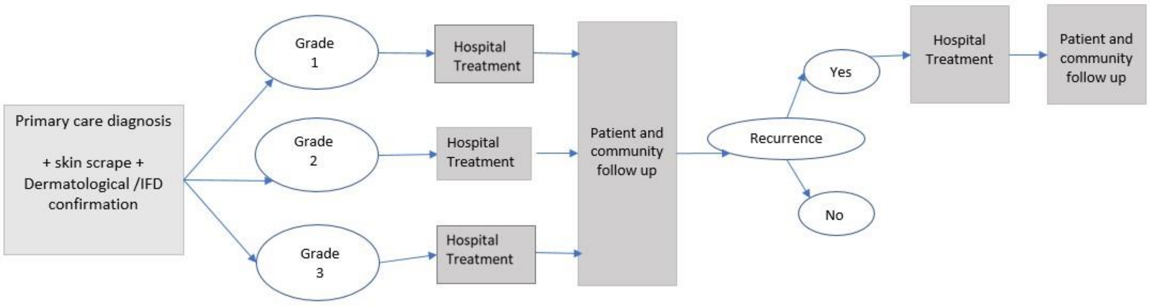
The aim of this section is to provide estimates of the annual costs associated with managing and treating CS. We developed a cost-of-illness (COI) model that calculates the expected average cost of treating one patient diagnosed with CS over a one-year period. This expected cost is then multiplied by the number of patients diagnosed with CS each year to arrive at a total annual cost.

Methods

The perspective taken in this analysis is that of the healthcare system. Whilst this approach ignores important patient and family costs associated with the disease (such as lost productivity by patients), it is consistent with most economic evaluations in health care and is advocated by Australian guidelines on health economic evaluation and elsewhere (Australian Government Department of Health, 2016a). Wherever possible, we have attempted to use the overall health system costs associated with managing CS including contributions made by third party payers (usually government) as well as out-of-pocket costs incurred by patients for prescription drugs. We have included estimates of the travel costs of patients and providers for those patients living in remote areas. In the Northern Territory, many of these costs are borne by government, and this approach is therefore consistent with our healthcare system perspective approach.

The entry point of the COI model is when a patient is diagnosed with CS. At this point, there are costs involved with the initial visit, pathology tests, specialists review as well as associated health checks. At this point, the diagnosis is graded into one of three categories. Grading is based on clinical assessment in four key areas: the distribution and extent of crusting; the depth of crusting; the degree of skin cracking and pyoderma; and the number of previous episodes (Davis et al. 2013). The patient then moves into a treatment phase which, in almost all instances, is provided in hospital. Once treatment is complete, the episode of care moves into a follow-up phase that involves not only the patient but also their family and other household members to reduce the risk of re-infection and infection of others. The COI model considers the probability of CS recurrences based on the grading of the episode. The model allows for possibility that the probability of recurrence differs by the grade of the previous CS episode. Figure 1 illustrates the diagnostic, treatment, follow-up and recurrence phases.

Figure 1: Crusted Scabies Cost-of- Illness Model-estimating the expected cost per patient



The model has been specifically designed to inform future evaluations of CS prevention programs and can form the basis of cost-effectiveness analysis. This information is of value to policy makers and evaluators who wish to examine the potential impact of new programs on health care service use, costs and health outcomes. The model is able to reflect the potential impact of program through changes in the rate of CS, the grading and the likelihood of recurrence.

Populating the model requires three key data inputs. The first is the probabilities of a patient transitioning through the model. Specifically, the model requires the likelihood of being diagnosed with grade 1, 2 or 3 CS as well as the probability of suffering a recurrence of CS conditional on grade. The second key input are the health care resources used by patients in the diagnosis, treatment and follow-up of CS. These include the number of clinical visits, pathology tests, hospitalisations, pharmaceuticals and resources used in following-up the patients through, for example, the number of nursing hours spent ensuring the patient and other household members are treated and checked. The third input are the unit costs associated with the resource use. This entails finding the cost of, for example, a, primary care visit, a pathology test, hospitalisation and pharmaceuticals that are typically used in the treatment of CS.

The following sections describes how we obtained all three data inputs. We then go on to combine these inputs to estimate the expected cost for treating one patient.

CS grades and probability of recurrence

PHC data was used for this part of the analysis as it had more complete grading information than the CDC data. The probability of recurrence was derived over a twelve-month period. For each patient, a notification was categorised as an *initial* episode of CS if there was at least a 12-month observation period following on from the notification. Notifications that occurred within a 12 month period of a previous *initial* notification for any specific patient was categorised as a recurrence. This implies that for some patients who had multiple recurrences, it is feasible for a specific notification to be classified as both an initial and recurrent CS episode.

Through this categorisation process, 37 episodes were classified as initial although two of these did not contain grade information. Fifteen episodes were classified as recurrent and, again, for two of these the grade information was absent. For all recurrent episodes we identified the grade of the preceding initial episode. This enabled us to estimate the probability of recurrence by grade. The results are shown in *Table 12*. It shows that patients who were diagnosed with grade 1 CS in their *initial* episode had a 27% chance of suffering another episode of CS. The probability of recurrence increase has the CS grade increases.

Table 12: Probability of recurrence within a 12-month period by initial grade. One Disease audit of crusted scabies notifications, July 2016 – May 2018, Top End Northern Territory

Initial Grade (n, %)	Probability of recurrence
1 (n=11; 31)	0.27 (n=3)
2 (n=13; 37)	0.38 (n=5)
3 (n=11; 31)	0.45 (n=5)
All Grades 1-3 (n=35; 100)	1.00 (n=13)
Unknown (n=2)	1.0 (n=2)

Note the numbers may vary slightly to those reported previously in this report due to our classification of what constitutes an initial and recurrent episode

Unit Costs

Unit cost information was derived from standard Australian sources which are routinely employed in economic evaluations: the Independent Hospital Pricing Authority (IHPA) National Hospital Cost Data Collection (NHCDC), Medicare Benefits Schedule (MBS) for medical consultations and diagnostic test costs and the Pharmaceutical Benefits Scheme (PBS) for the prescription drug costs (Australian Government Department of Health, 2016a, 2016b, 2018a, 2018b; IHPA, 2018). Where required, these sources were supplemented with information from Pharmacy Direct for non-prescription drugs and input from OD staff regarding the human T-lymphotropic virus-1 (HTLV-1) test, patient travel to the hospital, treatment of the household prior to hospital discharge including the costs of a nurse and driver and travel to a remote location and CDC time for contact tracing. The Central Australian Rural Practitioners (CARPA) Standard Treatment Manual was also used to estimate the costs of medications used to treat scabies cases and contacts (Centre for Remote Health, 2017).

Table 13 provides the unit prices for each of the items associated with the primary care diagnosis phase of the model for patients with crusted scabies shown in Figure 1. This phase comprises:

- Diagnostic tests for comorbidities such as chronic kidney disease (CKD) and Type II diabetes mellitus
- The initial clinic visit which pertains to the first assessment of patients who experienced an episode of crusted scabies after OD commenced involvement with clinic staff at the patients' main PHC service. This visit also includes:
    - Collection of blood samples
    - Skin scrapings of suspected crusting or mite burrows to be sent to the laboratory for analysis
    - Taking photos of the affected skin sites
    - Administering surveys to capture the patients' history of alcohol and other substance abuse

Table 13: Unit prices for each of the items associated with primary care diagnosis phase for the 42 patients with crusted scabies in the PHC dataset. One Disease audit of crusted scabies notifications, July 2016 – May 2018, Top End Northern Territory

Item	Description	Unit cost
Type II Diabetes Mellitus	Quantitation HbA1c (glycated haemoglobin) (MBS Item 66841) [a]	$14.30
Chronic Kidney disease (CKD)	Urea, Electrolytes, Creatinine (U&E), Microalbumin - quantitation in urine & Full Blood Count (FBC) (MBS Items 66512, 66560 & 65070, respectively) [a]	$60.90
Systemic Lupus Erythematosis (SLE)	Antinuclear antibodies (ANA), Double-stranded DNA antibodies & FBC unless FBC has not been done for CKD (MBS Items 71097, 71099 & 65070, respectively) [a]	$43.35
Human T-lymphotropic virus-1 (HTLV-1)	The cost is comprised of a screening assay at RDH and analysis of the test at another pathology laboratory (No MBS Item).	$40.00

Initial Clinic Visit	1st assessment for CS after OD began involvement with clinic staff at the patients' main PHC service (MBS Item 715) [a]	$212.25
	Skin - microscopy & culture of material from MCSS (MBS Item 69306) [a]	$28.70
	FBC (MBS Item 65070) [a]	$14.45
	U&E, Liver function test (LFT) and C-Reactive Protein (CRP). (MBS Item 66512) [a]	$15.05
	Human Immunodeficiency Virus (HIV) diagnostic tests (MBS Item 69384) [a]	$13.35
	HTLV-1	$40.00
	ANA (MBS Item 71097) [a]	$20.80
	T-cell subsets (MBS Item 72849) [a]	$88.70
Patient travel to hospital	Return Plane Charter for Remote locations outside Darwin (Top End Central, Daly River, Katherine etc) [b]	$2,000.00
	Return Plane Charter for Very Remote locations outside Darwin Arnhem Land, Maningrida, Yirrkala etc)[b]	$5,000

Sources a=MBS [Australian Government Department of Health, 2018a]; b= OD

Table 14 provides the unit prices for each of the items associated with Emergency Department and Hospital Treatment phase of the model for patients with crusted scabies shown in Figure 1. This phase consists of either a non-admitted emergency department presentation or a hospitalisation. In the case of hospitalisation, this table shows the:

- Direct cost for the average length of stay (ALOS) for the Australian Refined-Diagnosis Related Groups (AR-DRG) codes for each hospital separation
- Daily add-on cost for the AR-DRG code J68A

AR-DRG codes are used to determine an average cost per hospital episode based on the National Hospital Data Collection (NHCDC) costs for public hospital patients which are determined by the Independent Hospital Pricing Authority (IHPA). Crusted scabies does not have a unique AR-DRG code but the OD audit data revealed that most CS patients were coded under a range of skin-related AR-DRGs as well as some non-skin related AR-DRGs that were presumably chosen on the basis of the patients’ comorbidities and corresponding procedures.

To determine the unit costs for hospital treatment for patients with crusted scabies, the following assumptions were made:

- The majority of patients with crusted scabies in the OD audit (65.9 %; see Table 17) have an AR-DRG code of J68A – major Skin disorder, J64A - Cellulitis, Major Complexity, T01A - Infectious and Parasitic Diseases WOR Procedures, Major Complexity and T64A - Other Infectious and Parasitic Diseases, Major Complexity.

These AR-DRG codes were considered to correspond to a hospitalisation for crusted scabies alone and therefore no adjustment to the ALOS was necessary.

- For the remainder of the patients in the OD audit who have other AR-DRG codes, an adjustment to the ALOS was required. An example of these was E62A Respiratory Infections and Inflammations, Major Complexity which was considered to consist of major skin disorder (crusted scabies) + Respiratory Infections and Inflammations, Major Complexity (non-skin disorder).

We needed to account for complexities in treatment of individual episodes of care for CS by adjusting the average costs associated with each AR-DRG code for each individual patient's length of stay when it differs from average length of stay used in NHCDC. This involves identifying the cost for each extra or fewer days of hospital stay in comparison to average length of stay (ALOS). This adjustment was performed by identifying the expenses which tend to be upfront costs & essential services likely to be incurred once or at the start of a hospital admission (e.g. costs associated with critical care, operating rooms, emergency departments and special procedure suites). A daily add-on cost estimate was calculated by dividing (the average direct cost of hospitalisation for the AR-DRG (eg. $4,690 for J68A) minus these essential service costs) by the average length of stay used in cost schedules for public hospitals. As indicated in Table 14, this daily add-on cost for the AR-DRG, J68A was $1,112.44. The adjusted average cost for each hospital patient's episode of care for CS was then estimated by adding or subtracting the daily add-on cost for each of the days the patient stayed in hospital shorter or longer than average length of stay for that AR-DRG code. This approach has been used in previous studies (Longden et al., 2018a, 2018b).

Table 14: Unit prices for each of the items associated with Emergency Department and Hospital Treatment phase-. One Disease audit of crusted scabies notifications, July 2016 – May 2018, Top End Northern Territory

Item	Description	Unit cost
Crusted-scabies emergency department visit	Non-admitted Emergency department presentation [a]	$517.00
Hospitalisation	Average direct cost per AR-DRG [a]	
	J68A: Major Skin Disorders W Catastrophic or Severe CC J64A Cellulitis, Major complexity T01A: Infectious and Parasitic Diseases W OR Procedures, Major Complexity T64A Other Infectious and Parasitic Diseases, Major Complexity	$4670.00
	K60A: Diabetes, Major Complexity	$8290.00
	E62A: Respiratory Infections and Inflammations, Major Complexity	$7325.00
	D04A: Maxillo Surgery, Major Complexity	$10,457.00
	H07B: Open Cholecystectomy, Intermediate Complexity	$16,336.00
	E64A: Pulmonary Oedema and Respiratory Failure, Major Complexity	$9,034.00
	F14A: Vascular Procedures, Except Major Reconstruction, W/O CPB Pump, Major Complexity	$26,412.00
	B02A: Cranial Procedures, Major Complexity	$53,001.00

	F62A: Heart Failure and Shock, Major Complexity	$9,246.00
	E65A: Chronic Obstructive Airways Disease, Major Complexity	$6,830.00
	L65A: Kidney and Urinary Tract Signs and Symptoms, Major Complexity	$5,660.00
	G67B: Oesophagitis and Gastroenteritis, Minor Complexity	$1,469.00
	E69A: Bronchitis and Asthma, Major Complexity	$4,450.00
	Daily add-on cost [b]	$1,112.44

a=IHPA NHCDC [IHPA, 2018]; b [Derived using the adjustment procedure described above]

Patients were discharged under 16 different types of AR-DRG codes, although the majority of patients receiving hospital treatment were coded under J68A. This is an AR-DRG code that is related to major skin disorders which includes treatment of CS but is not exclusively used for this purpose. One important finding is that the length of stay in hospital for patients in the sample was substantially higher than the respective average length of stay (ALOS) for the respective DRG groups. In fact, the length of stay for over 90% of separations in our sample was higher than the ALOS. For example, the national ALOS for AR-DRG J68A is 3.57 days, whereas patients in our sample had an ALOS of 11.6 days. The additional number of days may reflect the complex nature of the patients in our sample but may also be due to the required length of staying for appropriately treating patients with CS.

The substantial difference between ALOS and the length of stay for CS patients raises some important funding issues. Under activity-based funding arrangements, it may suggest that hospitals are underfunded for treating crusted scabies. This is particularly true if the additional length of stay for CS patients reflects systematic additional resource use and costs and where particular hospitals are more likely to be treating patients with crusted scabies under each of the relevant AR-DRG codes like J68A. This is because hospitals are compensated based on set prices, rather than the actual cost per patient.

Although some adjustments to national hospital cost-weights are made for patients from remote areas and those from an indigenous background, these may not adequately reflect the additional costs of treating crusted scabies within the existing AR-DRG codes. Future work may be warranted in justifying and developing a new AR-DRG code that is specific to the treatment of CS. Such work should follow the guidelines set by the Australian Consortium for Classification Development (https://www.accd.net.au/Submissions.aspx?page=3).

Table 15 provides the unit prices for each of the items associated with patient and community follow-up phase of the model for patients with crusted scabies shown in Figure 1. This phase comprises the following items:

- CS recall if a patient with crusted scabies does not self-present to the clinic
- Episodes of care
- Patient medications
- Treatment of the household prior to the patient's hospital discharge

The unit costs in *Table 16* were based on expert advice provided by OD and assumptions regarding the weight bracket of patients with crusted scabies to determine the dose of ivermectin administered, the amount of nurse and driver time associated with CS recall and treatment of the household prior to hospital discharge including the type of staff who perform the household treatment, the travel distance from Darwin to remote locations, the quantity of tablets given and creams applied, respectively, in each dose of ivermectin, permethrin and 10 % urea, 5% lactic acid in moisturising cream. The assumption was also made that no benzyl benzoate was administered to the cases with scabies and their contacts.

Table 15: Unit prices for each of the items associated with patient and community follow-up phase. One Disease audit of crusted scabies notifications, July 2016 – May 2018, Top End Northern Territory

Item	Description	Unit cost
CS recall	Salary including 30% on-costs	
	N4 nurse: $47.66/hr [a] (1 hr assumed)	$47.66
	Driver: $28.77/hr [a] (2 hrs assumed)	$57.54
	Total	$105.20
Episode of care	Services Provided By A Practice Nurse Or Aboriginal And Torres Strait Islander Health Practitioner On Behalf Of A Medical Practitioner [b] (MBS Item 10987)	$24.00
Patient Medications	Ivermectin (3mg tablet, 4 tablets/pack) [c] (PBS Code & Prescriber: 2868YMPNP) (Number of tablets prescribed depends on weight of patient (200 microgram/kg/dose). Assumption made all patients fall into 60-70 kg weight bracket so ivermectin dose for each patient corresponds to 4 tablets (1 pack) [a]	$46.49
	Permethrin (5% cream, 30 g) [c] (PBS Code & Prescriber: 3054RMPNP) (Assumption: approximately 30 g/ application (dose)/person) [a]	$18.64
	Calmurid® (10 % urea, 5% lactic acid in moisturising cream) 25 g [d] (Assumption: 25g per application/person used so 4 applications to the tube or $2.67/application (dose) [a]	$2.67
Contact tracing	CDC time to do first stage of disease notification and contact tracing which involves confirmation of the patient contacts and completion of documentation. Salary including 30% on-costs [a] N4 nurse: $47.66/hr Assumption: approximately 8 hrs.	$381.28
Treatment of household (pre-hospital discharge)	Salary including 30% on costs	
	N4 nurse: $47.66/hr [a] (24 hrs over period of week) [a]	$1,143.84
	Driver: $28.77/hr [a]	$690.48
	Total N4 nurse and driver	$1,834.32
	Medications to treat scabies cases and contacts	
	Permethrin (5% cream, 30 g) [c,e]	$18.64
	Ivermectin (3mg tablet, 4 tablets/pack) [c]	$46.49
	Travel to remote location (ATO tax rate 0.68/km) (400km return trip assumed) [a, f]	$272.00

a=OD; b=MBS [Australian Government Department of Health, 2018a]; c=PBS [Australian Government Department of Health, 2016b, 2018b]; d=Pharmacy Direct [Pharmacy Direct, 2018]; e= CARPA Standard Treatment Manual [Centre for Remote Health, 2017]; f=ATO [Australian Government Australian Taxation Office, 2018]

Resource Use

Table 16 shows the resource use for items associated with the primary care diagnosis phase of the model for patients with crusted scabies shown in Figure 1. The average number of units per patient was determined from the OD audit data.

Table 16: Resource Use for each of the items associated with primary care diagnosis phase for the patients with crusted scabies. One Disease audit of crusted scabies notifications, July 2016 – May 2018, Top End Northern Territory

Item	**Description**	**Average number of units per patient**	**Measurement Unit**
Type II Diabetes Mellitus	HbA1c (glycated haemoglobin)	0.93	test
Chronic Kidney disease (CKD)	U&E, Microalbumin - quantitation in urine & FBC	0.95	test
Systemic Lupus Erythematosis (SLE)	ANA, Double-stranded DNA antibodies & FBC	0.55	test
	HTLV-1	0.76	test
First Clinic visit	Initial assessment for CS after OD began involvement with clinic staff at the patients' main PHC service (Hospital ED or Darwin (NRU) or Daly Clinic etc).	1.00	visit
	Skin - microscopy & culture of material from MCSS	0.98	test
	FBC	0.95	test
	U&E, Liver function test (LFT) and C-Reactive Protein (CRP).	0.98	test
	HIV	0.88	test
	HTLV-1	0.69	test
	ANA	0.71	test
	T-cell subsets	0.43	test
Patient travel to hospital	Return plane charter for remote locations outside Darwin (Top End Central, Daly River, Katherine etc)	0.29	flights
	Return plane charter for very remote locations outside Darwin Arnhem Land, Maningrida, Yirrkala)	0.26	flights

Table 17 shows the resource use for items associated with the emergency department and hospital treatment phase of the model for patients with crusted scabies shown in Figure 1. The average number of units per patient was determined from the OD audit data. The majority (65.9%) of the hospitalisations were for a crusted scabies-related stay alone (ie. AR-DRGs: J68A, J64A, T01A and T64A). The remaining hospitalisations were for other AR-DRGs, for example, K60A - Diabetes, Major Complexity which includes a major skin disorder (crusted scabies) component and a non-crusted scabies component.

Table 17: Resource Use for each of the items associated with emergency department and hospital treatment phase. One Disease audit of crusted scabies notifications, July 2016 – May 2018, Top End Northern Territory

Item	**Description**	**Average number of units per patient**	**Measurement Unit**
Emergency Department	Crusted-scabies related Emergency department visit	0.02	visit
Hospitalisation	Crusted scabies -related hospital stay J68A: Major Skin Disorders W Catastrophic or Severe CC J64A Cellulitis, Major complexity T01A: Infectious and Parasitic Diseases W OR Procedures, Major Complexity T64A Other Infectious and Parasitic Diseases, Major Complexity	65.9	%
	K60A: Diabetes, Major Complexity	4.9	%
	E62A: Respiratory Infections and Inflammations, Major Complexity	4.9	%
	D04A: Maxillo Surgery, Major Complexity	2.4	%
	E62A: Respiratory Infections and Inflammations, Major Complexity	2.4	%
	D04A: Maxillo Surgery, Major Complexity	2.4	%
	H07B: Open Cholecystectomy, Intermediate Complexity	2.4	%
	E64A: Pulmonary Oedema and Respiratory Failure, Major Complexity	2.4	%
	F14A: Vascular Procedures, Except Major Reconstruction, W/O CPB Pump, Major Complexity	2.4	%
	B02A: Cranial Procedures, Major Complexity	2.4	%
	F62A: Heart Failure and Shock, Major Complexity	2.4	%
	E65A: Chronic Obstructive Airways Disease, Major Complexity	2.4	%
	L65A: Kidney and Urinary Tract Signs and Symptoms, Major Complexity	2.4	%
	G67B: Oesophagitis and Gastroenteritis, Minor Complexity	2.4	%
	E69A: Bronchitis and Asthma, Major Complexity	2.4	%
	Total AR-DRGs above	100.0	%

Table 18 shows the resource use for items associated with the patient and community follow-up phase of the model for patients with crusted scabies shown in Figure 1. The average number of units per patient was determined from the OD audit data.

Table 18: Resource use for each of the items associated with patient and community follow-up phase. One Disease audit of crusted scabies notifications, July 2016 – May 2018, Top End Northern Territory

Item	**Description**	**Average number of units per patient**	**Measurement Unit**
CS recall	N4 nurse: $47.66/hr + Driver: $28.77/hr	0.48	Phone call or Visit follow-ups
Episode of care	Services Provided By A Practice Nurse Or Aboriginal And Torres Strait Islander Health Practitioner On Behalf Of A Medical Practitioner	66.26	Clinic Visit
Patient Medications	Ivermectin (3mg tablet, 4 tablets in pack; 1 dose=4 tablets)	2.21	doses
	Permethrin (5% cream, 30 g)	5.83	doses
	Calmurid® (10 % urea, 5% lactic acid in moisturising cream)	5	doses
Contact tracing	Salary including 30% on costs N4 nurse: $47.66/hr	1.00	follow-up
Treatment of household (pre-hospital discharge)	Salary including 30% on costs N4 nurse: $47.66/hr Driver: $28.77/hr	0.36	household treatments
	Medications to treat scabies cases and contacts		
	Permethrin 5% (Lyclear), 30g (20 tubes per household treatment)	7.14	doses (household treatment)
	Ivermectin (4 tablets=1 dose=1 packet)	0.21	doses
	Travel to remote location (ATO tax rate 0.68/km)	0.29	visits

Average cost per patient for each phase of the model

The average cost per patient for each of the three phases of the crusted scabies model was calculated by multiplying the average number of units used for each resource item by its unit cost and summing these values.

Table 19: Cost for each of the components of the model for patients with crusted scabies. One Disease audit of crusted scabies notifications, July 2016 – May 2018, Top End Northern Territory

Model phase		**Average cost per patient ($)**
Primary care diagnosis		2,367.42
Emergency Department and Hospital Treatment	ED visit	12.31
	Hospitalisation	
	Grade 1	15,170.51

	Grade 2	24,276.92
	Grade 3	22, 882.10
Patient and Community Follow-up		3,123.71

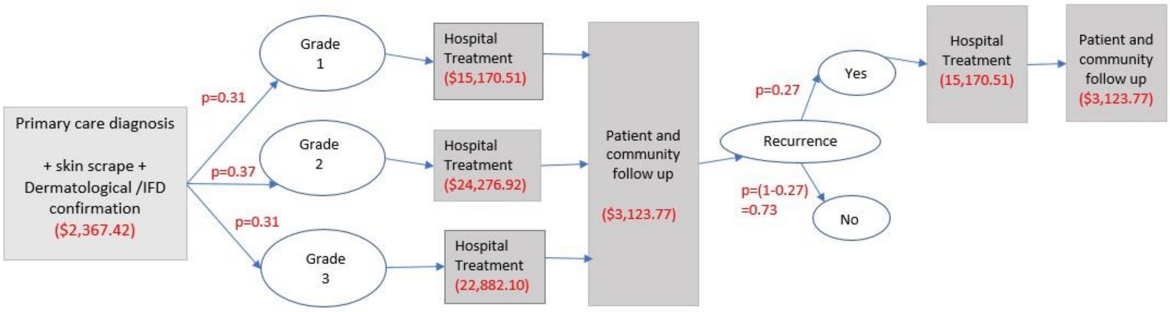
Table 19 indicates that the highest average cost per patient is associated with the hospital treatment phase which also varies across crusted scabies grade, with Grades 2 and 3 being the higher average cost per patient ($24,276.92 and $22,882.10, respectively) and Grade 1 the lowest ($15,170.51). There is no difference between the average cost per patient associated with the hospital treatment phase for patients with Grades 2 or 3. However, compared with patients with CS Grade 2, there is a substantial reduction in the average cost per patient (approximately $9,000) associated with the hospital treatment phase for individuals with CS Grade 1. It should be noted that 98% of the patients in the OD audit underwent hospital treatment for their crusted scabies. As one patient had a non-admitted emergency department presentation for crusted scabies and clearly deviates from this finding, they were excluded from the hospital treatment phase and subsequent cost-of-illness calculations. ED costs for patients who visited the emergency department prior to their hospitalisation are accounted for in the IPHPA costs.

Following on from the hospital treatment phase, we did not differentiate subsequent costs (ie. those costs relating to the patient and community follow-up phase) by grade. Upon discharge from hospital all patients with CS should have a clear skin scraping and most patients will have been treated as we expect post-follow-up and post-hospital treatment costs will be similar across patients with initially different CS grades of severity.

Expected cost per patient and total annual cost

The costs and transition probabilities provided in Figure 2 below were used to calculate the expected average cost of treating one patient diagnosed with CS over a one-year period. This cost was calculated to be $31,209.20. The number of patients diagnosed with CS each year was determined using the number of patients with only one presentation for CS using the CDC CS registry data over a one-year period. In 2017, 44 patients were diagnosed with CS in the Northern Territory. To derive a total annual cost for CS, the expected average cost of treating one patient diagnosed with CS over a one-year period ($31,209.20) is multiplied by the number of CS patients diagnosed each year (44). Thus, the total annual cost for CS in the Northern territory is $1,373,204.87.

Figure 2: Crusted Scabies Cost-of-Illness Model containing costs and probabilities used to estimate the expected cost per patient



Discussion

This report provides the first analysis of the cost of treating CS. Using data extracted from the electronic record has delivered a rich source of information on CS diagnosis, treatment and follow-up care. This has enabled us to estimate the expected health care cost per patient diagnosed with CS. Based on the data, we developed a simple model of CS that accounts for the probability of recurrence. Furthermore, the model differentiates treatment costs based on the grade.

The expected health care cost per patient diagnosed with CS is $31,209.20 resulting in an overall cost of $1,373,204.87 for managing all patients diagnosed in the Northern Territory in a given year. This includes the costs associated with diagnosing, treating patients in hospital, and follow-up care relating to the patient and members of their family and household. By far the biggest component of the health care costs falls on the public hospital system.

One of the strengths of this COI analysis is that it provides a basis for future cost-effectiveness analysis on the impact of CS elimination and prevention programs such as those run by OD. The COI results show that for every episode of CS prevented the health care system can be expected to save $31,209.20. In addition, the model developed here can also be used to examine the impact of the program on preventing higher grades of CS through earlier recognition and treatment, as well as efforts to reduce the incidence of recurrence.

Limitations

There are several limitations associated with the analysis. First, as is always the case, a cost-of-illness analysis informs us about the health care costs associated with managing and treating disease. It gives us an understanding of the size of the problem in terms of the health care resources. It does not tell us about the personal costs associated with the disease through the loss in quality-of-life to the patient and the household. This project is continuing to work on this aspect of the overall burden of CS by collecting quality of life data from patients in the NT. Further work in this area is needed if we are to obtain an overall assessment of the health burden of CS.

Second, to the greatest possible degree we have tried to isolate the health care costs of treating CS from other underlying diseases. However, it is highly plausible that for some aspects of the hospital treatment costs, patients were not just treated for CS but were also treated for other conditions. This potentially exaggerates the CS costs. However, it should be noted that only those hospital episodes where CS was being treated were included in the analysis. Furthermore, for those episodes where we can identify that other conditions were also treated, the difference in costs is relatively small when compared to episodes where CS was the primary reason for the hospitalisation.

Another limitation is that the model takes the perspective of an individual patient diagnosed with CS and follows that patient through their various phases of management. Some additional costs associated with treating the house and household members are incorporated but this aspect of the model could be expanded. In particular, future models of the disease pathway should incorporate the potential impact of CS on household members and, perhaps, even local communities. By elaborating on this aspect of the model, it will become feasible to undertake future analysis of eradication/prevention program and their impact on not just the patient but also households and communities. This is particularly important in programs such as those advocated through One Disease as many of their efforts are focused on the household through education and outreach. These limitations provide opportunities for future research.

In addition, future research efforts should focus on using the results of this COI in a full economic evaluation, combined with effectiveness research. Such research will require comparative analysis which could be achieved by comparing the incidence and recurrence of CS in communities who are part of the program, versus those who are not. The current data infrastructure is an important starting point to obtain such information.

6. Barriers and enablers to implementation

This section addresses the question "How and to what extent has the program been implemented and what are the barriers and enablers to implementation in different settings and for different client groups?

Methods

Data for this component of the evaluation were collected from key documents and via interviews with clinicians and other stakeholders associated with the program, either face-to-face in Darwin and remote health centres or via phone. In total 19 people participated in individual interviews and an additional 5 staff in a remote health clinic and 3 OD staff participated in a focus group. Interviews took anywhere between 20 minutes and one hour to complete and the focus groups around 1 hour. With the permission of the stakeholders interviews were digitally recorded and transcribed verbatim, then uploaded into QSR International's NVivo 11 Software which was used to assist with data management, including coding and analysis.

Data were analysed thematically against the evaluation questions, then compiled by stakeholder type and by region for comparison. Data are presented in terms of stakeholders' perceptions of the coherence of the program, building relationships for implementation, barriers and enablers to implementing the program, key success factors and embedding the program in future.

Provider perceptions

Perceived Coherence and program fit

The extent to which a program can be implemented depends, in part, on whether it is perceived as coherent by the stakeholders. This means there must be a clear understanding of what the program is, including how it differs from what is already in place, as well as an understanding of its intent and benefit. At interview, it was clear the program was well regarded by health sector staff, both hospital and PHC (ACCHS and NT Health), working with OD at the coalface. They perceived the program as an addition to what they already offered and believed it delivered benefits to patients, providers and to the system.

An NT Health Senior Doctor and Manager described the program as follows:

> *So the approach is an organised approach. It's driven by knowledge of which patients are affected. It's a collaborative approach with health centre managers and doctors. And its protocol driven, I believe. And it features, in my experience, it features availability in excess of what we normally have in our clinical services. And in my experience, it features good collaboration with other service providers within the community health centres and health teams….. Well firstly, it offers additional clinical input from dedicated personnel. And by and large we're very limited in that type of clinical input in our healthcare services. We often have people multi… well particularly Aboriginal health professionals, community health centre's nurses and doctors have to manage conditions across the full gamut of clinical conditions. So it offers focused and resourced input. And it also offers a service that is responsive with respect to time. So I've observed that. One Disease personnel can attend to review a patient in a much shorter time frame than we would get people from other services to attend.* Senior medical officer/manager NT Health

There was unilateral agreement that the time and focus on skin had delivered benefits for clients, and hospital staff believed the program was resulting in reductions in recurrences of CS. Staff of the two major hospitals perceived the strategy as reducing recurrent admissions

> *Prior to them (One Disease) coming we'd get revolving door turnarounds, so they'd go out to the community, treatment and then come back in still having scabies. So that revolving door changed. There are less like, except for ones that take their own leave there are less coming in with the reoccurrence of crusted scabies.* Hospital nursing manager
>
> *Another thing, I know, is that it's gone from 12 admissions per year to I think it's about 3. So I think we've had a lot to do with that.* Senior doctor

Staff were enthusiastic about the benefits to clients, as demonstrated by this hospital nursing manager

> *When he came back finally and he said "that's the first time I've never itched… Yeah. He was one of our success stories because he didn't want treatment, didn't want treatment, we'd say come on you've got to have treatment.*

Others commented on the 'fit' between the context and the program, suggesting that the time was right for CS

> *So the fact that CS was made notifiable in the same kind of timeframe as OD decided or made available the resource of a staff member, those two things were very synergistic. The other thing, the other component was the interest of the hospital and the local physician who took an interest in scabies. So all of that lifted the profile of scabies from being a kind of backwater issue that hadn't been receiving a lot of attention to a much higher profile.* Senior Medical Director

Notwithstanding this support, several people interviewed were initially concerned the program lacked a sufficient focus on the social determinants, arguing that the notion of addressing one disease at a time was antithetical to public health practice. They argued in favour of a social determinants approach that aims to address underlying determinants common to all chronic diseases.

> *And we have a real bug bear about treating one disease because there's so much more to it than treating one disease. So just targeting these individual illnesses or conditions and not looking at the whole person really discounts all the social determinants of health and a whole range of other challenges that people have in the bush. Whilst we're not against the idea of One Disease at all, and we work closely with them… but it's almost like a theoretical argument.* PHC Director

Linked to a social determinants approach was a perception that the entrepreneurial approach did not provide sufficient attention to advocacy and working in partnership with Aboriginal organisations

> *They've got a medical model of dealing with it and they're not social determinants models…… A lot of people are feeling that in primary care I suppose we are peddling to keep still in as far as how much we can progress, when things - especially with diseases of poverty – when people are so poor and the housing is so bad. From what I understand they don't get involved in advocacy but they could work in conjunction with Aboriginal organisations around advocacy but not take the lead. That would be the appropriate way I think…. With the entrepreneurial approach you need to put yourself out in front and not necessarily the Aboriginal organisation because you*

> *have to get the money and that's been a bit of a tension I think… I guess the money is going to OD at a time when PHC is not getting any extra resources* Public health doctor

These concerns did not impact on the willingness of the service providers we interviewed to work with OD however. One manager in the ACCHS sector who initially held these concerns attributed the good relationships that had developed with OD to the leadership style of the OD Director. He commented that because of her knowledge of the health sector and extensive experience working within it, she was able to acknowledge differences and find ways of overcoming obstacles to working together that met both sets of values and imperatives.

> *I mean X has been great in that space, really pragmatic and goes yeah I see where you're coming from. She's been working in this area for so long and she's not got rose coloured glasses… So it's great to have her in that role to be able to have those frank conversations… I think if you had a … different person come into that role, not understanding the context, not necessarily being pragmatic and realistic, and telling us how it's got to be and how we can eliminate this. Whereas you can have your say and say these are our challenges and she goes I know them all, I'm totally cool with that and this is how we can work together and let's try and do that.* PHC Director

Building relationships for implementation

The new context for notification of CS in the NT under the Notifiable Disease Act, and the introduction of the OD CS program into the sector at the same time, has necessitated that OD and CDC staff have had to work closely together and with participating hospital and PHC providers to develop and coordinate roles and responsibilities vis a vis implementation of the OD program and to establish effective ways for CDC to integrate the public health response (under Notification arrangements) into routine practice.

Not only is CDC responsible for the public health response which includes oversight of cleaning, contract tracing and the treatment of household contacts to ensure that a scabies-free zone is initiated and individual household members are treated in accordance with the new protocol for CS, it is also funded by OD for two public health nursing positions to implement the OD program in 2 Top End regions. OD had initially discussed potential for funding these positions with the Aboriginal Community Controlled Health Sector in an attempt to embed the project into the sector. For various reasons, including a view that the funding was insufficient, the sector had declined.

> *And for us to become the fund holder just creates a whole burden of, and pressure around making that work. So we were quite supportive of the idea of that money going to an external organisation like CDC, for a couple of reasons. One that there probably wasn't enough money for us to deliver a whole position out of, and two was that it meant that the position wasn't beholden to one individual organisation. And we've got lots of experience with regional positions and they don't work very well. PHC Manager ACCHS*
>
> *At the time it was presented we didn't want to take on recruiting issues… so we didn't put our hand out for the funding and we did support it going to Territory Health…. I must admit though I was really annoyed when I saw that Territory Health had been able to use that funding to combine it into a different position with a job description that went beyond just CS as public health nurses in CDC. We could have done that too if it was put to us that way.* Senior Medical director ACCHS

There was some concern that the scope of the CDC positions would limit time available to focus on providing support to CS patients beyond coordinating the public health response, as CDC public health staff also provide services for all notifiable diseases under the Act. One PHC manager commented:

> *And I said, you've got a big job, and I'd be concerned about how much time you can really dedicate to crusted scabies in our region, 'cause you're doing the three services plus town...and it's notoriously badly staffed there. …….. Whilst being separate to the services is a benefit, being embedded in another service that's notoriously under-resourced is a challenge."* PHC Manager

But despite these early concerns the sector was working closely with the CDC staff who were implementing the public health response and providing services under contract to OD. The complementarity of roles and commitment to working together for implementation was clearly reflected in comments from a medical director in the community controlled sector. Referring to the relationship between CDC and ACCHS he said,

> *Having the [OD funded] position as a kind of project officer in this area, who can devote much more resources particularly in the in-patient phase. Once patients come back into the community though we're keen to have a high profile in the management of these cases. We would see it as a joint management with CDC while the position was there… While there's a dedicated position there we're more than happy to work with and grateful to work with that position. In the couple of cases that we're currently involved in, there's lots of emails and lots of dialogue and joint meetings with x at CDC.* Medical Director ACCHS

As the program has developed a clear articulation of the difference in roles has emerged and the sectors have been worked closely together to define and implement them. An OD staff member explained the difference in focus between CDC and OD roles as follows:

> *CDC are focused at the broader population level and OD at the community level. CDC is responsible for oversight of processes but they don't do the contract tracing, that is done by OD or the PHC service. CDC will ring the clinic to get them to do that, OD support clinics to get that done.* OD Staff member

Table 20 summarises the reported activities undertaken by One Disease and CDC staff.

Table 20: Activities undertaken by One Disease and CDC staff.

One Disease	**CDC**
Improve detection • Audit PHC charts against case definition **Improve treatment and procedures** • Develop hospital care pathway incl. discharge planning for scabies free zone • Develop electronic care plans for PHC **Education** • Education for hospital & PHC staff • AHP Certificate 4 Skin module • Community education • Developed community resources	**Initiation and oversight of the public health response for all notifiable diseases including CS** • Oversight of contact tracing • Oversight of treatment of household contacts for CS • Oversight of household cleaning to • establish a scabies free zone **Surveillance and monitoring activities** • Access to Communicare database

Monitoring care • Access to Communicare database to review progress, input recalls and feedback into care processes • Review CS diagnosis and contact PHC Manager/doctor if inappropriate • Perform recalls **Improve understanding and reduce stigma** • Provide practical assistance to support completion of treatment; care seeking, self-management	• Audit charts and provide feedback into care processes • Review CS diagnosis and contact PHC Manager/doctor if inappropriate • Perform recalls **Education** • Provide education to staff • Developed community resource

Barriers and enablers to implementing the program

Staff involved in implementing the program have had to adopt new practices within their own organisations and to work across organisations to facilitate links between hospital, PHC and home that ensures treated patients return to a scabies-free home. Existing practices in the hospital were adapted under the hospital care pathway developed by OD to align with CARPA guidelines and to focus specifically on best practice treatment and discharge planning. In PHC electronic care plans for CS were developed and implemented into CIS in both NT Health and ACCH CIS. At the time of interview in March 2018 at least 16 care plans were in active use in the community controlled sector, where the system had been activated and training of staff to do CS recall completed. Training on CS care plans for NT PHC clinics had been scheduled but subsequently delayed due to the cyclone event early in 2018. Electronic care plans were therefore not operational in NT government clinics at that time. Referral arrangements between OD, CDC, hospital and PHC centres were developing under the new arrangements, both OD and CDC notification processes.

Competing priorities in PHC

Competing priorities were repeatedly named by stakeholders in the PHC sector as a major barrier to embedding the level of service currently provided to CS patients under the OD model into routine PHC practice. They recognised that once a patient returned to the community, ongoing support and education with individuals and families to secure a scabies free environment was core PHC business, but commented that the demands of acute and chronic care, made it difficult to find time to focus on these patients.

> *Cause while it relies on one person doing surveillance and the staff on the ground doing the work, with all the competing priorities it's always fraught. And whilst we all know its core business and it's part of what we need to do, the reality of service delivery is that ten other things will come up on the same day. And it's hard to make people on the ground aware of the priority when they might see another priority, so they might agree with you, yeah, it's a priority, but I'm just so busy. And we run an emergency service too.* PHC Director

Finding time to provide intensive support to a relatively small patient group was seen as difficult, resulting in skin sometimes being overlooked. At the same time, it was noted that skin checks are included in routine screening but they are just one item in a long list. Finding time to add additional skin checks into routine care was difficult.

> *It's really hard. Because I mean we have in our annual health checks a skin check, and we have in all our child health checks a skin check, and we have in our chronic disease checks a skin check. They're just one of 50 other items that need to occur. And some of these checks, if you did them comprehensively, would take an hour, each. And clients, and like every body part program wants to add their bit. Eye health wants to do their vision screening, and long vision screening, and they want it to be more and more complex as time goes on. And then the cardiology team came and gave us halter monitors for two of our communities, so we have to go and put halter monitors on clients. And ear health there's always expectations, the paeds come and then you've got to do a whole range of things for children. So trachoma as well. And like it's really hard as a clinician on the ground to see the long term outcome of crusted scabies when you're thinking about diabetes and heart disease, and child health [35:38], those things.* PHC Program director
>
> *Child health nurses do a lot of home visits and are out there in the community a lot, but with the child health visits in particular, there's about 40 components to one check. The skin check is only one of the other 40 components…* Child health nurse

In hospital OD staff have coordinated the development of the care pathway and established a network through which implementation issues can be discussed and problem areas identified and resolved as they arise. A stakeholder at one hospital reported this was working well, commenting that at least some of the work had been in resolving debates about where responsibility for certain activities such as fingernail and toenail cutting resided. She was positive about the processes and felt they were working well.

In other places relationships between hospital and PHC may not have been perceived as quite so positive. One PHC medical director commented on what he perceived as a misunderstanding in the hospital about the role of ACCHS and his desire to improve relations for discharge planning and support of hospital patients going forward and particularly to absorb the OD into the future.

> "*We actually don't talk to the hospital very much. So we know that the staff in the hospital get a bit of compassion fatigue… But there is a misunderstanding of the what the role of Indigenous health services are and how they evolved and what really are the effects of dispossession and being a non-dominant culture in a dominant culture world. And we want to create an ongoing discussion in that area to talk with the staff and have some of our senior health workers and Indigenous staff to actually have some of those hard discussions and start a bit of a two way dialogue, and as a regular structured sort of professional development process"* Medical Director

Maintaining a scabies-free zone

Maintaining the scabies-free zone was seen as the hardest thing by some, particularly in the face of endemic scabies. Investing support at the household level was considered essential. One Medical Director commented,

> *Most people with just normal low level infections of scabies don't present to our services. So it's very hard to maintain a scabies-free environment … It depends on your relationship with the family and it involves being very generous with Lyclear or Benzyl…. The investment really needs to be in the family because it's not a highly*

> *technical medical problem, but they need to have the family resourced with knowledge and understanding. And then a generous supply of creams.*

All of the strong women workers and the health promotion staff members interviewed stressed the importance of having an Aboriginal health worker workforce for building relationships with families and households.

> *They [PHC Clinics] can't work without the Aboriginal workers with them. Need equal numbers to the clinical staff. Otherwise it is just going to be band-aid stuff, it will repeat and repeat.* Strong woman worker
>
> *There are not enough local health workers. Need to recruit more. Numbers of health workers has gone down a lot in recent years. We only have one accredited health worker doing Cert 4. There's never been an updated recruitment and retention plan – especially how to retain Aboriginal workers.* Strong woman worker

The importance of the community being an active part of the program was also stressed.

> *You need strong people in the community to be involved. To get the message out there and to keep it going. There are not many strong elders.*
>
> *People don't associate this [CS] with sick hearts. Health homes program can't be a handout.* Health promotion officer

Addressing the social determinants for embedding the program in future

Many people commented on the need to address scabies and the importance of addressing the social determinants of health, especially poor housing and overcrowding as well as housing hardware.

> *What is the root of the problem? This is important to think about. If you don't have running water or a fridge or a washing machine. How many people in houses? Thirty plus people living in a three bedroom house. All these things need to be addressed in conjunction with the skin stuff. Strong woman worker*
> *We don't actually have control over education or housing or food security or things like that… there's not the same buy in if it's not a health organisation because more broadly in government the social determinants aren't considered as important as health.* PHC Manager
>
> *Housing is always going to be an issue. The overcrowding. If you don't sort this then you can't get rid of scabies. You need washing machines and mattresses that are affordable. Community development approach that is needed…. Put washing machine in the ladies centre – come in have a cup of tea, do the washing. Even just have a laundromat. There isn't one here. Not even clothes lines and washing machines in some places.* Strong women program worker.
>
> *And they keep telling us, most are telling us no washing machine, doing with hands… Like me I got no washing machine"* Strong women program worker.
>
> *This is where money management should be getting together a bit here and being able to get washing machines for a better price. I mean it's just ridiculous what they're paying out here. It's completely unfair.* Chronic disease coordinator

Perceived key success factors

Reflecting on the program over time, stakeholders articulated the key benefits they perceived the program offered to participating services and to patients. Specialised knowledge and provision of training were highly valued, particularly in the context of organisations with high staff turnover. So too was support provided for Aboriginal health practitioners to take a lead role in providing education and support to communities for implementing the scabies-free zone. The fit of staff, the relationships they have developed with patients and services, and the respectful way of working were repeatedly singled out as key to the success of the program.

> *It fits very well … they [OD staff] integrate themselves within our service to an extent when they're clinically managing a patient, they provide a high level of information exchange and communication with members of the team.* Senior medical practitioner/manager

Resources for a dedicated team

Having a dedicated team with time to spend building relationships was seen as essential.

> *"The One Disease program has a wonderful ability in that when they're in the community the constraints on their time is not so strict, so for example if we're referring families with recurrent scabies in six months or three times let's say, the ability that she had was she could go back multiple times and just spend time building a relationship with that family and then taking as long as it needed to have discussions and find out if there's other family members… whereas the clinic staff are so over-run that time is really hard to get that extra support."* Child health nurse
>
> *I think long term sustainability, that resourcing probably needs to increase, to have a more individual service targeted approach.* PHC Manager

Relationships with patients and providers

Strong relationships with patients was perceived as central to the operation of the program

> *One of the key things is the relationship that is developed with the patients. I've seen that the OD staff demonstrate good support of relationships with affected people. And I've been struck by how that differs from the broader relationships with clinicians. So the personal relationship element is certainly a strength. I think the case management element is a strength. I mean I'm thinking this might be because the case numbers aren't very high but I don't know"* Senior Medical practitioner/manager
>
> *At the end of the day, it's about a person's approach and approachability and you know empathy and ability to communicate properly"* Health promotion officer
>
> *… I can tell you it's about having the same person that right person is really important*" Chronic disease program coordinator
>
> *She [OD nurse] was good. And she could talk and we know each other. And she always come to visit and she always kept asking me for my family, ask how your family's going…. And also she's [OD nurse] good for two way learning. She listens and asks us questions and learns from us.* Strong women program worker
>
> *She [OD staff member] was really easy to work with, had a really good knowledge base and she seemed to really care about the families out there. They are really a*

> *support than a hindrance and I think just because they built those relationships, it was so important with the clinic staff as well as the community"* Child health nurse

OD staff could motivate staff in busy PHC services to find new ways to support CS patients.

> *They've provided motivation. Let's get up, let's do something about this. Let's get down to the house and have a look and pick them up and see how they're going. OD had said, look she needs to have a bath and she needs to be covered with this lotion. And the health worker was going I don't want to do that. But within a few days I saw her [the health worker] and she said I bought her up, I'm giving her a bath here in the clinic and I'm putting the stuff on her. And I think that the support, keeping the motivation going was really good."* Senior medical practitioner/manager

Components of coordination - education, professional development and practical support

Education and professional development were highly valued, in hospital and PHC services as well as in community organisations.

> *They [OD] do some education classes for my nurses, especially for my newbies. We have lots of junior grads come through so we get, one time we had six graduate nurses.* Hospital nurse manager
>
> *Plus she comes out regularly and connects with all the other organisations and she's linked into the youth groups so she does regular health promotion and she often brings a colleague … and they make that interesting and visual and hands on.* Health promotion officer

Others highlighted the problem solving, navigation and coordination aspects of the role as critical in going forward.

> *It's that coordinator who says, I'm going to facilitate this patient being seen or maybe they're going to have access to the CIS to put a recall in. Maybe they're going to monitor the recall. Maybe they're going to ring the doctor and the health centre manager from the community and say your patient is coming home, this is what's happened and this is what we need to do, would you be able to get to have that recall done. That sort of stuff. In bigger communities where there's possibly a number of people with this condition, you would almost have a community based worker, who might be a health worker or they might be a mentor.* Senior Medical officer

Embedding the program in future

When asked how the model could be maintained if OD were not there to deliver it, one Senior medical practitioner/manager replied that it could not. However he identified education resources and a clinical nurse consultant role as valued program elements that would need to be embedded in future.

> *If OD wasn't here well we wouldn't [be able to sustain it]. It would all fall down. I mean OD is an extraordinary phenomena in the sense that they are able to provide a level of care and a level of visitation to very small number of patients that just wouldn't cut the mustard within our program models…. But to look at it positively and say what could sustain it? You would want to have some diagnostic resources that are better that what's in CARPA. So if I just started working in the bush, I go, what's all this stuff about different stages of CS and is it half a millimetre thick or is it five millimetres thick and where is it? Where's the app and diagnostic aid... pictures are good… and that should be online. And there should be an identified and*

> *committed person to refer to when you have questions…. So you could have an app and a clinical nurse consultant working closely with either infectious diseases or dermatology.*

A Chronic disease program manager emphasised the practical support

> *In an ideal world it would be nice to have somebody actually out here that sits down with the people and finds the barriers and works out what to do.*

A strong woman worker emphasised leadership by local Aboriginal workers supported by a OD team

> *Set up a dedicated team in the local community – have local workers. So OD sets this up and supports it but the local people are the ones who keep this going. They drive it, it gives employment.* Another strong woman worker

Lived experience

Three short case studies are presented below illustrate the variety of strategies and practical supports provided by OD to people in the program. The cases provide some insight into the lived experiences of people with CS and highlight the lack of control over social determinants, particularly living conditions which can undermine an individual's capacity to maintain healthy skin.

The cases also provide examples of ways in which health clinics can mitigate the effects of overcrowding, homelessness and poor living conditions in the short term while advocating for better housing in the longer term. For example, in Case Study 1 the AHW offered the client showers at the clinic so she could maintain her hygiene and obtain assistance with administering topical treatments.

Case 2 highlights the importance of trusted relationships, an issue that many stakeholders commented on at interview (see above). Working effectively with individuals, families and households relies on trust and this takes time to develop and is underpinned by respect and two way learning.

Many people at interview talked about the competencies and ways of working that need to be in place to effectively engage with Aboriginal people and there was a view that this was not always widespread. An experienced Medical Director expressed the view that

> *…when people come to hospital, they feel very disempowered, racially profiled and very uncomfortable. And this is affecting our ability to provide services...there is a misunderstanding of …what really are the effects of dispossession and being a non-dominant culture in a very dominant culture world.*

Together insights gained from case studies and interviews highlight stakeholder perceptions that *how* OD staff work is as important as *what* they do.

> *You need someone with a fire in their belly. Someone like [OD staff member] who gets it. Wants to look at an issue from a number of different perspectives and try different things.*

Building respectful relationships through two way learning and outreach in communities is perceived as critical but takes time that staff in busy clinics and hospitals do not have. Staff perceive that the care coordination resources provided by OD which incorporate case management and navigation is a gap in health service delivery needed to address CS into the future. The Aboriginal health workforce is critical to making this work.

> *When you look at positions allocated to clinics it's all clinical positions… but they can't work without the Aboriginal workers with them.*

Case study 1

Woman in remote community aged in her 40s with recurrent crusted scabies

This woman lives in a remote community in hostel style accommodation with shared kitchen and bathroom facilities. There is a lot of fighting over shared facilities in the hostel and residents do not have much control over washing and cleaning of kitchen and bathroom facilities. The woman has limited knowledge of crusted scabies and treatment requirements. She needs information and support to overcome shame and build confidence that she can get rid of the CS and help to find ways of dealing with inadequate washing facilities and other problems that make it difficult to maintain healthy skin.

<u>Health Care</u>

The health clinic does limited community visits and staff are overwhelmed with acute care needs and the ongoing demands of poor community health and well-being. The Local council has not conducted spraying or rubbish removal or held healthy skin days for a long time, which used to include providing washing powder and soap.

<u>One Disease</u>

One Disease provides education about crusted scabies to the patient; encourages her to access the clinic for treatment; and coordinates cleaning to facilitate a scabies-free zone. They work with clinic staff to motivate them to re-engage with the woman in the community and to assist her by providing practical support to overcome some of her housing difficulties that impact her crusted scabies.

<u>Response</u>

Household is cleaned

AHW visits the woman in her home, provides education, cream and encourages her to attend the clinic for treatment.

The AHW also offers the woman showers at the clinic and helps to administer the cream to ensure it is applied correctly.

A care plan for treatment and ongoing management is put into place

Case study 2

Young man with crusted scabies living in long grass in Darwin while visiting from a remote community

An OD staff member is approached at the Larrakia BBQ by a woman who is the young man's aunt. She knows the OD staff member from previous contacts and trusts her. The woman is concerned about her nephew's skin and asks OD to make contact with him.

<u>Health care</u>

The young man has previously presented to the Emergency Department with scabies and been given Lyclear to take away.

<u>One Disease</u>

With the assistance of Larrakia Nation, OD locates and makes contact with the man. Four months since his visit to ED, his skin has deteriorated significantly and is crusted. He agrees to go into the ED with the OD staff member and is admitted. OD spends time with the man to explain his diagnosis, treatment and admission procedures. The man is upset and frightened so OD make contact with the aunt who encourages him over the phone to stay in hospital. He is found to have a number of other co-morbidities and transferred to

ICU. OD liaise with the man's workplace to organise leave from work and continue to visit him throughout his hospital stay.

Response

The man remains in hospital for 7 weeks.

OD staff visit him regularly to support him to stay in hospital and complete his treatment.

The man maintains his job and is linked to a PHC service at discharge.

Case study 3

Man on dialysis, residing in hostel accommodation in Darwin, has crusted scabies

This man lives in hostel accommodation in Darwin, away from his family and community, with others who also attend the Renal Unit. Like many people on dialysis he feels sick a lot of the time but the hostel does not have nursing staff. It is not easy for him to obtain cream for his skin or get assistance with his activities of daily living.

Healthcare

He is referred to OD when his CS is diagnosed at the Renal Unit in Darwin.

One Disease

OD work with CDC on the public health response to support a scabies free environment at the hostel. They visit the hostel to conduct contact tracing. They identify people with scabies and provide education, support and Lyclear. They assist with hospital admission and visit the man in hospital to support him to stay and complete his treatment.

Response

The man completes his hospital treatment and is linked to a PHC clinic on discharge for ongoing support and case management.

Summary

The OD program has been widely implemented among Top End PHC and hospital services. Despite some early concerns in the ACCHS sector about a potential for clash in values and whether an entrepreneurial NfP organisation would sufficiently advocate for the social determinants of health through working in partnership with ACCHS, there was broad support for the program among those who were interviewed. They perceived the program had contributed focused resources for CS and by working together with services had successfully raised the profile of crusted scabies and led to improvements in care and outcomes for clients.

A wide variety of strategies have been implemented to increase detection, improve management, reduce stigma, and establish scabies-free households to prevent recurrence. Key strategies include audits of primary care records, provision of education and technical expertise and support to staff and affected individuals to improve the management of CS. The development of a hospital care pathway to improve discharge planning and electronic care plans in PHC aim to embed ongoing management. Care plans had not been fully implemented into NT Government clinics at the time of data collection.

Key enablers for implementation of the program overall were thought to include the coalescence in timing between notification of CS in the NT and the roll-out of the current OD program, the partnership and systems approach to embedding change in existing services and the strength of relationships between OD staff, providers and clients. The prior experience of the OD manager and staff within the Aboriginal health sector in the Top End and the ways in which staff worked to develop trust with clients and motivate PHC staff were well regarded and deemed to be key success factors for increasing knowledge and changing behaviour. Having a dedicated team with time to invest in working with providers across the system and at multiple levels, and the practical approach to supporting clients were features of the support provided.

The context for embedding the program into the future is challenging without dedicated resources for coordination. PHC providers report that competing demands for acute and chronic care limit the time available for building relationships and providing education and health promotion in the community. The degree of coordination and timing required to ensure that households are cleaned and residents and other contacts treated prior to a patient returning from hospital continues to pose significant challenges, in the context of overcrowding and poor living conditions. Implementation of scabies-free zones relies on building good relationships with households and there is a widespread view this cannot be achieved without the central involvement of the Aboriginal health workforce and the involvement of communities and households as active partners in passing on the story of CS and developing a community approach to supporting scabies-free households. Overcrowding and the expense of basic appliances such as washing machines and mattresses in remote communities are seen as significant barriers to achieving scabies-free households.

Clients with limited control over their household environment and daily living activities, who had limited outreach support from PHC and other services, seemed to experience most difficulty in maintaining treatments and ongoing self-management. Case studies suggest that practical support and outreach in the community can assist clients to gain some control over their daily living activities and continue with treatments to improve skin health. Supporting people throughout out their hospital treatment and providing showers and assistance with applying creams in the community when living conditions make this difficult were important contributions that assist people to gain some control over their health and do not appear to be provided under usual care arrangements.

Limitations

This section is based on interviews and focus groups with 27 stakeholders. Not all invited individuals responded to our invitation to participate in interviews and while we have no reason to believe their views may be different, it is possible that the views expressed in this section may not be indicative of those held by others.

7. Patient reported Quality of Life

The quality of life (QoL) for patients with Crusted Scabies (CS) is unknown, and it is unknown how QoL is impacted over the different stages of the disease. This limits the information that is available for the economic evaluation of CS related treatments. Only few measurements of QoL have been performed in simple scabies (SS), and these have been undertaken with disease specific instruments that are not appropriate for use directly for calculation of quality-adjusted life years (QALYs). In addition, there are specific challenges associated with measurement and valuation of QoL for the populations most at risk from CS, including challenges associated with remoteness, language and cultural differences. Even with a dermatology specific QoL instrument, the impacts of CS in terms of QoL may not be well captured.

The evaluation team is conducting a QoL pilot study which aims:

- To test methods for measuring QoL for people who have experienced CS in the Northern Territory.
- To compare different instruments in terms of their sensitivity, comprehension and feasibility and face validity.
- To determine what resources would be needed for wider implementation of the preferred measure(s).

The pilot study consists of three phases, with the following activities:

1) Pre-measurement:
    - Systematic literature review of existing QoL studies in scabies and/or CS (finalised).
    - Testing the face validity of QoL measurements (21/11/2017).
2) Measurement:
    - Measuring QoL in ~100 individuals (as soon as ethics clearance has been obtained).
3) Analysis and planning:
    - Analysing the results of phase 2 (to be determined).
    - Determine if/how the preferred measures should be implemented (to be determined).

Whilst the QoL work is ongoing, this part of the report provides the initial results and progress to date.

Pre-measurement

In the first stage of this work, a systematic review of scabies related quality of life measurement was undertaken to examine the available evidence published since the year 2000. The focus of the review was on studies that examined patient quality of life and resource use, including models used to undertake economic evaluations in scabies interventions. The Strengths and limitations of identified scabies models were evaluated and used to design a model structure. Potential model inputs were identified and discussed.

The review confirmed the very limited number of previous papers in this area. Four scabies models were published but none specifically addressed crusted scabies. The review found that there is a lack of reliable, comprehensive information about scabies biology and the impact this disease has on patients and society.

The review provides the foundation and justification for undertaking further work in the area QoL research in the area of CS. It is particularly important to develop a greater understanding of the impact that CS has on the QoL of patients. This is essential for future researchers to undertake economic evaluations of CS prevention or treatment programs.

The work on this stage of the work has included a focus group with Indigenous researchers from the Menzies School of Health Research in November 2017. The focus group explored whether the questions from three relevant QoL questionnaires reflects the things that are important to people and are sufficiently easy to answer and culturally appropriate. The three QoL instruments are:

- The modified Dermatology Life Quality Index: due to being specific to dermatology, this questionnaire is expected to be most sensitive in picking up scabies-related effects on QoL.
- The EQ-5D-5L: this is a preference-based measure (PBM). PBMs measure health and QoL and include a utility value set based on the health preferences of a population which can be used directly to calculate QALYs for use in economic evaluation. The EQ-5D-5L includes both physical and mental QoL questions and is hypothesised to have some level of sensitivity alongside the Dermatology Life Quality Index.
- The ASCOT: this captures social care related QoL (e.g. accommodation, cleanliness, dignity), which is an area that One Disease hopes to impact on.

Focus group members group were asked to comment on the following issues with respect to each of the survey questions:

- Do you think this question reflects something that you think is (or would be) important to your QoL?
- Do you think this question reflects something that may be impacted by scabies, CS, or interventions against scabies/CS?
- How easy or difficult is it to answer this question?
- Do you think there is a better way we could ask this?

Per questionnaire, the following was asked:

- Within this group of questions, do you think there is anything missing that is important to your QoL, or to the QoL of scabies/CS patients?
- Do you think there are other areas of your life that are important that aren't covered within these themes? Do you think these could be impacted upon by treatment/care?
- Do you think images/pictures might help answering any of the questions?
- Would you have any preference for completing these questionnaires on paper versus on an Ipad (given that One Disease staff will ask the questions and will complete the questionnaires, not the patients themselves)?

Results were used to evaluate whether the questionnaires are relevant, acceptable and whether there is any way to improve upon them. One of the main outcomes from the focus group was to re-design the QoL instruments to improve ease of understanding. This included work by One Disease to develop pictorial aides to complement the questions and possible responses.

Measurement

After adjusting the combination of QoL instruments and rephrasing the questions outlined above, a new instrument is currently being tested in a sample of 100 individuals (≥18 years). The instrument will be implemented using a face-to-face computer-assisted survey, on a tablet (unless otherwise decided based on focus group results). The survey will be implemented in English, filled out by One Disease staff, with an interpreter if necessary. Local language interpreter services are generally available in the hospitals and communities.

The included sample consists of:
~30 individuals with SS
~70 individuals with current CS, representing all different grades (including patients who are/were hospitalised). Patients are being recruited by the One Disease team at the time of diagnosis and questionnaires administered to consenting patients and readministered at 12 weeks.

Patients with SS will be recruited through One Disease networks and via a microscopy trial which is currently being conducted in Darwin. In addition to the QoL questions, the following information will be obtained from respondents:

Additional information obtain from pilot respondents:
Age
Gender
Postal code
Number of persons in household. Number of these who have had simple scabies? Number of these who have had crusted scabies?
Do you currently have simple scabies? If not, when did you last have simple scabies?
Do you currently have crusted scabies? Which grade, if known? If not, when did you last have crusted scabies? Which grade, if known?
Was there any question in the QoL questionnaires you found particularly difficult to answer?
Do/did you experience any impact of scabies/CS which has not been taken into account in the questionnaires?

Analysis and planning

Published algorithms for the various questionnaires will be used to calculate QoL scores in case questionnaires were used in their validated form. QoL will be determined separately for SS, CS, and the various grades of CS, with and without discriminating between patients who have active or past disease. Alongside reporting the values, we will report the descriptive scores on each item/dimension to see where the responses are most likely to not be at the best level.

The relationship between the individual measures included in this pilot will be examined using validity and agreement analyses and regression at the item, utility and dimension score level. Validity assesses the extent to which an instrument measures what it is intended to measure and is difficult to prove, as there is rarely a 'gold standard' against which to compare. This means that validity is compared across measures using various well-established tests and guidelines about the magnitude of the relationship.

- Concurrent validity will be used to assess the strength of the relationship between measures of the same concept using Pearson correlations.
- Known group validity will be used to assess the extent to which scores on an instrument differ across groups where they are expected to differ (e.g. different CS grades).
- Agreement between measures will be assessed using Bland Altman plots, which are used to visualise the relationship between measures scored on the same scale.
- Regression analysis will be used to examine the extent to which the scores on one measure explain the scores on another at both the overall and item level.

These analyses will provide further evidence about the measurement overlap between instruments.

It is anticipated that the sample will be recruited throughout 2018 and analysed early in 2019 or when sufficient data is available to do so. Reporting to One Disease will occur thereafter.

8. Findings and Conclusions

The OD program is a well-regarded strategy that fits within the NT health service context, is acceptable to participating providers and has been widely implemented in the Top End. The program offers coordination, navigation, education and support services that are not routinely available for CS patients. A variety of strategies have been implemented to increase detection, improve management, reduce stigma, and establish scabies-free households to prevent recurrence. These include audits of primary care records against the new case definition, provision of education, technical expertise and support to increase knowledge among staff, and support for affected individuals to access and complete treatment. The development of a hospital care pathway aims to embed a focus on discharge to a scabies free environment and electronic care plans in PHC support ongoing follow-up for treated patients.

Perceived strengths include having a dedicated team with time, resources and a focus on CS; the provision of technical expert advice to staff and practical support and education to assist affected people to maintain treatments and gain greater control over their self-management in the context of overcrowded housing, poor living conditions and sometimes limited access to resources such as washing machines and mattresses. Coordination of care has helped to achieve vertical integration of patient care pathways and horizontal strategies for strengthening primary care capacity to improve follow-up and support self-management and a scabies free zone.

Key enablers for implementation of the program overall include the coalescence in timing between notification of CS in the NT and the roll-out of the current OD program which has arguably provided a mandate for a focus on CS, as well as other critical enablers including the partnership approach to working with existing services. This is underpinned by strong leadership from people with a deep knowledge of the local context and ways of working who have been able to successfully negotiate partnerships across organizational boundaries and to design and adapt strategies to achieve program objectives. Respectful two-way learning which fosters trust and good relationships with staff, communities and individuals has been critical for increasing knowledge and influencing behavior change.

Audit data shows that the program is improving treatment completion and trends in recurrences are positive. Perhaps the most significant impact of the program on care processes is the increased length of hospital treatment which has more than doubled in the period following July 2016 compared with the period prior, suggesting that patients are more often completing treatment in hospital. The length of treatment also generally matched the grade of disease and most patients had a clear skin scraping on discharge. This is a remarkable achievement for a NfP organisation which has had to establish relationships and work across multiple organisational boundaries to influence care pathways and support clients.

Other processes of care in the community also improved. Data showed that following the completion of hospital treatment, more frequent contact was provided in the community. This is a positive result, particularly as the patient cohort have high levels of disadvantage that pose a challenge to delivering recommended treatment in the community. Half were homeless, and all homeless patients had a chronic condition that may impair immune function, in particular end stage renal disease. The duration of treatment was shortest among patients with alcohol dependence, especially when the patient was also homeless. Substance abuse was a common factor in the majority of patients with frequent recurrences of CS and these individuals had poor contact with health services after discharge. Data showed that use of recall was patchy which can be attributed to delays in establishing electronic care plans in NT Health service CIS due to a cyclone event in Darwin which delayed scheduled training. Routine use of care plans and recall for people with a previous episode of CS may be expected to improve the follow up of patients leaving hospital in future as care plans are embedded into routine practice. Data were of insufficient quality to comment on medication prescribing in the community.

Overall trends in recurrence were positive. The majority of patients with an initial episode of CS after July 2016 did not have a recurrence during follow-up. Only 4 of 26 patients with an initial episode after July 2016 had a recurrence and it appears these were acquired in the community. Of 16 individuals with a recurrence prior to July 2016, only 5 had a recurrence after July 2016. None of these new recurrences had more than 2 episodes during the follow- up period. In all but one case the grade of disease was less at the recurrence. Duration between episodes is six months or more, before which the disease is seen as a recrudescence of incomplete initial treatment. The hypothesis that the disease was reacquired in the community is supported by the long length of initial treatment and the presence of a clear scraping in 4 of the 5 cases. This converges with qualitative data which suggests that maintaining a scabies free zone is challenging. It requires extensive coordination, good timing, contract tracing and follow up and is underpinned by good relationships with communities and individuals. Many stakeholders believe this must be supported by Aboriginal leadership in future, with support from a program such as OD. This may be challenging in the context of difficulties recruiting and retaining the Aboriginal health workforce, particularly in remote communities.

The expected health care cost per patient diagnosed with CS is $31,209.20 resulting in an overall cost of $1,373,204.87 for managing all patients diagnosed in the NT in a given year. This includes the costs associated with diagnosing, treating patients in hospital, and follow-up care relating to the patient and members of their family and household. By far the biggest component of the health care costs falls on the public hospital system. The COI results show that for every episode of CS prevented the health care system can expected to save $31,209.20.

COI analysis provides a basis for future cost-effectiveness analysis on the impact of CS elimination and prevention programs such as those run by One Disease. In addition, the model developed here can also be used to examine the impact of the program on preventing higher grades of CS through earlier recognition and treatment, as well as efforts to reduce the incidence of recurrence. The process of the audit highlighted difficulties in data collection that should be addressed to improve monitoring of future elimination efforts. There is a need to develop systems to prospectively collect data that will inform CS elimination.

Together these results highlight the major challenge in moving towards elimination of crusted scabies. While there have been marked improvements in initial hospital treatment, these disadvantaged patients are then returning to scabies endemic environments. In this context there is always a risk of re-infection and without measures to markedly decrease scabies prevalence, it may be that what can be achieved is control of crusted scabies, with detection of the disease at an early stage and high quality initial treatment, rather than elimination.

While potential for elimination is as yet uncertain, progress towards establishing elements of an elimination approach have been made. The OD program has worked closely with the NT Government Centre for Disease Control and service providers to improve accurate diagnosis through applying the CS case description, supporting implementation of standardized treatment protocols (CARPA), and working towards effective recording and reporting systems. The program has well defined objectives with identified timeframes for elimination and includes coordination strategies to improve care integration across primary and secondary care as well as horizontal strategies to strengthen primary care systems and provide support to clients in the community. *Table 21* below describes the NT program and OD strategies in relation to criteria for elimination.

Table 21: Criteria for elimination programs and One Disease strategies

Criteria for Elimination programs	
Criteria for elimination programs drawn from literature	**NT Context and OD Program**
Social & political criteria: Sustained social and political commitment, perceived social appeal and interest in the disease that recognises it as an issue of public health importance and that there are clear reasons for eradication that will maintain support	The notification of CS in the NT suggests it is a recognized public health issue. Significant government funding has been provided to OD by the Australian Government, though this is not ongoing.
Interventions must be feasible and developed by technical experts as well as in consultation with affected communities	OD approach has proven feasible and acceptable to stakeholders. Workforce turnover, and recruitment and retention of the Aboriginal health workforce are challenges. Scabies free zone are difficult to sustain.
Programs have “a well-defined scope with a clear objective and endpoint, and the duration is limited.	Program has well defined objectives with identified timeframe for elimination.
Targeted vertical approach in addition to what control programs offer which are usually integrated in horizontal programs focused on strengthening primary care, improving surveillance and training personnel.	OD program offers: • Audits of PHC records against case definition helps to establish accurate numbers collection but needs improvement Integration of vertical care pathways • Coordination of services between specialists, hospitals and PHC to improve access to services and promote continuity across primary and secondary care. Clinical hospital pathways for linking discharge with scabies free zone and treatment in the community. Horizontal integration • Strengthening PHC systems to improve management & lifelong follow-up in PHC (care plan) • Coordination of public health, environmental and community services and households to support scabies free zone • Training, education, expert advice to staff • Education and support to individuals and households

Programs produce sustainable improvement in health and provide a high benefit cost ratio” must address the issues of equity and be supportive of broader goals that have a positive impact on the health infrastructure to provide a legacy in addition to eradication of the disease’	Sustained improvement and cost benefit ratio not yet known. Evaluation shows promising results for observation period. Trends in recurrences are positive and treatment completion and follow-up is improving. Scabies endemic environments pose major risk for reinfection of treated CS patients. The COI results show that for every episode of CS prevented the health care system can expected to save $31,209.20

The NT context of notification for CS, together with long standing involvement of PHC services in community based scabies control programs provides a unique context for implementation of the OD program that may not be in place in sites in WA and QLD where roll-out of the program is planned. Scaling up requires an assessment of need and the alignment of policy context, as well as an assessment of the likely acceptability among stakeholders and the organizational, technical, human and financial resources required to deliver the program effectively. Lessons from the NT experience suggest a strong policy fit, identified need, and widespread adoption among stakeholders. Factors that appear to be important to the success of the program, as outlined above, include having a mandate to address crusted scabies; a partnership approach with strong leadership from people with a deep knowledge of the local context and ways of working, as well as respectful two-way learning which fosters trust and good relationships with communities and individuals. Engaging the Aboriginal health workforce early and providing mentored support for a leadership role in community development for scabies-free zones could be expected to assist with filling what is a perceived gap in service at the household level.

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