FINAL REPORT ON THE CRUSTED SCABIES ELIMINATION PROGRAM (2021-2023) FOR THE COMMONWEALTH GOVERNMENT DEPARTMENT OF HEALTH

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Part A: Introduction

As set out in Section E.5 of the *Commonwealth Standard Grant Agreement between the Commonwealth represented by Department of Health and One Disease Limited,* executed on 4 May 2018, and supported by the *Deed of Variation in relation to Indigenous Australians Health Program*, executed on 29 June 2021, this is the final report for the three-year period 2021-2023 (fiscal years) on the learnings and outcomes of the One Disease Crusted Scabies Elimination Program.

The report addresses the points in Items A and B of the Agreement, using as evidence:

- data collected by the One Disease Program Team
- data and analyses within the external evaluation team's reports
- Northern Territory Centre for Disease Control (CDC) data on Crusted Scabies
- information within our approved yearly Work Activity Plans and Performance outcomes, as stated in our six- and twelve-monthly reports to the Government during the reporting period.

For clarity purposes, appendices in this report, for the most part, do not duplicate appendices provided in previous performance reports.

Part B: Overall Aims of the Crusted Scabies Elimination Plan

Organisational Goal: Educate and enable patient self-management to eliminate Crusted Scabies as a public health concern across Australia by 2022.

Overall Aim: For Crusted Scabies to be easily managed within existing primary health-care systems and ultimately eliminated as a public health problem in Australia.

Supporting aims:

To support improvement of the detection and diagnosis of Crusted Scabies.

To prevent recurrences of Crusted Scabies in clients who have been successfully treated, by embedding local systems and ensuring treated clients live in a Scabies Free Zone.

Improve detection and diagnosis and prevent recurrence in successfully treated clients.

Evaluate One Disease's Crusted Scabies Elimination Model.

Part C: Key Performance Indicators and Achievement Strategies

KPI: 1. To improve detection of Crusted Scabies.

KPI: 2 Eliminate Crusted Scabies as a public health concern in the Northern Territory by attaining a recurrence rate of Northern Territory Crusted Scabies clients less than 5% of the total cumulative cases.

Key strategies implemented to achieve KPIs.

Building Capability for Case Detection

- Promoting the use of data from recall and reminder systems for Crusted Scabies
- In-service training of health workers and individuals

Monitoring and Surveillance

- Working with the Northern Territory Government towards an enhanced dataset for Crusted Scabies.

Education and Workforce Capacity Development

- Community education and health promotion to improve health literacy among individuals and families
- Inservice training for hospital nurses, primary health care and community providers
- Curriculum for skin health incorporated into Aboriginal Health Worker training: Certificate IV in Aboriginal and/or Torres Strait Islander Primary Health Care Practice: HLTAHW016 Assess clients physical wellbeing (Batchelor Institute).
- Storytelling tool for health and non-health professionals such as in aged care, child-care etc
- Education videos for health workers of remote communities.

Community Mobilisation and Health Promotion

- Mass media advertisements, social media and other strategies to raise community awareness, reduce stigma, and promote access to health services for treatment.

Hiring of Small Indigenous Workforce

- Six Indigenous Healthy Skin Community Based Workers (Galiwin'ku/Darwin) providing skin hygiene education to their communities.

Treatment Completion

- Social support for people in hospital to complete treatment
- Hospital pathway and discharge planning to ensure referral to scabies-free homes and PHC for follow up care.

Secondary Prevention and Follow Up

- PHC care coordination model to prevent recurrences.

Healthy Environments

- A strong focus on the creation and maintenance of Scabies Free Zones.

Part D: Final Statistics

As of the end of December 2022, there were 241 Crusted Scabies clients in the Northern Territory with 20 of these clients notified in the final quarter of reporting.

Of these 20 clients, 13 were new cases and 7 were recurrences.

One Disease has promoted a range of strategies to improve detection, leading to additional cases of Crusted Scabies being identified and therefore meeting the first KPI of identifying more cases of this condition.

The KPI of keeping recurrences under 5% is also constantly being achieved. Presently, the recurrence grade is 2.9% (*7 clients of 241 clients had a recurrence of Crusted Scabies in Q2 FY23).*

The mean recurrence rate for the entire reporting period is 2.6%.

Importantly, of the Crusted Scabies cases notified across the reporting period, the majority (88%) were not Grade 3 (the most severe grade). Appendix 1 contains the full data set.

Proportion of Cases of Crusted Scabies Grades for the Reporting Period

Crusted Scabies Grade 1 (10x infectivity): 46 % of clients

Crusted Scabies Grade 2 (100 x infectivity): 40 % of clients

Crusted Scabies Grade 3 (1000 x infectivity): 14 % of clients

In comparison the data from 2016, prior to the Crusted Scabies Elimination Program being developed and implemented, showed only 51% of all cases (new and recurrent) were detected as Grade 1 and 2.

This signals the effectiveness of the One Disease program's processes for early detection when clients are less likely to develop severe symptoms and are less infectious.

The key achievement being that the most severe grade of Crusted Scabies is under control in an environment where scabies is still endemic.

Part E: Partnerships

Participating Services

The Crusted Scabies Elimination Program was developed in conjunction with disease experts and health practitioners from remote communities, and its execution during the final 3-year reporting period involved the following participating services:

Health Service Provider	Area
Northern Territory Aboriginal Community Controlled Health Services	
Miwatj	
	Galiwinku
	Gunyangara
	Nhulunbuy
	Yirrkala
Katherine West	
	Bulla
	Timber Creek
	Yarralin
	Amanbidji
	Nitjpurru
	Daguragu
	Kalkarindji
	Lajamanu
Sunrise	
	Manyallaluk
	Barunga
	Beswick
	Mataranka

	Jilkminggan
	Minyerri
	Bulman/Weemol
	Ngukurr
	Rittarangu
Wurli-Wurlinjang	
	Binjari
	Katherine
Danila Dilba	
	Darwin
Northern Territory Department of Health	
	Adelaide River
	Alyangula (Groote Eylandt)
	Angurugu
	Bagot
Queensland	
Torres & Cape Region	Apunipima Health

Part F: Key Areas of Work and Achievements within the Reporting Period: Financial Years 2020 - 2023

Financial Year 2020-21

Early in this fiscal year, to assist with early detection, One Disease began reporting on the grades of Crusted Scabies cases; Grade 1 being the lowest in infectivity and Grade 3, the highest. The rationale for this was when diagnosed earlier in their disease progression, clients have reduced infectivity.

To continue to ensure the cultural appropriateness of the Crusted Scabies Elimination Program and enhance community engagement, six Indigenous healthy skin community-based workers (Galiwin'ku/Maningrida/Darwin) were employed and trained to provide skin

hygiene sessions on a one-to-one basis and to community organisations/groups.

Over 212 Crusted Scabies and scabies education sessions were held, reaching more than 2205 individuals from hospitals, clinics, households, aged care facilities, renal services, clients, men's and women's groups, schools and Families as First Teachers (FaFT) groups. Sessions were held via teleconferencing when COVID-19 restrictions were in place.

During this time, the One Disease community-based workers also established a Community Skin Hygiene Group on Facebook. The aim being to encourage community members to share stories of skin hygiene. The workers also assisted their communities' clinic teams to set-up hand hygiene stations at different organisations and provided COVID-19 messages in Yolngu Matha.

449 health professionals completed the One Disease Crusted Scabies Module on the RAHC[1] website.

We completed the Scabies and Crusted Scabies Storytelling App which was launched virtually in May 2020: https://storytelling.onedisease.org The stories are in 22 Australian Indigenous languages and English. There is an accompanying Facilitators Guide for group education and a User's Guide. Feedback from community has been very positive.

The educational video called *Walking Together Working Together*, primarily for health professionals working in remote communities was finished. Due to COVID-19, a small launch was held rather than the intended large event. Link to film: www.youtube.com/watch?v=mhpGHgyeewg&list=PLEYsKUJbjKmJViAjliN5E8A6zNba2QzDO&index=25&t=0s

We also completed twelve short video clips with community members discussing accurate scabies treatment (in their languages): https://onedisease.org/resources-1.

The renal brochure to promote skin health for people on dialysis was finalized and translated in Yolngu Matha language.

Intensive mass and social media campaigns were begun to increase understanding of scabies detection, treatment and prevention and the reach of our messages.

This involved:

- bus advertisements in Darwin/Alice Springs
- TV ads broadcasted on Imparja TV (Northern Australia), Goolarri Media (Broome region) and GWN TV (Kimberley region).
- including Indigenous music from West Arnhem, Tiwi Island, Groote Eylandt within the TV ads and promoting the ads via native Facebook postings and dark ads concentrating on remote communities' postcodes

[1] Remote Area Health Corps

The TV ads can be viewed here: www.onedisease.org/advertisements-saltwater-band/transmission

HOT NORTH[2] and One Disease Skin Health Symposium was held in Darwin. A hundred health professionals attended including sponsored NACCHO representatives.

Video Microscopy Pilot Project was completed. The instrument was useful in providing education to inpatients and One Disease staff used the microscope in community education. However, the method and consistency of diagnosis was not considered, at this point, easily transferable to teach non-specialists to use.

The One Disease website was revised to encourage the use of resources and booking education sessions (face to face and virtual): www.onedisease.org. All the resources available on the One Disease website were also made available on Australian Indigenous HealthInfoNet.

Financial Year 2021-2022

In February 21, One Disease delivered a workshop in Darwin to better understand the random sample concept which was developed with researchers from the Peter Doherty Institute to determine scabies prevalence and how to best explain this concept to community. This was conducted in preparation for delivering scabies prevalence activities and feedback cycles to community for Healthy Skin Treatment days. It was decided that a fishing analogy would be used to explain the random sampling process.

Following, the One Disease team worked closely with local community teams to explain the process of selecting a random sample.

In May and June 21, One Disease conducted scabies prevalence surveys in two remote communities in East Arnhem. The purpose of the visit was to estimate the prevalence of scabies in the community, and work alongside local community workers and Aboriginal Health Practitioners from the health clinics to guide their understandings of current scabies prevalence in their communities.

Visiting randomised lot numbers throughout the community, One Disease explained the purpose of the visit to the head of the household to gain consent to engage. From there, information was gathered on household members and visitors, after the exposed skin (predominantly arms and legs) of those who were at home and consented was checked.

This was to identify any possible scabies and contact with scabies cases using a simple skin check and conversation.

[2] HOT North is an NHMRC funded research program led by Menzies School of Health Research, which draws on more than three decades of research collaboration, education and translational leadership to address these enduring health challenges. A multidisciplinary collaboration involving eight of Australia's leading health research organisations, HOT North aims to improve health outcomes in the tropical north through projects that link organisations, translate research into outcomes and create pathways for health professionals.

It was the first time that One Disease has used a random sample method, and it was a successful approach. The team screened 65 houses, a total of 365 people, and early findings suggested there may be less scabies than expected with only a small number of affected households.

One Disease received considerable positive feedback, with community members being very happy to be part of the skin screening. There were even several requests for Lyclear scabies cream to keep 'just in case', or for planning ahead for visitors – a strong testament for the work undertaken.

358 health professionals completed the One Disease Crusted Scabies Module on the RAHC website during this year.

The Q&A videos called "I mite tell you" Including frequently asked questions about Crusted Scabies/scabies detection, treatment and management were completed. Link to the videos: www.youtube.com/watch?v=FExRrCqlG38&list=PLEYsKUJbjKmKIzgow1U6yytVc6RFwlASK&index=2

One Disease used a structured interview schedule with Crusted Scabies clients who experienced recurrences to understand what may be helpful in preventing recurrences. This feedback was used to inform primary healthcare providers/ hospital staff on how to improve Crusted Scabies care outcomes.

Local health services including Miwatj and Mala'la were advised and assisted to undertake a data cleanup to confirm their Crusted Scabies clients lists and enable consistent client management.

One Disease frequently contacted the Northern Territory Centre for Disease Control offices in Darwin, Gove, Tennant Creek, Katherine, and Alice Springs to receive information on current Crusted Scabies cases – to better understand cases, contact relevant health services, and send educational resources so Crusted Scabies patients can go home to scabies free zones.

During the acute rheumatic fever outbreak in the East Arnhem region, the One Disease team assisted the Northern Territory RHD program. We conducted the contact tracing for the outbreak and undertook house to house skin checks.

The Crusted Scabies Beside Pathway chart was completed and Royal Darwin Hospital team overseeing the guidelines led its distribution process.

The Crusted Scabies guidelines for CARPA were updated, which are of relevance to the broad hospital network across the Northern Territory. The Crusted Scabies chapter incorporated the revised information including guidelines for clear discharge summary directives for community clinics. In conjunction, discussions and recommendations for these guidelines to align hospital care with Centre for Disease Control reporting requirements and community care providers were held.

Two Indigenous community-based workers (CBWs) were employed during this year and worked in the West Arnhem region delivering education sessions on Crusted Scabies and

scabies to their communities. One Disease continued to provide mentoring, support, and training to the CBWs to promote healthy skin and healthy communities. The CBWs provided Crusted Scabies/scabies education in various settings, ie Households, clinics, FAFTs, hospitals. In Maningrida, One Disease worked closely with Mala'la Health Service Aboriginal Corporation. A working MoU was installed for the purposes of supporting the CBWs and embedding them within the Mala'la RHD[3] Team to ensure Scabies Free Zones at the household/family level.

The One Disease Scabies and Crusted Scabies Storytelling App had 341 users (with 338 being new users), engaging in 383 sessions, during the reporting period. English was the most popular language. Other languages accessed included: Anindilyakwa, Anmatyerr, Arrernte, Central Arrernte, East Side Kriol, Kimberley Kriol, Murrinh Patha, Yolngu Matha.

The Scabies Awareness Media Campaign continued with four 45 second scabies television commercials, airing on Imparja TV, and scabies awareness posters advertised on buses in both Darwin and Alice Springs.

The scabies screening survey which One Disease conducted in June 21 estimated that the prevalence of scabies is greater than 10% in an East Arnhem community. In September, One Disease senior public health nurse presented on these findings to the Mala'la Health Service Aboriginal Corporation regarding the appropriateness of conducting a Mass Drug Administration program for the region in 2022. A full HREC ethics application to Northern Territory Government and the Menzies School of Health Research was developed and submitted to conduct a formal prevalence assessment to occur alongside the planned Ivermectin-based MDA treatment program in Maningrida.

In October 21, a house-to-house scabies survey was undertaken in Galiwinku; the positive outcome being that scabies prevalence was found to be less than 10%.

One Disease initiated a process with other stakeholders to prepare and submit a Pharmaceutical Benefits Scheme (PBS) submission to have Ivermectin included as a first-line treatment for scabies on the PBS. The overall goal is to promote Scabies Free Zones by treating all community members with either Lyclear or Ivermectin with two doses, one week apart.

305 education sessions were run by the One Disease team reaching at least 2500 attendees.

Healthy skin days led or supported by One Disease during this period:

- Lajamanu children screening for scabies
- Yirrkala
- Marngarr
- Ngukurr healthy skin awareness event
- Sunrise Health Service Community Health Day.

[3] Rheumatic Heart Disease

To improve coordination between hospital and local health services a Letter for Clinic Managers of hospitals and a Scabies Brochure were developed. The letter named the Crusted Scabies patient, informed of One Disease's role, asked that the Crusted Scabies patient is placed on a long-term care plan (recall/reminder) on discharge, and provided links to Crusted Scabies and Scabies Free Zones information. The brochure provided accessible advice on scabies. This information was sent to the relevant staff for circulation at: Royal Darwin, Gove District Hospital, Tennant, Alice Spring and Katherine.

The enhanced dataset for Crusted Scabies notifications within the notifiable diseases system (NDS) of the Northern Territory Government Public Health Unit (Centre for Disease Control) was completed and went live. This was a huge achievement that had been several years in planning and negotiation. This work meant detailed information can be collected, allowing Crusted Scabies notifications to have clearer recorded information on recurrences, household treatment and treatment completion among other data points. The data will be entered, secured and managed in the NDS by the Public Health Unit.

Clinic health staff reported that they continue to have increased workloads related to COVID-19. Therefore, One Disease took over as lead for liaising with home communities to ensure Crusted Scabies clients are discharged to Scabies Free Zones.

One Disease co-hosted the Katherine HOT NORTH healthy skin workshop in August 21 alongside the HOT NORTH and Rheumatic Heart Disease Australia teams.

The "Scratching the Surface" podcast was launched in November 21 on most major podcast platforms: www.onedisease.org/podcast.

Financial Year 2022–2023 (Quarters 1 and 2)[4]

One Disease was approached by the Northern Territory government staff who provide services to local community health staff, once it was noticed there was an increase in scabies in Darwin's remote communities in the southwest region. Working together with the local health staff, the One Disease senior community nurse, undertook a house-to-house approach to inform households about scabies using our Scabies and Crusted Scabies Storytelling tool. Whenever scabies was found to be present, the entire household was treated.

One Disease staff also acted as a surge team for scabies detection and treatment in community in the following regions during the reporting period: Darwin, Daly River, Top End West, and Katherine. Scabies free zones promotion work was also undertaken in the East Arnhem region and East Katherine.

In the previous years, One Disease had actively supported the development of a double points elective subject in Skin Health for the new Post Graduate Certificate in Primary

[4] Crusted Scabies Elimination Program ended on 31 December 2022.

Health Care at Charles Darwin University and our work on this unit was also provided to RAHC, the Batchelor Institute of Indigenous Tertiary Education, and the Northern Territory education platform – My Learning to incorporate into their learning modules.

Two new episodes of the One Disease Podcast were completed – additional stories from community health workers. The podcast was promoted via a special electronic direct mail edition.

On 1st April 2022, there was a change to the PBS criteria listing for Ivermectin as a first-line treatment for the management of scabies in Aboriginal and Torres Strait Islander populations across Australia, following a successful submission that was co-authored by One Disease and National Aboriginal Community Controlled Health Organisation (NACCHO) and reviewed by the Pharmaceutical Benefits Advisory Committee.

Our Scabies Awareness Media Campaign concluded. An internal evaluation report which was prepared by CEO, Michelle Dowden indicated the campaign was effective.

The App – SCAN (Skin Checks Across Northern Australia) was completed and made available in English and Yolŋu Matha. One Disease worked with the SCAN app developer to make a self-management language portal, so that additional languages can be included, without re-engaging the developer.
One Disease wrote the Infectious Diseases section of the latest version of the Public Health Bush Book, which was developed to support and strengthen public health practice in community settings.

In June 2022, One Disease supported an allied health workshop on skin issues. Attendees were Northern Territory Department of Health outreach workers from various fields.

The One Disease Scabies & Crusted Scabies Storytelling Tool had 649 users (with 648 being new users).

A major revision of the One Disease e-learning Crusted Scabies Module on the RAHC website was carried out. This module was undertaken by 101 health workers during this fiscal year.

Over 40 education sessions were delivered - totalling approximately 1000 attendees.

Final communications of the One Disease resources were: the inclusion of an article and full-page advertisement of the One Disease resources in “Partyline” – an online magazine of the National Rural Health Alliance, and the sending out of an electronic newsletter, outlining the key resources, to all stakeholders.

Two of our key resources – the Scabies and Crusted Scabies Storytelling tool and the SCAN (Skin Checks Across the North) app are currently being transferred to the Telethon Kids Research Institute.

Part G: A discussion of issues, problems or delays which One Disease experienced in its performance of the Crusted Scabies Elimination Program, and an explanation of how One Disease dealt with those issues, problems and delays, and learnings from the Activity.

During the reporting period, One Disease worked through expected and unexpected challenges which encouraged important learnings and actions.

Competing Health Priorities

Challenge

Indigenous remote communities experience a wide range of health problems including diabetes, rheumatic heart disease, chronic kidney disease and respiratory diseases. One Disease understood that to keep scabies and Crusted Scabies in the community's mind, the team needed to develop strong relationships with community health services and community members. This was particularly important as many existing diseases are linked to scabies and Crusted Scabies.

Learnings and actions

One Disease's approach was to work alongside community - employing two-way learning – to gain knowledge from each other and develop the most effective strategies together to eliminate Crusted Scabies, as a public health concern. All the resources we developed were in consultation with the community, as were the education sessions delivered, and workshops run, which were all extremely well received.

Furthermore, One Disease resources are enduring; all have been posted on the Australian Indigenous HealthInfoNet website and the 'Stop Scabies' channel on HitNet, and our two key resources: Scabies and Crusted Scabies Storytelling Tool and the SCAN App (Skin Checker for Aboriginal and Torres Strait Islanders) are in the process of being transferred to the Telethon Kids Institute.

In addition, despite being a small team, One Disease worked diligently at developing partnerships with many health providers to disseminate healthy skin messages to as many people as possible. (Please see Partnerships on pp 6-7)

COVID-19 Pandemic

Challenges

When the pandemic emerged, remote communities urgently required accurate and accessible information on physical distancing and hand hygiene to prevent the spread of the virus. When it became available, the COVID-19 vaccine rollout in remote communities

placed significant demand on remote clinics and services. Among other competing priorities, this limited our travel to community and efforts towards scabies prevalence screening and regional workshops.

Learnings and actions

One Disease took immediate action by initiating a highly participatory pandemic prevention communication campaign via crowdsourcing. The videos produced directly engaged individuals in remote Aboriginal communities of the Northern Territory in COVID-19 prevention messaging on handwashing and physical distancing. We distributed the videos, which are in nine community languages, to remote area post-codes via targeted Facebook advertising. The resources were an immense success, viewed by well over 100,000 people.

This work was published in the journal - Frontiers of Public Health and highlighted the unique model of crowdsourcing for local messages and the strengths of using postcode-targeting on social media platforms to maximise reach.

While the pandemic did cause delays, One Disease continued to work alongside communities with the capacity to take on Scabies Free Zone efforts. For example, the scabies screening survey, which One Disease conducted in June 21, estimated that the prevalence of scabies was greater than 10% in an East Arnhem community. In September 21, One Disease senior public health nurse presented on these findings to the Mala'la Health Service Aboriginal Corporation regarding the appropriateness of conducting a Mass Drug Administration program for the region in 2022.

When restrictions prevented the One Disease team from travelling, we began an intensive social media campaign to curb scabies:

- Applying the same approach used to develop the COVID-19 videos, we produced a series of videos which included scabies awareness messaging by and for community members;
- We developed culturally appropriate Television and Bus Ads on scabies awareness, which our internal evaluation indicates have been seen widely and the messaging understood.

We also actively assisted during the acute rheumatic fever outbreak in the East Arnhem region in October 21 by supporting the Northern Territory RHD program. We undertook the contact tracing for the outbreak and the house-to-house skin checks. The condition of the skin of household members was found to be very good and only a handful of scabies was found.

Scabies Free Zones

Challenges

Scabies Free Zones are difficult to implement. Household overcrowding, which is a major determinant of scabies transmission, is a significant barrier in communities with high

prevalence of simple scabies, as treated individuals easily become re-infected. In this context, 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.

Learnings and actions

Our first external evaluation report revealed that many stakeholders interviewed 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 could be challenging in the context of difficulties in recruiting and retaining the Aboriginal health workforce, particularly in remote communities.

One Disease designed and implemented an Indigenous Community Based Workers (CBWs) program, which involved recruiting, training, and mentoring a small group of Indigenous workers to provide scabies education to their own communities. The CBWs delivered education to individuals, community groups and organisations. In total, approximately 2235 sessions were delivered across communities within three remote regions of the Northern Territory and in Darwin. The CBWs also held casual discussions with their family groups, personal friends, and visitors to their homes. In addition, when the COVID-19 pandemic emerged, the CBWs assisted in practical hygiene work and messaging on hand hygiene within their communities.

We also hired a highly experienced Indigenous Public Health Officer to work directly with community on healthy skin messaging.

Part H: Information about the Evaluation of the Activity

As discussed in the performance reports, the COVID restrictions limited travel and significantly added to the competing priorities of the health services. This meant the external research team led by Dr Karen Gardner, from the Public Service Research Group at the Business School University of New South Wales Canberra, were not able to undertake the methods which had been initially planned for the final evaluation report. They were unable to obtain audit data, nor interview, run focus groups or collect survey data that would enable an assessment of the extent of change and whether it is attributable to the Crusted Scabies Elimination Program.

Consequently, the researchers drew on data from their earlier evaluations (Part 1 and 2), together with program data compiled by One Disease, to provide an analysis of the program's strategies and key achievements in building system capacity for the elimination of Crusted Scabies in the Northern Territory. Appendix 2 contains the final report which was approved at the One Disease Company Director's meeting in October 2022.

Work on peer reviewed publications continued throughout the period and the final list is below:

Final draft completed and with authors

van der Linden N, Gardner K, van Gool K, Campbell M, Mulhern B, Lawripa, Woerle H, O'Mara I, Scolyer M, Dowden M, Viney R. Measuring health-related quality of life in indigenous Australians with Crusted Scabies: a pilot project

Agostino J, van Gool K, Campbell M, van der Linden N, Dickinson H, Renehan C, O'Mara I, Scolyer M, Woerle H, Glennie M, Dowden M, Gardner K, Crusted Scabies: Audit findings from an evaluation of a systems approach to elimination in the Northern Territory of Australia. PLoS Neglected Tropical Diseases

Revisions submitted

Miriam Glennie, Michelle Dowden, Meg Scolyer, Irene O'Meara, Geoffrey Angeles, Karen Gardner Community-led disease mapping: enhancing local-level scabies surveillance in remote Aboriginal communities in Australia. Tropical Medicine and Infectious Diseases

Published

van Gool K, Campbell M, Gardner K, Van der Linden N, Dickinson H, Dowden M, Viney R. (2022) Evaluating the cost-of-illness of crusted scabies in the NT, PLoS Neglected Tropical Diseases

Glennie M, Dowden M, Grose M, Scolyer M, Superina A, Gardner K. (2022) Crowdsourcing COVID-19 prevention messaging in Aboriginal languages for post-code targeted social media distribution to remote communities. BMC Public Health

Glennie M, Gardner K, Dowden M, Curry B. (2021) Active case detection methods for leprosy and crusted scabies: a scoping review. PLoS Neglected Tropical Diseases

Van der Linden N, van Gool K, Gardner K, Dickinson H, Dowden M, Regan D, Viney R. (2019) Modelling scabies: a systematic review to inform the design of a transmission model for evaluating the cost-effectiveness of scabies interventions, PLoS Neglected Tropical Diseases

Dickinson H; Gardner K; Dowden M; Van der Linden N, 2020, 'Driving Change Across Boundaries: Eliminating Crusted Scabies in Northern Territory, Australia', in Nugus P (ed.), Transitions and Boundaries in the Coordination and Reform of Health Services Building Knowledge, Strategy and Leadership, Springer Nature

Research Reports

Gardner K, Glennie M. Final Evaluation: One Disease, Crusted Scabies Elimination Program, University of New South Wales Canberra. April,2022

Gardner K, Glennie M. Part 2 Evaluation: One Disease, Crusted Scabies Elimination Program, University of New South Wales Canberra. July,2020

Gardner K, Van Gool K, Agostino J, Renehan C, Van der Linden N, Viney R, Dickinson H. Evaluation of the One Disease, Crusted Scabies Elimination Program, University of New South Wales. August,2018

Conference papers

Gardner K, Evaluation of a systems based approach to eliminating crusted scabies in Northern Territory, CHARM Conference Aug 2021

Dowden M, Scolyer M, Superina A, Grose M, Glennie M, Gardner K Crowdsourcing for local language, video-based COVID-19 prevention messaging to remote Aboriginal communities PHAA 2020

Campbell M, van Gool K, van der Linden N, Gardner K, Dowden M, O'Meara I, Woerle H, Scolyer M, and Viney R. A cost of illness model for crusted scabies in indigenous communities in the Northern Territory. Paper presented to HSRAANZ 4-6 December 2019 Auckland NZ.

Van der Linden N, Van Gool K, M, Campbell M, Mulhern B, Viney R, Gardner K Woerle H, O'Meara I, Dowden M. Assessing the impact of crusted scabies on quality of life in Indigenous communities in the Northern Territory: a pilot study. HSRAANZ Forum – the Pros and Cons of PROMs and PREMs. Sydney University 26 Nov 2018.

Dowden M, Gardner K, O'Meara I, Scolyer M, Woerle H, Agostino J, Van Gool K, Van der Linden N, Renehan C, Campbell M, Dickinson H Eliminating crusted scabies in Northern Territory: a systems based quality improvement approach PHCRIS Conference, Melbourne 2018

Dickinson H, Gardner K, Dowden M, Woerle H, Colyer M, O'Meara I. Driving change across boundaries: Eliminating crusted scabies in Northern Territory, Australia OBHCE Conference, Canada June 2018

Dowden M, Scoyler M, Omeara M, Woerle H, Gardner K. Eliminating crusted scabies in remote communities in Australia: a systems based quality improvement approach. HSRAANZ 2017

Book Chapter

Dickinson H; Gardner K; Dowden M; Van der Linden N, 2020, 'Driving Change Across Boundaries: Eliminating Crusted Scabies in Northern Territory, Australia', in Nugus P (ed.), Transitions and Boundaries in the Coordination and Reform of Health Services Building Knowledge, Strategy and Leadership, Springer Nature

These are considerable outputs - adding to knowledge and the sharing of findings with the world.

Part I: Summation

By developing and implementing the Crusted Scabies Elimination Program, One Disease made a giant stride towards the elimination of Crusted Scabies in Australia.

One Disease recognises that while scabies is present in remote Indigenous communities, there remains a risk that people who have poor immune function can develop Crusted Scabies after spending time with someone who has scabies.

However, Crusted Scabies is well on the way to being eliminated, as a public health concern, in Australia because the two key goals of the Crusted Scabies Elimination Plan are now continually being achieved:

1. To improve detection of Crusted Scabies

One Disease has promoted a range of strategies to improve detection, leading to more cases of Crusted Scabies being identified and treated.

There were 241 Crusted Scabies clients in the Northern Territory with 20 of these clients notified in the final quarter of reporting (31 December 2022).

2. To prevent recurrences of Crusted Scabies (recurrence rate to be less than 5%)

There are now less recurrences of Crusted Scabies cases, especially of the most severe type -Grade 3. The current recurrence rate is 2.9%

Most cases (currently 86%) of Crusted Scabies are now detected at the Grade 1 and 2 stages, when the scabies mite load is lower, and therefore the person detected with Crusted Scabies is less contagious.

This can be compared with the data from 2016 before the Crusted Scabies Elimination Plan was implemented when only 51% of all cases (new and recurrent) were detected as Grade 1 and 2.

Impact of One Disease's Work on Crusted Scabies

One Disease strongly believed in a partnership approach – working together with remote communities to achieve mutual key goals.

The impact on Crusted Scabies through the work of One Disease and its partners is a success story.

The idea behind the One Disease approach was that when the health system, together with the people with Crusted Scabies, can easily detect Crusted Scabies early, and implement treatment pathways and follow-up care, this is likely to reduce the chance of recurrences and interrupt the cycle of transmission between people with Crusted Scabies and others in their household and community.

In summary, with a specific focus on the remote communities of the Northern Territory, One Disease strengthened the health system by embedding sustainable strategies for:

1) The detection and treatment of Crusted Scabies, which develops from cases of untreated ordinary scabies in people who have weakened immune systems.
2) Keeping the recurrence rate of people treated for Crusted Scabies extremely low - at less than 5%. This is a key performance indicator for understanding that people who are susceptible to recurrences are having treatment for scabies infections early and/ or are living in scabies free environments.
3) Controlling the most severe form of Crusted Scabies (Grade 3) where a person may have millions of mites on their skin.

Given the high chance of recurrent infection associated with Crusted Scabies, the lack of a vaccine and the continued presence of scabies on individuals living in overcrowded conditions, this is a remarkable achievement.

This achievement is largely due to the following systems which One Disease, working in partnership with the Northern Territory government and remote communities, put in place:

System	One Disease Contribution
Surveillance	Enhanced Crusted Scabies dataset of people who have had Crusted Scabies; Scabies prevalence surveys in community to determine when Mass Drug Administrations for scabies should be undertaken.
Prevention	Education using a range of methods to target individuals and communities including social media, online tools, and materials; Education of health staff through training and skin health course modules.
Treatment and follow-up	Hospital bedside care pathway; Supporting hospital treatment completion.
Follow-up	Electronic care plans; Increasing understanding on the importance of two doses of lyclear cream at 7-day intervals; Successful advocacy for Ivermectin as a first-line treatment for Aboriginal and Torres Strait Islanders; Innovative work on the creation and maintenance of Scabies Free Zones within community.

A timeline of One Disease's key achievements since it was founded in 2011 is included as Appendix 3.

As previously mentioned, One Disease recognises that while scabies is present in remote Indigenous communities, there remains a risk that people who have poor immune function can develop Crusted Scabies because of spending time with someone who has scabies. Consequently, over the final 12 months, our focus was on curbing simple scabies and working with communities to develop and maintain scabies-free homes. It is essential that this on-the-ground work continues. Once scabies is under control, similarly to leprosy, Crusted Scabies will become a disease of the past.

Our program has ended. However, we will leave behind many resources, which are posted on the *Australian* Indigenous HealthInfoNet website. Our major resources, the SCAN app through which Aboriginal and Torres Strait Islanders can undertake a skin check, and the Scabies and Crusted Scabies Storytelling Tool which provides culturally relevant illustrations and information in 22 community languages are currently being transferred over to the Telethon Kids Institute to continue to share with remote communities and further develop as required.

Our disease elimination processes are documented within several peer reviewed journals, a book chapter and report. We also produced a public podcast series *Scratching the Surface* to provide information on scabies, Crusted Scabies, and our elimination program.

Collectively, these resources provide culturally appropriate information on how to keep Crusted Scabies under control and are the legacy of One Disease's work.

Part J: An income and expenditure statement covering the entire Project Period.

	FY2021-FY2023			
Description	**Direct Program - DOH**	**Direct Program - Grants**	**Other**	**Total**
Income				
Department of Health (DOH) Funding	1,500,000	s47G		
s47G	-			
Grants	-			
s47G	-			
Total	**1,500,000**			

s47G

One Disease Program Reporting Q1 FY21: July - September 2020

APPENDIX 1

ONE DISEASE

Key Performance Indicator by end FY21:

Eliminate Crusted Scabies as a public health concern in the Northern Territory by obtaining a recurrence rate of Northern Territory Crusted Scabies clients less than 5% of the total cumulative cases.

Organisational Goal:

Educate and enable patient self-management to eliminate Crusted Scabies as a public health concern across Australia by 2022.

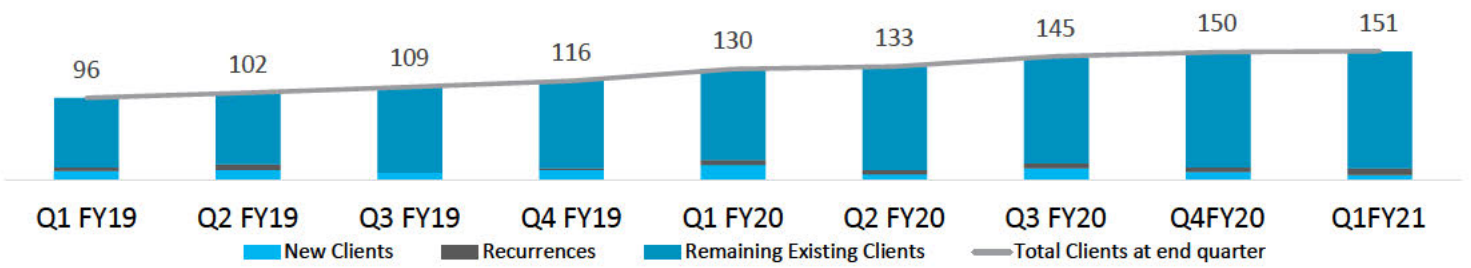
Recurrences Q1 FY21:

5.33%

8 clients of 150 (total clients at end of Q4 FY20) had a recurrence of Crusted Scabies in Q1 FY21.

In Q1 FY21, from 1 July to 30 September 2020, 15 CDC notifications were advised.
Of the 15 CDC notifications, 7 were new clients s47F and 8 were recurrent clients. s47F s47F In total, 151 unique clients are currently listed.

Trends in Northern Territory Crusted Scabies Cases Q1 FY19 – Q1 FY21



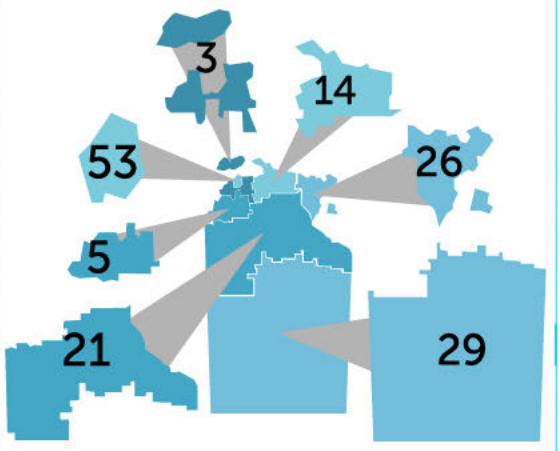
	Q1 FY19 (Jul 1 – Sep 30, 2018)	Q2 FY19 (Oct 1 – Dec 31, 2018)	Q3 FY19 (Jan 1 – Mar 31, 2019)	Q4 FY19 (Apr 1 – Jun 30, 2019)	Q1 FY20 (Jul 1 – Sep 30, 2019)	Q2 FY20 (Oct 1 – Dec 31, 2019)	Q3 FY20 (Jan 1 – Mar 31, 2020)	Q4FY20 (Apr 1 – Jun 30, 2020)	Q1FY21 (Jul 1 – Oct 30, 2020)
Total Crusted Scabies clients	*96*	*102*	*109*	*116*	*130*	*133*	*145*	*150*	*151*
CDC notifications	*14*	*18*	*8*	*13*	*27*	*11*	*19*	*14*	*15**
Recurrent Crusted Scabies clients	*4*	*7*	*0*	*2*	*6*	*5*	*6*	*5*	*8*
New Crusted Scabies clients	*10*	*11*	*8*	*11*	*17*	*6*	*13*	*9*	*5**

*Although there were 15 notified cases, s47F

Regional Crusted Scabies Client Statistics

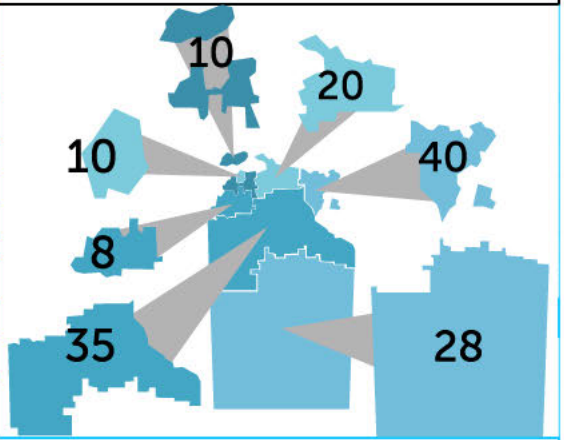
Crusted Scabies clients according to current location of residence

Region	Indigenous population, *n*	Total clients end Q4 FY20, *n*	Clients per 1000	New clients Q4 FY20 (incl. Q2-Q3 FY20), *n*	Recurrent clients Q4 FY20, *n*
East Arnhem	*10,582*	*26*	*2.46*	*1*	*3*
West Arnhem	*6,652*	*14*	*2.10*	*2*	*1*
Darwin^	*24,074*	*61*	*2.53*	*1*	*3*
Darwin Urban		*53*		*1*	*3*
Top End West		*5*		*0*	*0*
Top End Central		*3*		*0*	*0*
Katherine	*11,862*	*21*	*1.77*	*2*	*1*
Total Top End	*53,170*	*122*	*2.30*	*6*	*8*
Central‡	*21,376*	*29*	*1.36*	*0*	*0*
Total NT	*74,546*	*151*	*2.03*	*6*	*8*



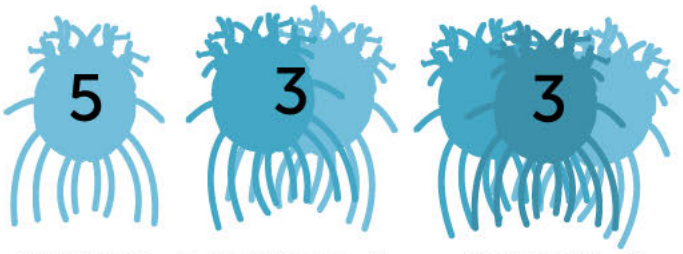
Crusted Scabies clients according to original place of residence

Region	Total clients end Q4 FY20, *n*	Clients per 1000
East Arnhem	*40*	*3.78*
West Arnhem	*20*	*3.01*
Darwin^	*28*	*1.16*
Darwin Urban	*10*	
Top End West	*8*	
Top End Central	*10*	
Katherine	*35*	*2.96*
Total Top End	*123*	*2.31*
Central‡	*28*	*1.31*
Total NT	*151*	*2.03*



^Darwin Region includes Darwin Urban, Top End West and Top End Central
‡Central Region includes Alice Springs and Barkly

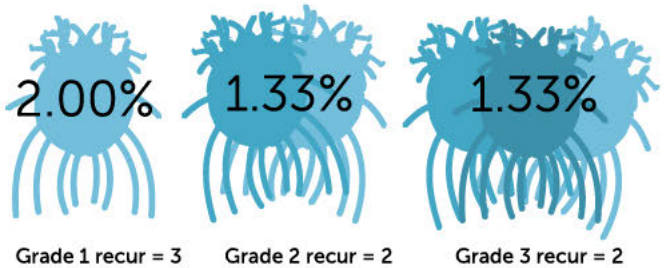
Crusted Scabies clients notified in Q1 FY21 by grade*:



Grade 1 cases = 5 (10x infectivity)
Grade 2 cases = 3 (100x infectivity)
Grade 3 cases = 3 (1000x infectivity)

*2 clients had grade unknown

Crusted Scabies recurrence in Q1 FY21 by grade*:

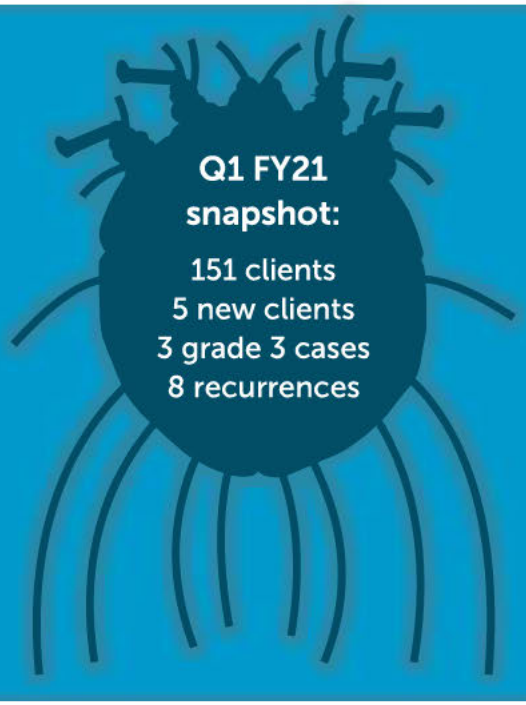


Grade 1 recur = 3
3 of 150 = 2.00%

Grade 2 recur = 2
2 of 150 = 1.33%

Grade 3 recur = 2
2 of 150 = 1.33%

*1 recurrent client had grade unknown



Further information on Crusted Scabies (CS) recurrences in Q1 FY21

Client	Notified cases of CS, *n*	Time since previous CS case	Previous time between CS cases (where >2 cases, average)
#1	*4*	*11 months*	*10 months*
#2	*2*	*1 year 3 months*	*NA*
#3	*4*	*1 year 7 months*	*1 year 4 months*
#4	*2*	*7 months*	*NA*
#5	*2*	*4 years 1 month*	*NA*
#6	*2*	*4 years 1 month*	*NA*
#7	*2*	*3 years 3 months*	*NA*
#8	*2*	*2 years*	*NA*

Of 8 recurrences, 6 had their first notified recurrence. Of these 6 clients, 3 experienced multiple episodes of CS, which had not been notified and several episodes, which have not been fully treated due to a range of reasons.

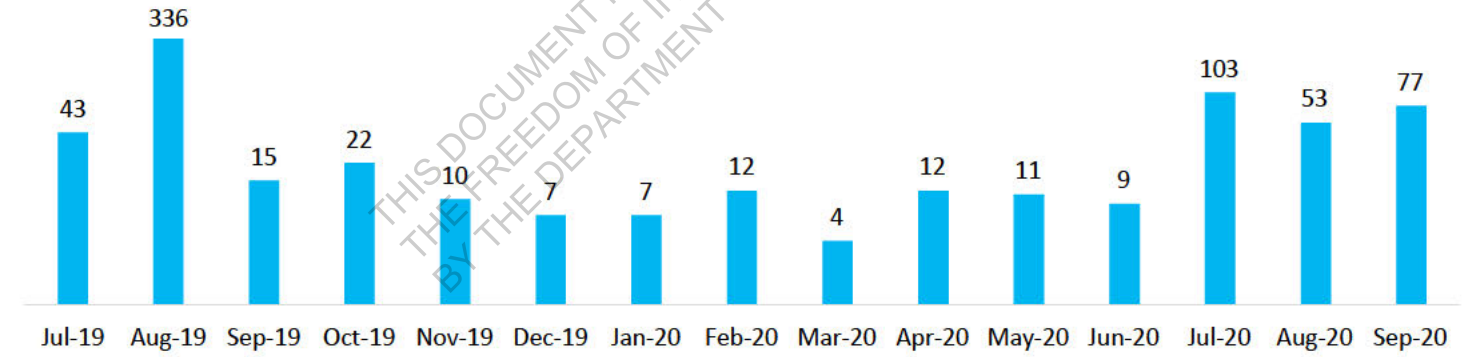
s47F

s47F One Disease is engaging with their services to provide support.

Further detail is provided in Supplementary pages.

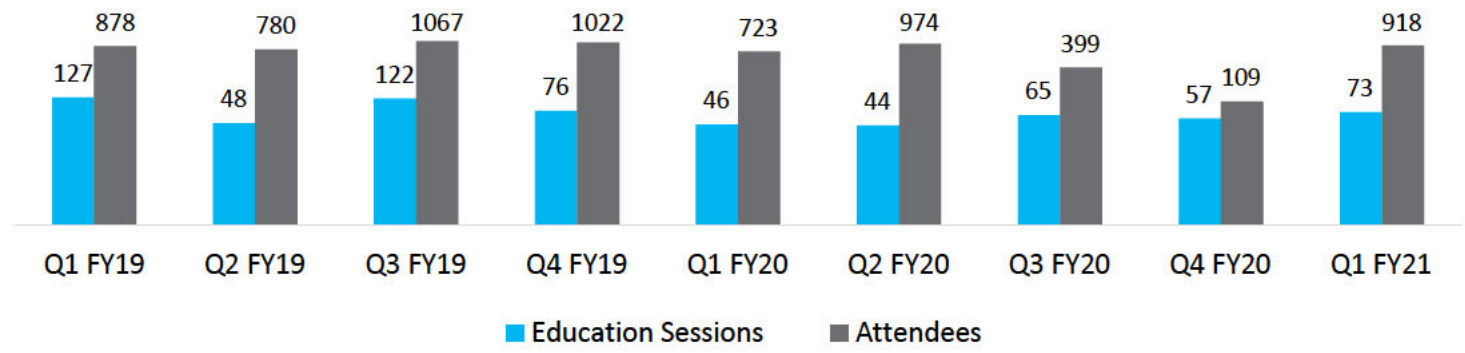
Crusted Scabies prevalence in the Northern Territory at end Q1 FY21 is 1 in 494

Utilisation of One Disease Crusted Scabies RAHC eLearning module, *n* (log²)



Increases in module completion in July, August 2019 and July, August, September 2020 are attributed to university courses who prescribe RAHC eLearning modules as assessment tasks

Trends in One Disease Crusted Scabies education sessions and audiences, *n* (log²)



Note: Q4 FY20 education sessions were predominantly provided remotely due to COVID-19, so attendance numbers are unavailable – audience numbers are underestimated.

Last modified: 30 November 2020

ONE DISEASE

CDC notified Crusted Scabies episode

Crusted Scabies episode (not notified)

Skin check documented: NAD

Skin check documented: abnormal; other skin condition

Skin check documented: abnormal; scabies

Skin check recall: not fulfilled; refused or lost to f/up

Skin check refused by client

Skin check refused by client: scabies likely; medication provided

Scabies medication provided: no further notes

Acronyms/shorthand: took own leave (TOL), discharged against medical orders (DAMA), crusted scabies (CS), treatment (tx), Katherine District Hospital (KDH), Gove District Hospital (GDH), Royal Darwin Hospital (RDH), Alice Springs Hospital (ASH), query (?).

s47F

One Disease Program Reporting
Q2 FY21: October-December 2020

ONE DISEASE

Key Performance Indicator by end FY21:

Eliminate Crusted Scabies as a public health concern in the Northern Territory by obtaining a recurrence rate of Northern Territory Crusted Scabies clients less than 5% of the total cumulative cases.

Organisational Goal:

Educate and enable patient self-management to eliminate Crusted Scabies as a public health concern across Australia by 2022.

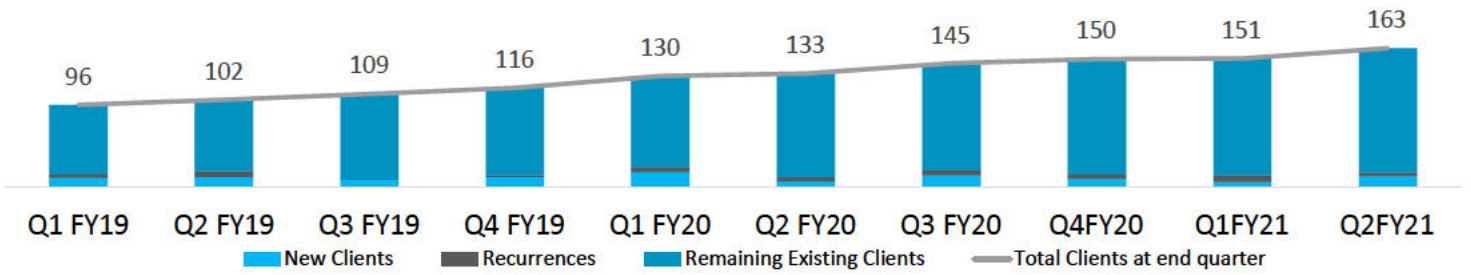
Recurrences Q2 FY21:

2.65%

4 clients of 151 (total clients at end of Q1 FY21) had a recurrence of Crusted Scabies in Q2 FY21.

In Q2 FY21, from 1 October to 31 December 2020, 16 CDC notifications were advised.
Of the 16 CDC notifications, 12 were new clients and 4 were recurrent clients. s47F
s47F In total, 163 unique clients are currently listed.

Trends in Northern Territory Crusted Scabies Cases Q1 FY19 – Q1 FY21

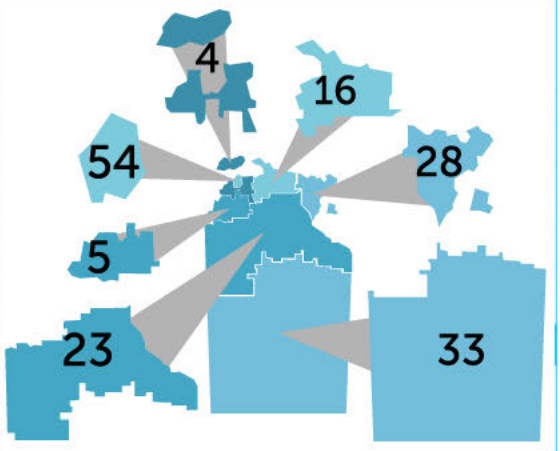


	Q2 FY19 (Oct 1 – Dec 31, 2018)	Q3 FY19 (Jan 1 – Mar 31, 2019)	Q4 FY19 (Apr 1 – Jun 30, 2019)	Q1 FY20 (Jul 1 – Sep 30, 2019)	Q2 FY20 (Oct 1 – Dec 31, 2019)	Q3 FY20 (Jan 1 – Mar 31, 2020)	Q4 FY20 (Apr 1 – Jun 30, 2020)	Q1 FY21 (Jul 1 – Oct 30, 2020)	Q2 FY21 (Oct 1 – Dec 31, 2020)
Total Crusted Scabies clients	*102*	*109*	*116*	*130*	*133*	*145*	*150*	*151*	*163*
CDC notifications	*18*	*8*	*13*	*27*	*11*	*19*	*14*	*15*	*16*
Recurrent Crusted Scabies clients	*7*	*0*	*2*	*6*	*5*	*6*	*5*	*8*	*4*
New Crusted Scabies clients	*11*	*8*	*11*	*17*	*6*	*13*	*9*	*5*	*12*

Regional Crusted Scabies Client Statistics

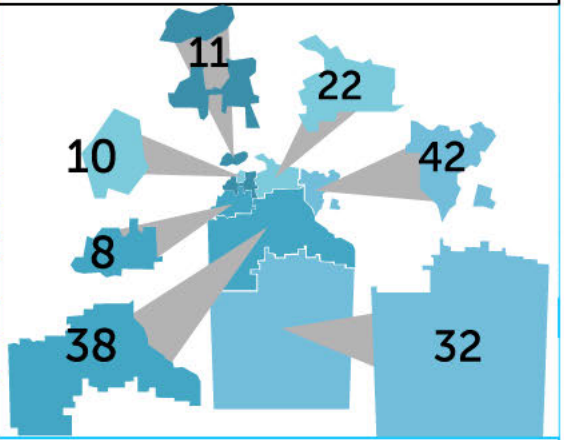
Crusted Scabies clients according to current location of residence

Region	Indigenous population, *n*	Total clients end Q4 FY20, *n*	Clients per 1000	New clients Q4 FY20 (incl. Q2-Q3 FY20), *n*	Recurrent clients Q4 FY20, *n*
East Arnhem	*10,582*	*28*	*2.65*	*2*	*2*
West Arnhem	*6,652*	*16*	*2.41*	*2*	*0*
Darwin*	*24,074*	*63*	*2.62*	*2*	*2*
Darwin Urban		*54*		*1*	*2*
Top End West		*5*		*1*	*0*
Top End Central		*4*		*0*	*0*
Katherine	*11,862*	*23*	*1.94*	*2*	*0*
Total Top End	*53,170*	*130*	*2.44*	*8*	*4*
Central‡	*21,376*	*33*	*1.54*	*4*	*0*
Total NT	*74,546*	*163*	*2.19*	*12*	*4*



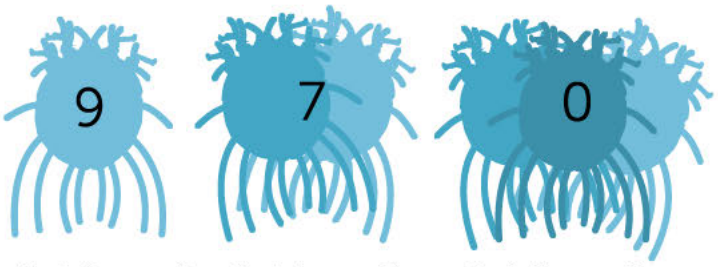
Crusted Scabies clients according to original place of residence

Region	Total clients end Q4 FY20, *n*	Clients per 1000
East Arnhem	*42*	*3.97*
West Arnhem	*22*	*3.31*
Darwin^	*29*	*1.20*
Darwin Urban	*10*	
Top End West	*8*	
Top End Central	*11*	
Katherine	*38*	*3.20*
Total Top End	*131*	*2.46*
Central‡	*32*	*1.50*
Total NT	*163*	*2.19*



^Darwin Region includes Darwin Urban, Top End West and Top End Central
‡Central Region includes Alice Springs and Barkly

Crusted Scabies clients notified in Q2 FY21 by grade*:

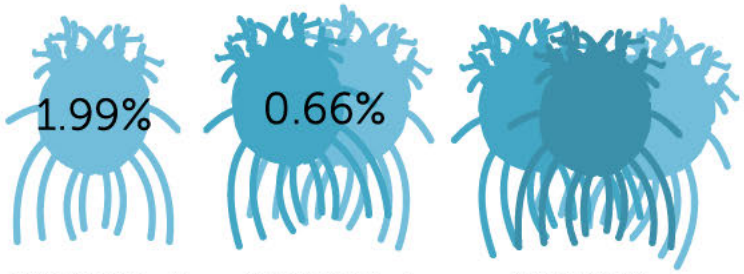


Grade 1 cases = 9 10x infectivity

Grade 2 cases = 7 100x infectivity

Grade 3 cases = 0 1000x infectivity

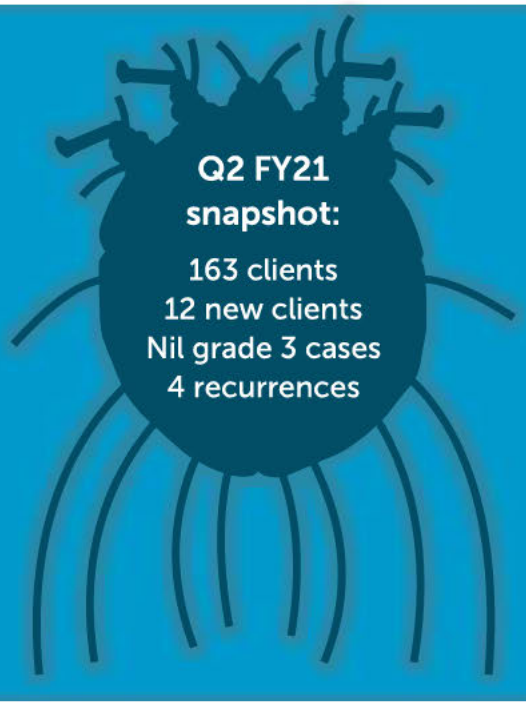
Crusted Scabies recurrence in Q2 FY21 by grade*:



Grade 1 recur = 3
3 of 151 = 1.99%

Grade 2 recur = 1
1 of 151 = 0.66%

Grade 3 recur = 0



Further information on Crusted Scabies (CS) recurrences in Q2 FY21

Client	Notified cases of CS, *n*	Time since previous CS case	Previous time between CS cases (where >2 cases, average)
#1	*2*	*1 year 2 months*	*NA*
#2	*3*	*12 months*	*17 months*
#3	*2*	*1 year 3 months*	*NA*
#4	*2*	*12 months*	*NA*

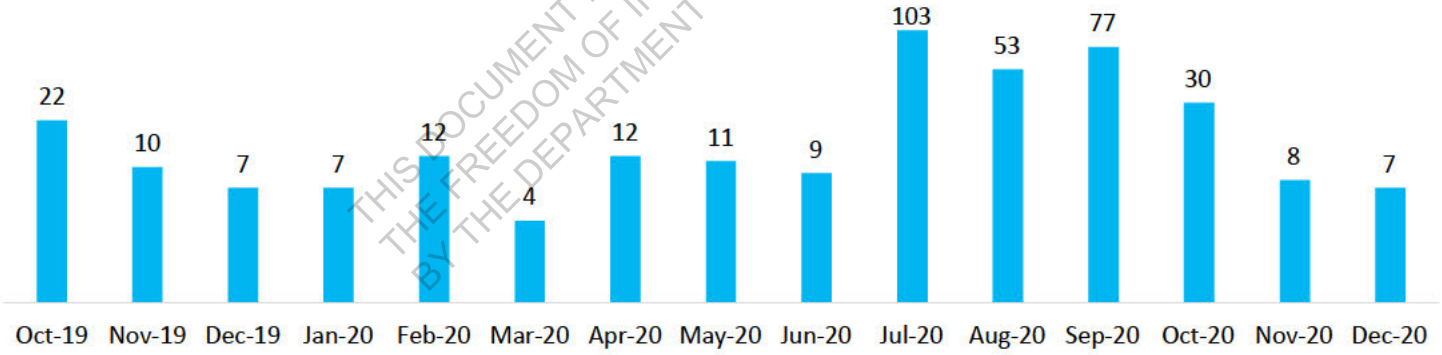
Of the 4 clients with CS recurrences, 3 had their first notified recurrence. Three of four clients were confirmed to have fully completed treatment with discharge care plans provided by their treating clinical team to their primary care providers. s47F

s47F

Further detail on these recurrent client timelines is provided in Supplementary pages.

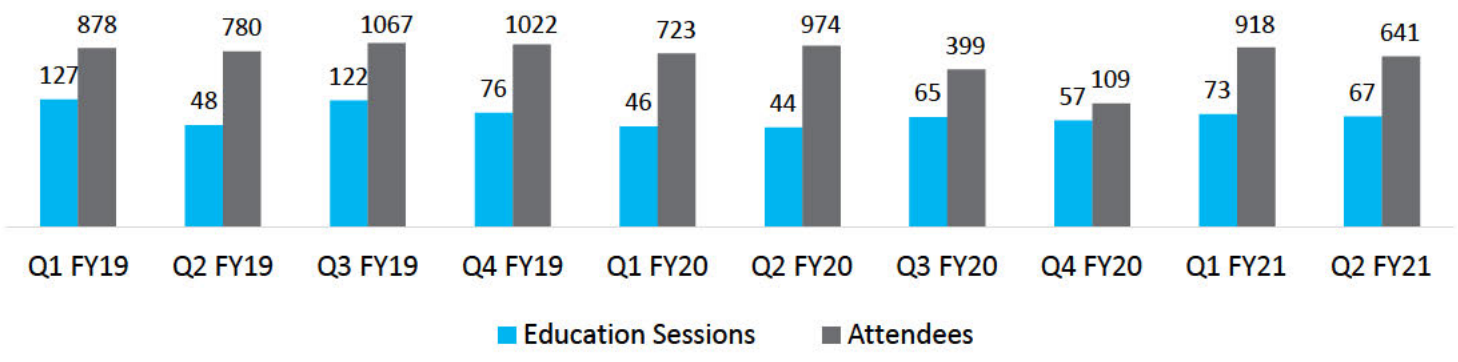
Crusted Scabies prevalence in the Northern Territory at end Q2 FY21 is 1 in 457

Utilisation of One Disease Crusted Scabies RAHC eLearning module, *n* (log²)



Increases in module completion July – October 2020 are attributed to university courses which prescribe RAHC eLearning modules as assessment tasks

Trends in One Disease Crusted Scabies education sessions and audiences, *n* (log²)



Note: Q4 FY20 education sessions were predominantly provided remotely due to COVID-19, so attendance numbers are unavailable – audience numbers are underestimated.

Last modified: 20 January 2021

ONE DISEASE

CDC notified Crusted Scabies episode

Crusted Scabies episode (not notified)

Skin check documented: NAD

Skin check documented: abnormal; nil scabie

Skin check documented: abnormal; scabies

Renal foot assessment: NAD

Renal foot assessment: abnormal; nil scabies

Renal foot assessment: abnormal; scabies

Acronyms/shorthand: took own leave (TOL), discharged against medical orders (DAMA), Crusted Scabies (CS), treatment (tx), Katherine District Hospital (KDH), Gove District Hospital (GDH), Royal Darwin Hospital (RDH), Alice Springs Hospital (ASH), query (?).

s47F

One Disease Program Reporting Q3 FY21: January – March 2021

ONE DISEASE

Key Performance Indicator by end FY21:
Eliminate Crusted Scabies as a public health concern in the Northern Territory by obtaining a recurrence rate of Northern Territory Crusted Scabies clients less than 5% of the total cumulative cases.

Organisational Goal:
Educate and enable patient self-management to eliminate Crusted Scabies as a public health concern across Australia by 2022.

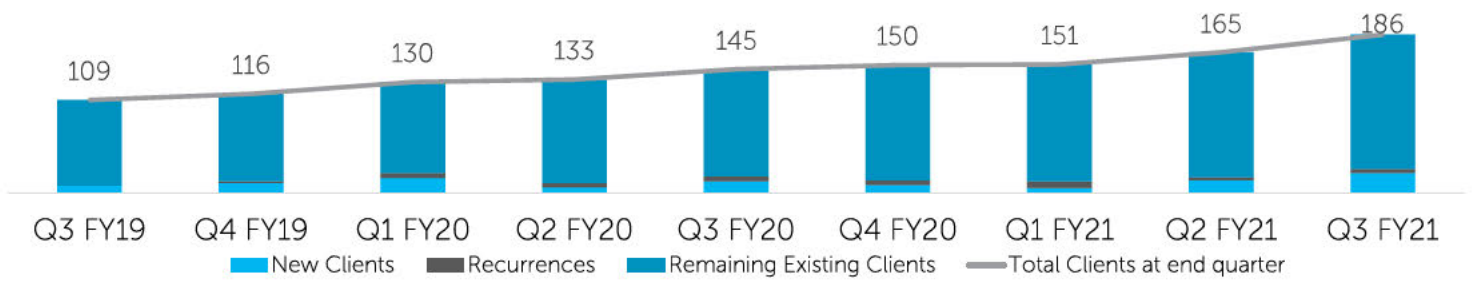
Recurrences Q3 FY21:

3.03%

5 clients of 165 (total clients at end of Q2 FY21) had a recurrence of Crusted Scabies in Q2 FY21.

In Q3 FY21, from 1 January to 31 March 2021, 30 CDC notifications were advised, of which 2 were retrospective new clients for late Q2 FY21. Accordingly, Q2 FY21 total has been adjusted to 165 from 163. Of the 28 CDC notifications attributable to Q3 FY21, 23 were new clients and 5 were recurrent clients. s47F s47F In total, 186 unique clients were listed at end Q3 FY21.

Trends in Northern Territory Crusted Scabies Cases Q3 FY19 – Q3 FY21



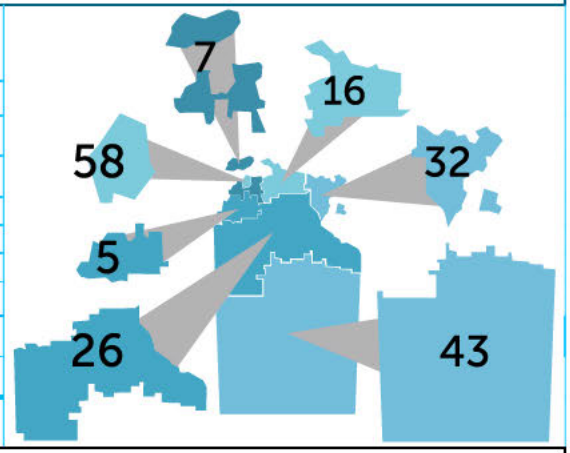
	Q3 FY19 (Jan 1 – Mar 31, 2019)	Q4 FY19 (Apr 1 – Jun 30, 2019)	Q1 FY20 (Jul 1 – Sep 30, 2019)	Q2 FY20 (Oct 1 – Dec 31, 2019)	Q3 FY20 (Jan 1 – Mar 31, 2020)	Q4 FY20 (Apr 1 – Jun 30, 2020)	Q1 FY21 (Jul 1 – Oct 30, 2020)	Q2 FY21 (Oct 1 – Dec 31, 2020)	Q3 FY21 (Jan 1 – Mar 31, 2021)
Total Crusted Scabies clients	*109*	*116*	*130*	*133*	*145*	*150*	*151*	*165**	*186*
CDC notifications	*8*	*13*	*27*	*11*	*19*	*14*	*15*	*18**	*28*
Recurrent Crusted Scabies clients	*0*	*2*	*6*	*5*	*6*	*5*	*8*	*4*	*5*
New Crusted Scabies clients	*8*	*11*	*17*	*6*	*13*	*9*	*5*	*14**	*23*

*Adjusted to reflect two new retrospective clients attributable to Q2 FY21.

Regional Crusted Scabies Client Statistics

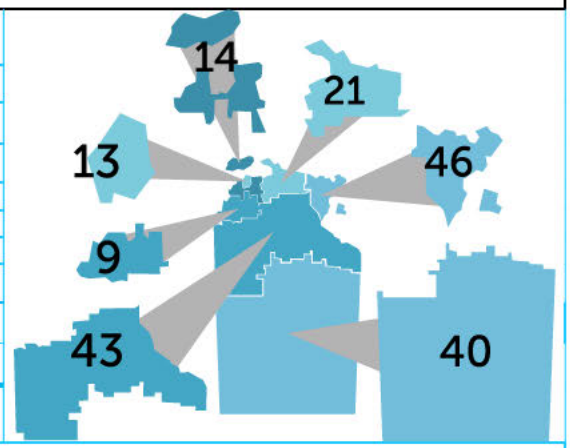
Crusted Scabies clients according to current location of residence

Region	Indigenous population, *n*	Total clients end Q3 FY21, *n*	Clients per 1000	New clients Q3 FY21, *n*	Recurrent clients Q3 FY21, *n*
East Arnhem	*10,582*	*32*	*3.02*	*4*	*2*
West Arnhem	*6,652*	*16*	*2.41*	*1*	*1*
Darwin*	*24,074*	*70*	*2.91*	*6*	*1*
Darwin Urban		*58*		*3*	*1*
Top End West		*5*		*0*	*0*
Top End Central		*7*		*3*	*0*
Katherine	*11,862*	*26*	*2.19*	*4*	*1*
Total Top End	*53,170*	*143*	*2.69*	*14*	*5*
Central‡	*21,376*	*43*	*2.01*	*9*	*0*
Total NT	*74,546*	*186*	*2.50*	*23*	*5*



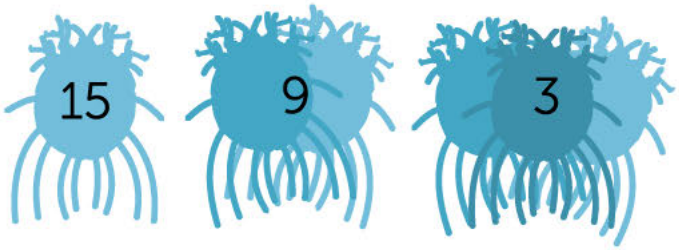
Crusted Scabies clients according to original place of residence

Region	Total clients end Q3 FY21, *n*	Clients per 1000
East Arnhem	*46*	*4.35*
West Arnhem	*21*	*3.17*
Darwin*	*36*	*1.50*
Darwin Urban	*13*	
Top End West	*9*	
Top End Central	*14*	
Katherine	*43*	*3.63*
Total Top End	*146*	*2.75*
Central‡	*40*	*1.87*
Total NT	*186*	*2.50*



*Darwin Region includes Darwin Urban, Top End West and Top End Central
‡Central Region includes Alice Springs and Barkly

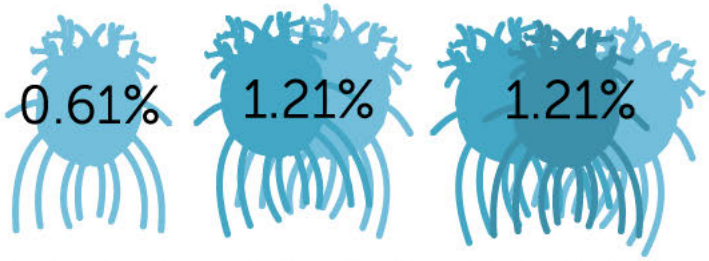
Crusted Scabies clients notified in Q3 FY21 by grade*:



Grade 1 cases = 17 (10x infectivity)
Grade 2 cases = 9 (100x infectivity)
Grade 3 cases = 3 (1000x infectivity)

*One case had no grade documented

Crusted Scabies recurrence in Q3 FY21 by grade:



Grade 1 recur = 1
1 of 165 = 0.61%

Grade 2 recur = 2
2 of 165 = 1.21%

Grade 3 recur = 2
2 of 165 = 1.21%

Q3 FY21 snapshot:

186 clients
23 new clients
Minimal grade 3 cases
5 recurrences

Further information on Crusted Scabies (CS) recurrences in Q3 FY21

Client	Notified cases of CS, *n*	Time since previous CS case	Previous time between CS cases (where >2 cases, average)
#1	*2*	*2 years 0 months*	*NA*
#2	*5*	*12 months*	*10 months average*
#3	*2*	*3 years 9 months*	*NA*
#4	*5*	*8 months*	*10 months average**
#5	*7*	*9 months*	*9 months average**

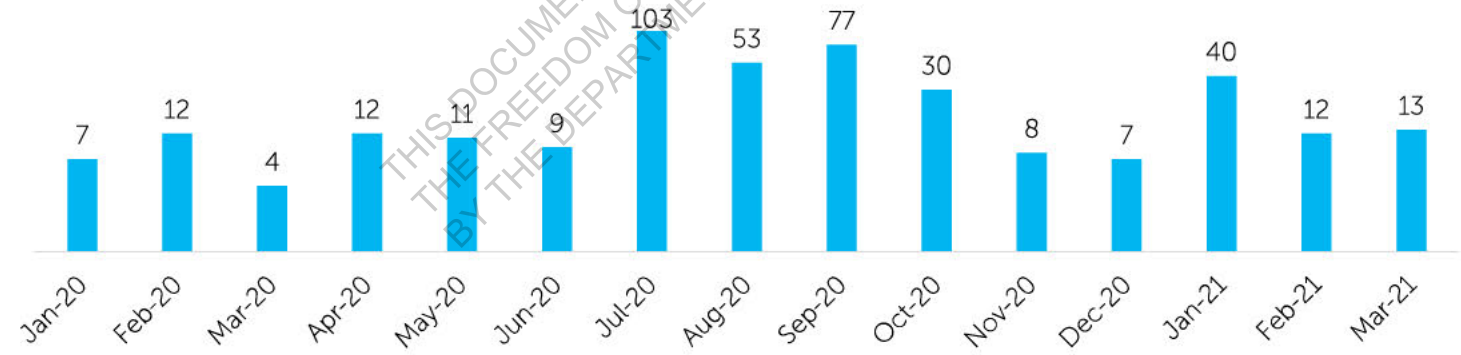
Of the 5 clients with CS recurrences, 2 had their first notified recurrence; both remained free of Crusted Scabies for a considerable period. Four of 5 clients were confirmed to have completed their full treatment. s47F

s47F

s47F One Disease is very closely working with services caring for these clients to improve engagement.

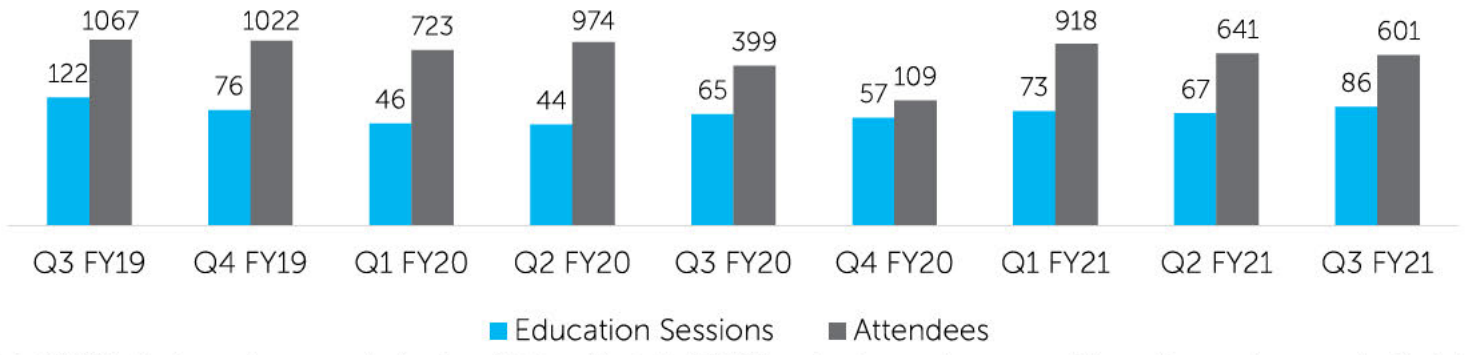
Crusted Scabies prevalence in the Northern Territory at end Q3 FY21 is 1 in 401

Utilisation of One Disease Crusted Scabies RAHC eLearning module, *n* (log²)



Increases in module completion July – October 2020 are attributed to university courses which prescribe RAHC eLearning modules as assessment tasks

Trends in One Disease Crusted Scabies education sessions and audiences, *n* (log²)



Note: Q4 FY20 education sessions were predominantly provided remotely due to COVID-19, so attendance numbers are unavailable – audience numbers are underestimated.

Last modified: 23 April 2021

ONE DISEASE

One Disease Program Reporting
Q4 FY21: April – June 2021

ONE DISEASE

Key Performance Indicator by end FY21:
Eliminate Crusted Scabies as a public health concern in the Northern Territory by attaining a recurrence rate of Northern Territory Crusted Scabies clients less than 5% of the total cumulative cases.

Organisational Goal:
Educate and enable patient self-management to eliminate Crusted Scabies as a public health concern across Australia by 2022.

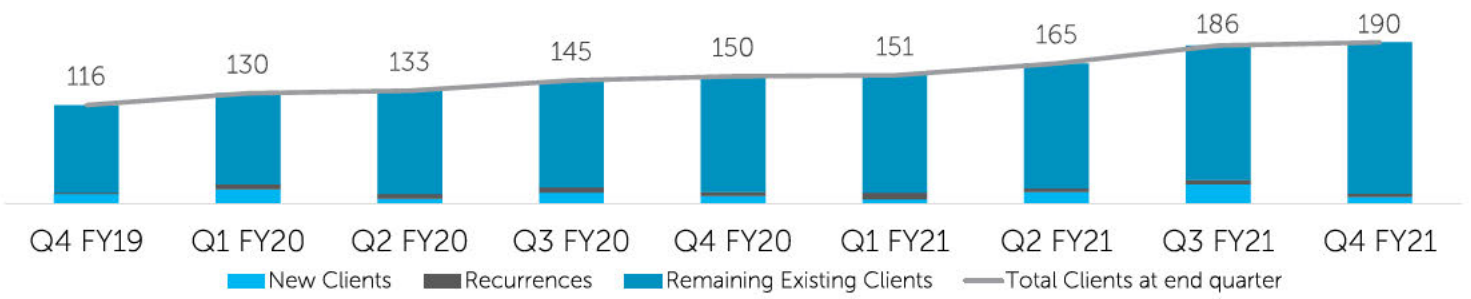
Recurrences Q4 FY21:

2.15%

5 clients of 186 (total clients at end of Q3 FY21) had a recurrence of Crusted Scabies in Q4 FY21.

In Q4 FY21, from 1 January to 31 March 2021, 12 CDC notifications were advised. Of the 12 CDC notifications attributable to Q4 FY21, 8 were new clients and 4 were recurrent clients.
s47F
s47F In total, 190 unique clients were listed at end Q4 FY21.

Trends in Northern Territory Crusted Scabies Cases Q4 FY19 – Q4 FY21

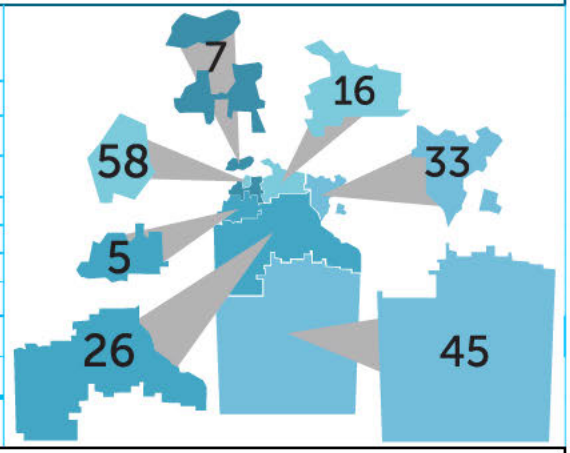


	Q4 FY19 (Apr 1 – Jun 30, 2019)	Q1 FY20 (Jul 1 – Sep 30, 2019)	Q2 FY20 (Oct 1 – Dec 31, 2019)	Q3 FY20 (Jan 1 – Mar 31, 2020)	Q4 FY20 (Apr 1 – Jun 30, 2020)	Q1 FY21 (Jul 1 – Oct 30, 2020)	Q2 FY21 (Oct 1 – Dec 31, 2020)	Q3 FY21 (Jan 1 – Mar 31, 2021)	Q4 FY21 (Apr 1 – Jun 30, 2021)
Total Crusted Scabies clients	*116*	*130*	*133*	*145*	*150*	*151*	*165*	*186*	*190*
CDC notifications	*13*	*27*	*11*	*19*	*14*	*15*	*18*	*28*	*12*
Recurrent Crusted Scabies clients	*2*	*6*	*5*	*6*	*5*	*8*	*4*	*5*	*4*
New Crusted Scabies clients	*11*	*17*	*6*	*13*	*9*	*5*	*14*	*23*	*8*

Regional Crusted Scabies Client Statistics

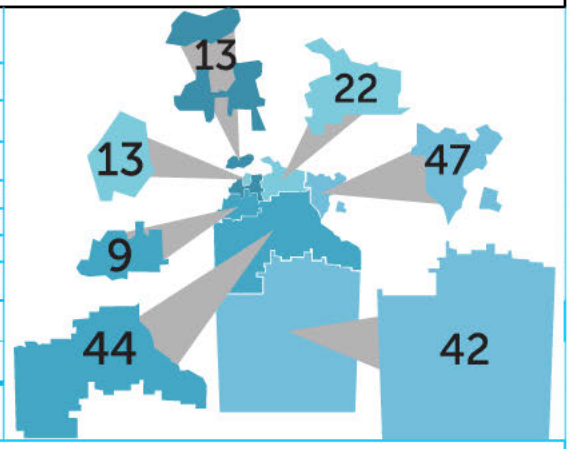
Crusted Scabies clients according to current location of residence

Region	Indigenous population, *n*	Total clients end Q4 FY21, *n*	Clients per 1000	New clients Q4 FY21, *n*	Recurrent clients Q4 FY21, *n*
East Arnhem	*10,582*	*33*	*3.12*	*1*	*2*
West Arnhem	*6,652*	*16*	*2.41*	*1*	*0*
Darwin*	*24,074*	*70*	*2.91*	*3*	*0*
Darwin Urban		*58*		*3*	*0*
Top End West		*5*		*0*	*0*
Top End Central		*7*		*0*	*0*
Katherine	*11,862*	*26*	*2.19*	*1*	*0*
Total Top End	***53,170***	***145***	***2.73***	***6***	***2***
Central‡	*21,376*	*45*	*2.11*	*2*	*2*
Total NT	***74,546***	***190***	***2.55***	***8***	***4***



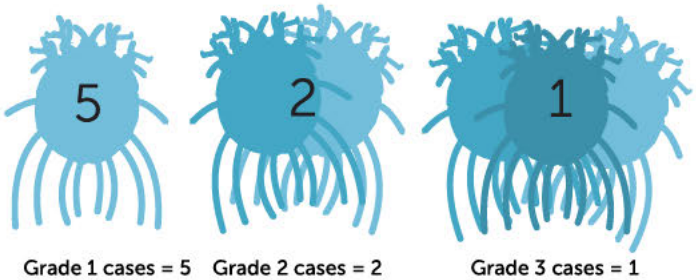
Crusted Scabies clients according to original place of residence

Region	Total clients end Q4 FY21, *n*	Clients per 1000
East Arnhem	*47*	*4.44*
West Arnhem	*22*	*3.31*
Darwin*	*35*	*1.45*
Darwin Urban	*13*	
Top End West	*9*	
Top End Central	*13*	
Katherine	*44*	*3.71*
Total Top End	***148***	***2.78***
Central‡	*42*	*1.96*
Total NT	***190***	***2.55***



*Darwin Region includes Darwin Urban, Top End West and Top End Central
‡Central Region includes Alice Springs and Barkly

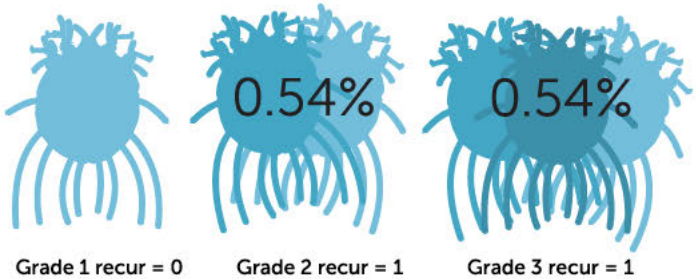
Crusted Scabies clients notified in Q4 FY21 by grade*:



Grade 1 cases = 5 (10x infectivity)
Grade 2 cases = 2 (100x infectivity)
Grade 3 cases = 1 (1000x infectivity)

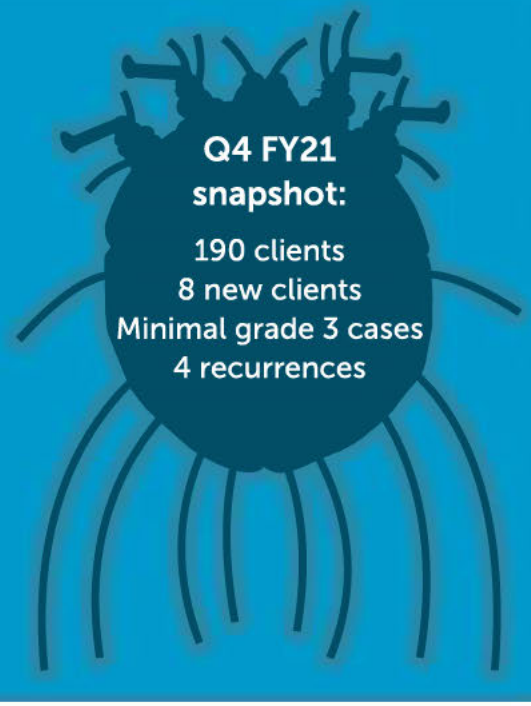
*Four cases had no grade documented

Crusted Scabies recurrence in Q4 FY21 by grade:



Grade 1 recur = 0 (0 of 186)
Grade 2 recur = 1 (1 of 186 = 0.54%)
Grade 3 recur = 1 (1 of 186 = 0.54%)

*Two recurrent cases had no grade documented



Further information on Crusted Scabies (CS) recurrences in Q4 FY21

Client	Notified cases of CS, *n*	Time since previous CS case	Previous time between CS cases (where >2 cases, average)
#1	*2*	*1 year 5 months*	*NA*
#2	*5*	*2 years*	*1 year 1 month average*
#3	*2*	*3 years 10 months*	*NA*
#4	*2*	*2 years 6 months*	*NA*

Of the four clients with Crusted Scabies recurrences in Q4 FY21, three had their first notified recurrence and all remained free of Crusted Scabies for a considerable period. All four clients unfortunately had no information available on treatment completion. This is attributed in two cases to discharge summaries still pending at the time of reporting. The other two did not have discharge summaries which were available, or which indicated sufficient information about their Crusted Scabies episode. s47F

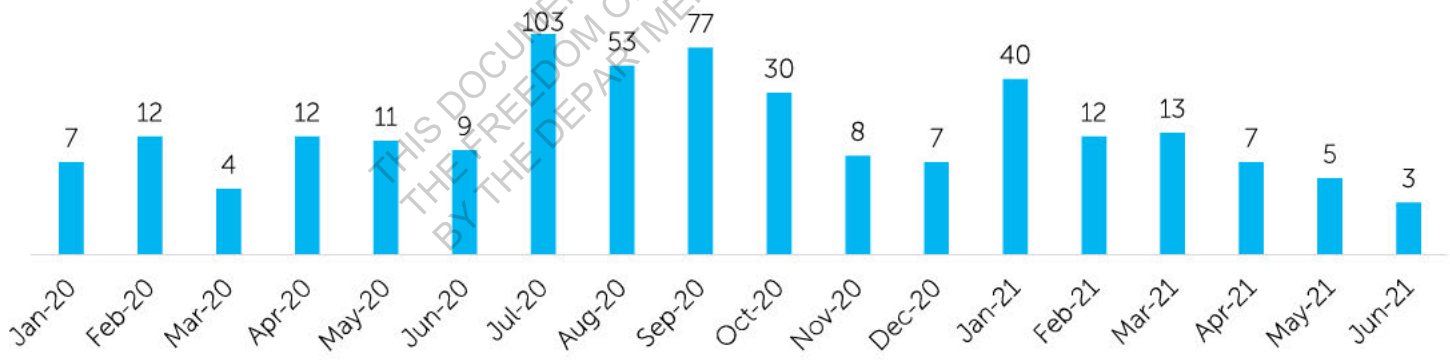
s47F

s47F Known information has been included in supplementary timeline data to provide available insight into these client's individual timelines. One Disease will be engaging with hospital and clinic services in the coming months to attempt to better documentation.

Further detail on these recurrent client timelines is provided in Supplementary pages.

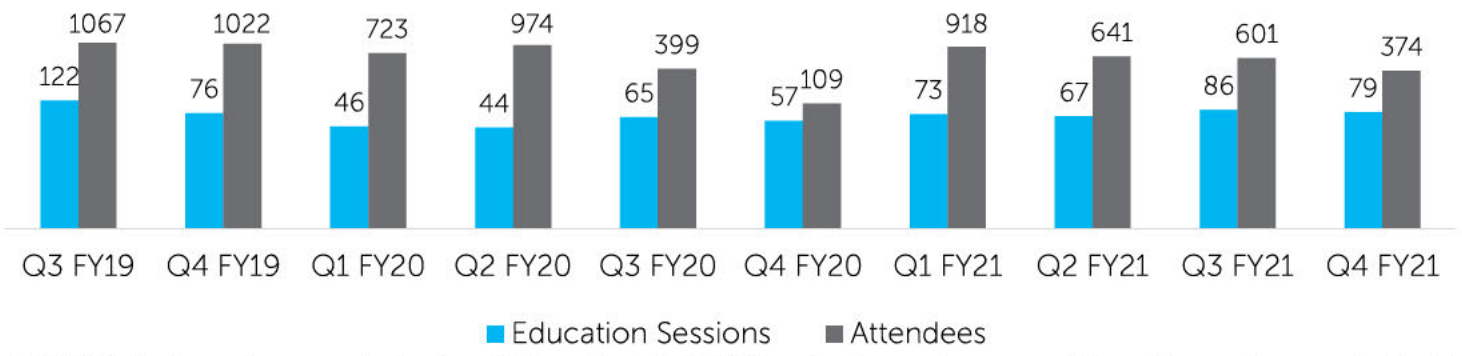
Crusted Scabies prevalence in the Northern Territory at end Q4 FY21 is 1 in 392

Utilisation of One Disease Crusted Scabies RAHC eLearning module, *n* (log²)



Increases in module completion July – October 2020 are attributed to university courses which prescribe RAHC eLearning modules as assessment tasks

Trends in One Disease Crusted Scabies education sessions and audiences, *n* (log²)



Note: Q4 FY20 education sessions were predominantly provided remotely due to COVID-19, so attendance numbers are unavailable – audience numbers are underestimated.

Last modified: 27 July 2021

ONE DISEASE

OneDisease – Q4FY21 Supplementary Recurrences Timelines

CDC notified Crusted Scabies episode

Crusted Scabies episode (not notified)

Skin check documented: NAD

Skin check documented: abnormal; nil scabie

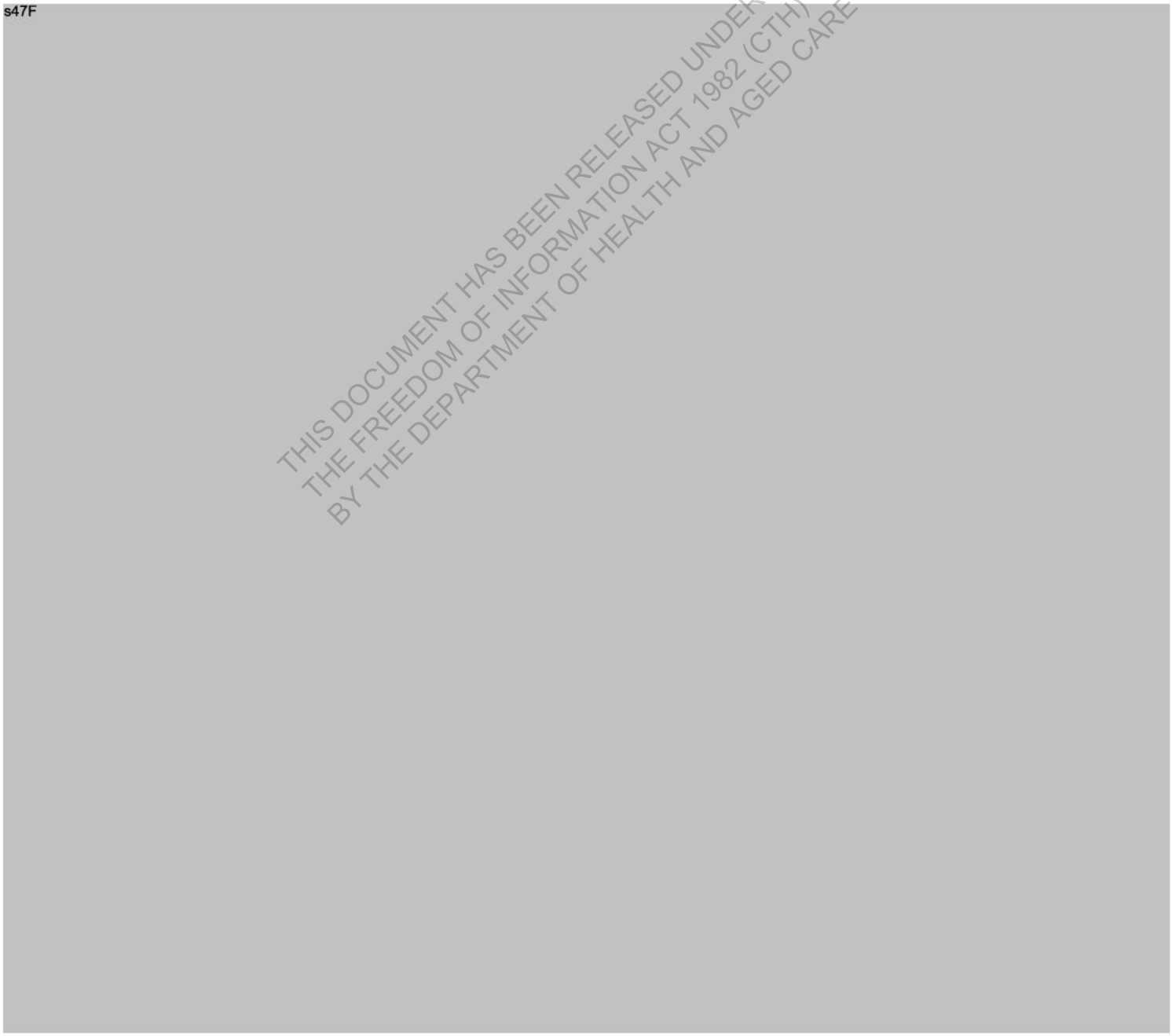
Skin check documented: abnormal; scabies

Skin check scheduled, refused by client

Scabies medication provided

Acronyms/shorthand: took own leave (TOL), discharged against medical orders (DAMA), Crusted Scabies (CS), treatment (tx), Katherine District Hospital (KDH), Gove District Hospital (GDH), Royal Darwin Hospital (RDH), Tennant Creek Hospital (TCH), Alice Springs Hospital (ASH), query (?), Top End Health Service (TEHS), Central Australia Health Service (CAHS), Clinical Information System (CIS), Primary Care Information System (PCIS), negative test results (-ive), positive test results (+ive), Shared eHealth Record (SeHR), Emergency Department (ED).

s47F



s47F

One Disease Program Reporting
Q1FY22: July – September 2021

ONE DISEASE

Key Performance Indicator:
Eliminate Crusted Scabies as a public health concern in the Northern Territory by attaining a recurrence rate of Northern Territory Crusted Scabies clients less than 5% of the total cumulative cases.

Organisational Goal:
Educate and enable patient self-management to eliminate Crusted Scabies as a public health concern across Australia by 2022.

Overall Aim:
For Crusted Scabies to be easily managed within existing primary health-care systems and ultimately eliminated as a public health problem in Australia.

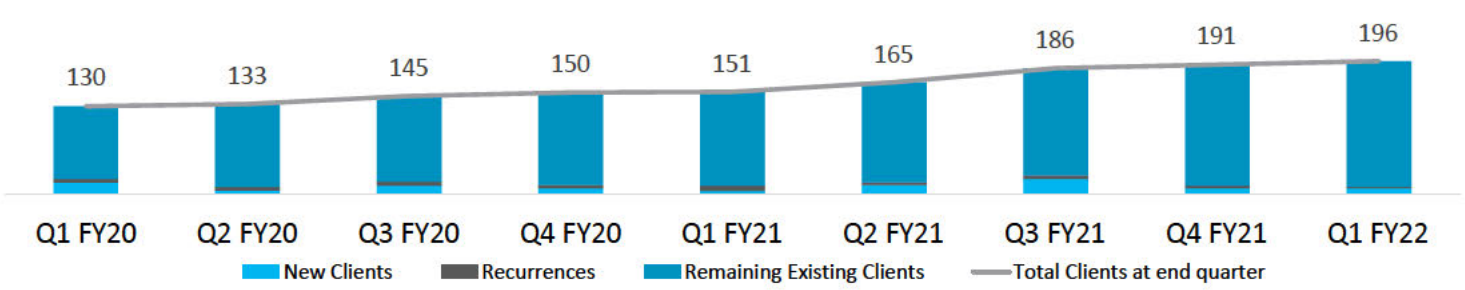
Recurrences Q1 FY22:

1.05%

2 clients of 191 (total clients at end of Q4 FY21) had a recurrence of Crusted Scabies in Q1 FY22.

In Q1 FY22, from 1 July to 30 September 2021, 11 CDC notifications were advised. Of the 11 CDC notifications attributable to Q1 FY22, 9 were new clients and 2 were recurrent clients. Additionally, one new client was retrospectively advised from late Q4 FY21. Trends table and graph have been adjusted accordingly. s47F In total, 196 unique clients were listed at Q1 FY22 end.

Trends in Northern Territory Crusted Scabies Cases Q1 FY20 – Q1 FY22



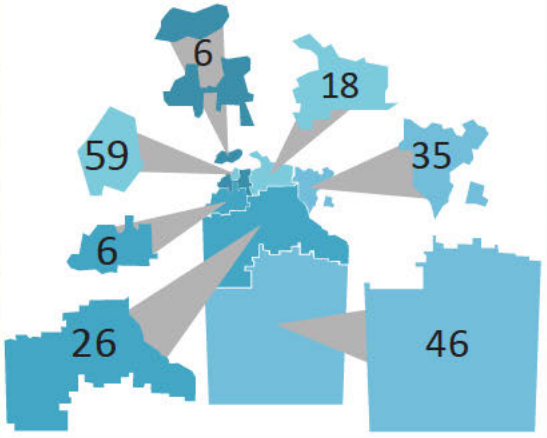
	Q1 FY20 (Jul 1 – Sep 30, 2019)	Q2 FY20 (Oct 1 – Dec 31, 2019)	Q3 FY20 (Jan 1 – Mar 31, 2020)	Q4 FY20 (Apr 1 – Jun 30, 2020)	Q1 FY21 (Jul 1 – Oct 30, 2020)	Q2 FY21 (Oct 1 – Dec 31, 2020)	Q3 FY21 (Jan 1 – Mar 31, 2021)	Q4 FY21 (Apr 1 – Jun 30, 2021)	Q1 FY22 (Jul 1 – Sep 30, 2021)
Total Crusted Scabies clients	*130*	*133*	*145*	*150*	*151*	*165*	*186*	*191**	*196*
CDC notifications	*27*	*11*	*19*	*14*	*15*	*18*	*28*	*13**	*12*
Recurrent Crusted Scabies clients	*6*	*5*	*6*	*5*	*8*	*4*	*5*	*4*	*2*
New Crusted Scabies clients	*17*	*6*	*13*	*9*	*5*	*14*	*23*	*9**	*9*

*Retrospective notification adjusted

Regional Crusted Scabies Client Statistics

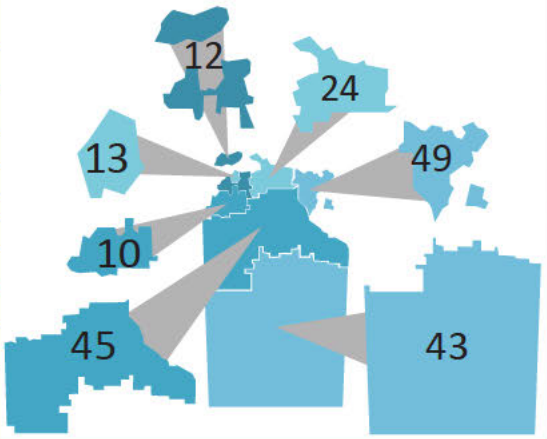
Crusted Scabies clients according to current location of residence

Region	Indigenous population, *n*	Total clients end Q1 FY22, *n*	Clients per 1000	New clients Q1 FY22, *n*	Recurrent clients Q1 FY22, *n*
East Arnhem	*10,582*	*35*	*3.32*	*1*	*0*
West Arnhem	*6,652*	*18*	*2.71*	*3*	*0*
Darwin*	*24,074*	*71*	*2.95*	*2*	*1*
Darwin Urban		*59*		*1*	*0*
Top End West		*6*		*1*	*1*
Top End Central		*6*		*0*	*0*
Katherine	*11,862*	*26*	*2.19*	*2*	*1*
Total Top End	*53,170*	*150*	*2.73*	*8*	*2*
Central‡	*21,376*	*46*	*2.15*	*1*	*0*
Total NT	*74,546*	*196*	*2.63*	*9*	*2*



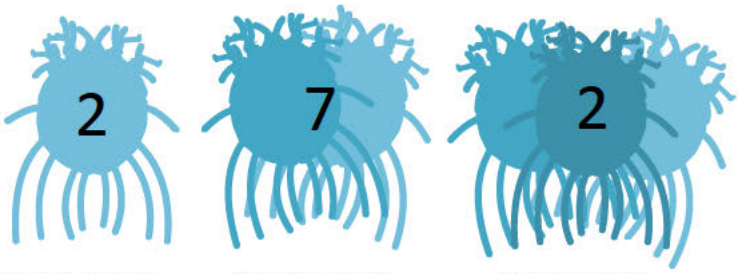
Crusted Scabies clients according to original place of residence

Region	Total clients end Q1 FY22, *n*	Clients per 1000
East Arnhem	*49*	*4.63*
West Arnhem	*24*	*3.61*
Darwin^	*35*	*1.45*
Darwin Urban	*13*	
Top End West	*10*	
Top End Central	*12*	
Katherine	*45*	*3.91*
Total Top End	*153*	*2.88*
Central‡	*43*	*2.01*
Total NT	*196*	*2.63*



^Darwin Region includes Darwin Urban, Top End West and Top End Central
‡Central Region includes Alice Springs and Barkly

Crusted Scabies clients notified in Q1 FY22 by grade:

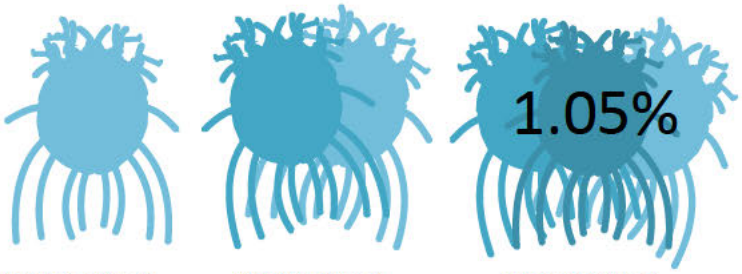


Grade 1 cases = 2
10x infectivity

Grade 2 cases = 7
100x infectivity

Grade 3 cases = 2
1000x infectivity

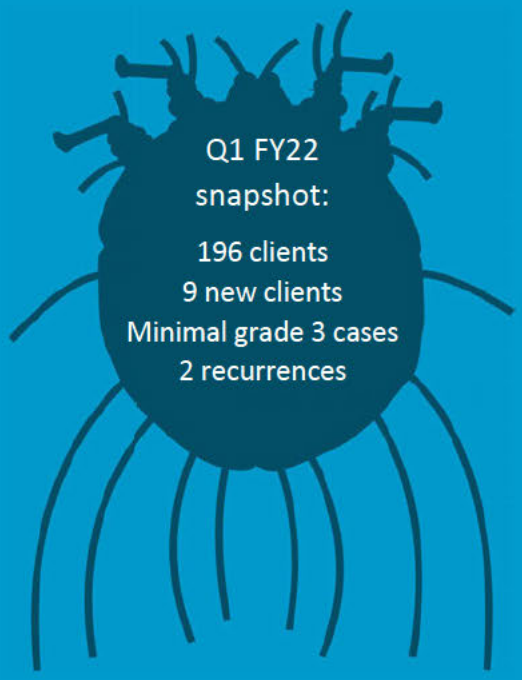
Crusted Scabies recurrence in Q1 FY22 by grade:



Grade 1 recur = 0
0 of 191

Grade 2 recur = 0
0 of 191

Grade 3 recur = 2
2 of 191 = 1.05%



Further information on Crusted Scabies (CS) recurrences in Q1 FY22

Client	Notified cases of CS, *n*	Time since previous CS case	Previous time between CS cases (where >2 cases, average)
#1	*6*	*1 year 4 months*	*1 year*
#2	*6*	*1 year 5 months*	*1 year 1 month*

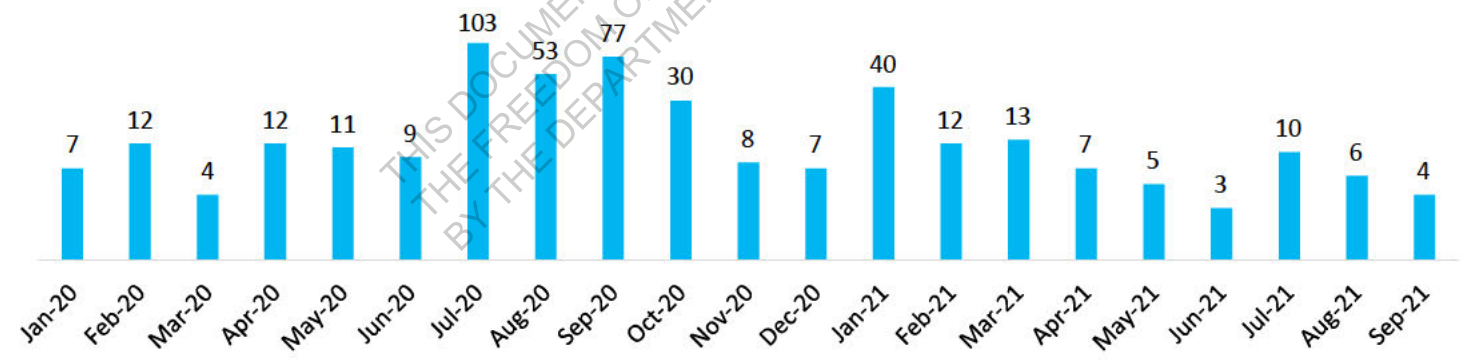
Of the two clients with Crusted Scabies recurrences in Q1 FY22, one completed treatment in hospital with clinical resolution of scabies. s47F

s47F

Further detail on the timelines for the recurrent clients above is provided in the Supplementary pages.

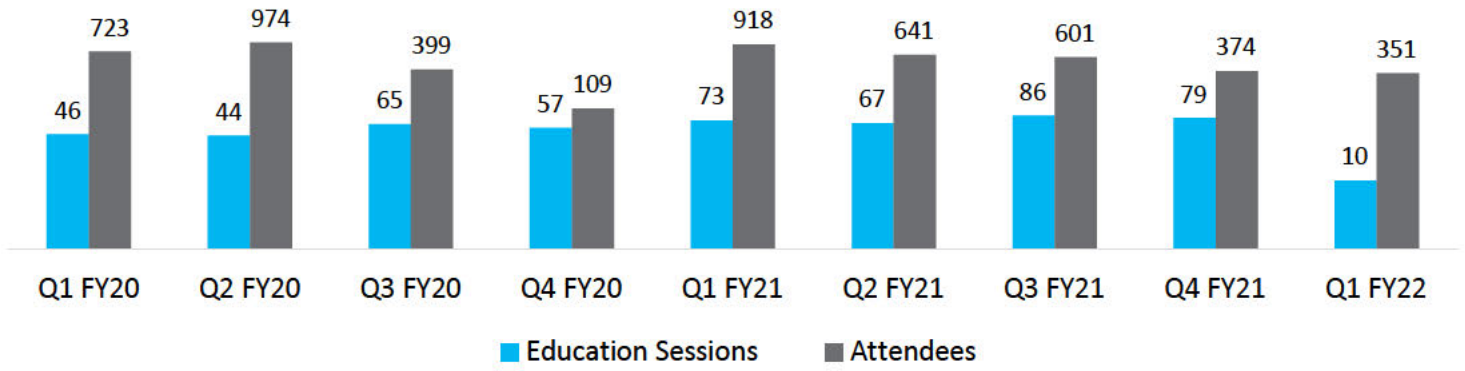
Crusted Scabies prevalence in the Northern Territory at end Q1 FY22 is 1 in 380

Utilisation of One Disease Crusted Scabies RAHC eLearning module, *n* (log²)



Increases in module completion July – October 2020 are attributed to university courses which prescribe RAHC eLearning modules as assessment tasks

Trends in One Disease Crusted Scabies education sessions and audiences, *n* (log²)



Note: Q4 FY20 and Q1 FY22 education sessions were predominantly provided remotely due to COVID-19, so attendance numbers may be underestimated.

Last modified: 22 November 2021

ONE DISEASE

One Disease – Q1 FY22 Supplementary Recurrences Timelines

CDC notified Crusted Scabies episode

Crusted Scabies episode (not notified)

Skin check documented: NAD

Skin check documented: abnormal; nil scabies

Skin check documented: abnormal; scabies

Renal foot assessment: NAD

Renal foot assessment: abnormal; nil scabies

Renal foot assessment: abnormal; scabies

Skin check scheduled, refused by client

Scabies medication provided

Acronyms/shorthand: took own leave (TOL), discharged against medical orders (DAMA), Crusted Scabies (CS), treatment (tx), Katherine District Hospital (KDH), Gove District Hospital (GDH), Royal Darwin Hospital (RDH), Tennant Creek Hospital (TCH), Alice Springs Hospital (ASH), query (?), Top End Health Service (TEHS), Central Australia Health Service (CAHS), Clinical Information System (CIS), Primary Care Information System (PCIS), negative test results (-ive), positive test results (+ive), Shared eHealth Record (SeHR), Emergency Department (ED).

s47F

One Disease Program Reporting
Q2 FY22: October – December 2021

ONE DISEASE

Key Performance Indicator:
Eliminate Crusted Scabies as a public health concern in the Northern Territory by attaining a recurrence rate of Northern Territory Crusted Scabies clients less than 5% of the total cumulative cases.

Organisational Goal:
Educate and enable patient self-management to eliminate Crusted Scabies as a public health concern across Australia by 2022.

Overall Aim:
For Crusted Scabies to be easily managed within existing primary health-care systems and ultimately eliminated as a public health problem in Australia.

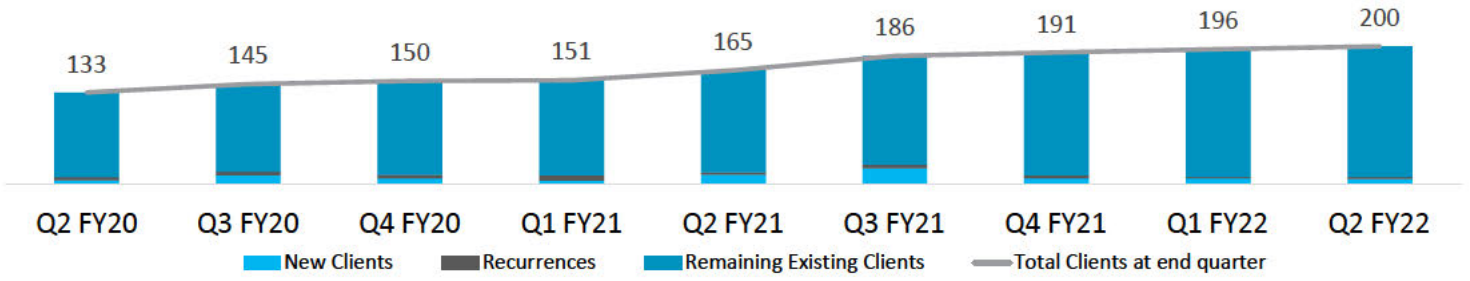
Recurrences Q2 FY22:

1.53%

3 clients of 196 (total clients at end of Q1 FY22) had a recurrence of Crusted Scabies in Q2 FY22.

In Q2 FY22, from 1 October 2021 to 31 December 2021, 11 CDC notifications were advised. Of the 11 CDC notifications attributable to Q2 FY22, 8 were new clients and 3 were recurrent clients. s47F s47F In total, 200 unique clients were listed at Q2 FY22 end.

Trends in Northern Territory Crusted Scabies Cases Q2 FY20 – Q2 FY22

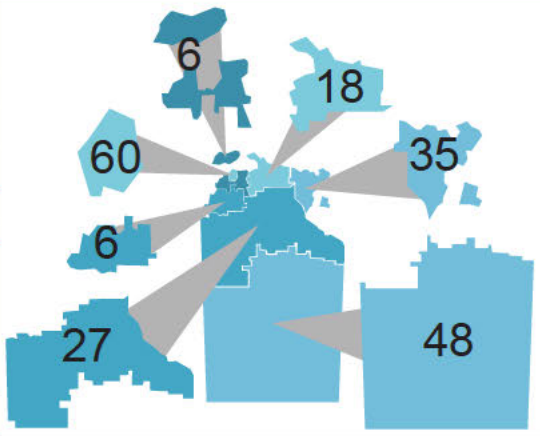


	Q2 FY20 (Oct 1 – Dec 31, 2019)	Q3 FY20 (Jan 1 – Mar 31, 2020)	Q4 FY20 (Apr 1 – Jun 30, 2020)	Q1 FY21 (Jul 1 – Oct 30, 2020)	Q2 FY21 (Oct 1 – Dec 31, 2020)	Q3 FY21 (Jan 1 – Mar 31, 2021)	Q4 FY21 (Apr 1 – Jun 30, 2021)	Q1 FY22 (Jul 1 – Sep 30, 2021)	Q2 FY22 (Oct 1 – Dec 31, 2021)
Total Crusted Scabies clients	133	145	150	151	165	186	191	196	200
CDC notifications	11	19	14	15	18	28	13	12	11
Recurrent Crusted Scabies clients	5	6	5	8	4	5	4	2	3
New Crusted Scabies clients	6	13	9	5	14	23	9	9	8

Regional Crusted Scabies Client Statistics

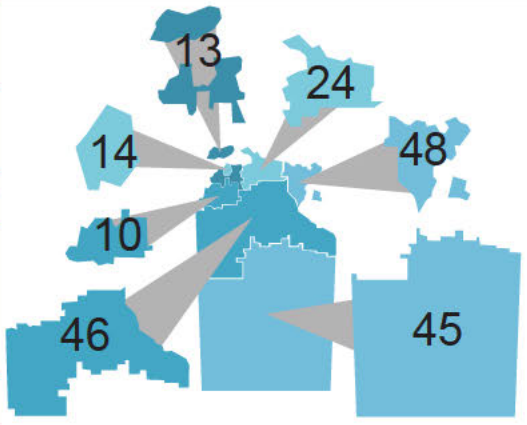
Crusted Scabies clients according to current location of residence

Region	Indigenous population, *n*	Total clients end Q2 FY22, *n*	Clients per 1000	New clients Q2 FY22, *n*	Recurrent clients Q2 FY22, *n*
East Arnhem	10,582	35	3.32	1	1
West Arnhem	6,652	18	2.71	0	1
Darwin*	24,074	72	2.99	3	1
Darwin Urban		*60*		*3*	*1*
Top End West		*6*		*0*	*0*
Top End Central		*6*		*0*	*0*
Katherine	11,862	27	2.28	2	0
Total Top End	53,170	152	2.86	6	3
Central‡	21,376	48	2.24	2	0
Total NT	74,546	200	2.68	8	3



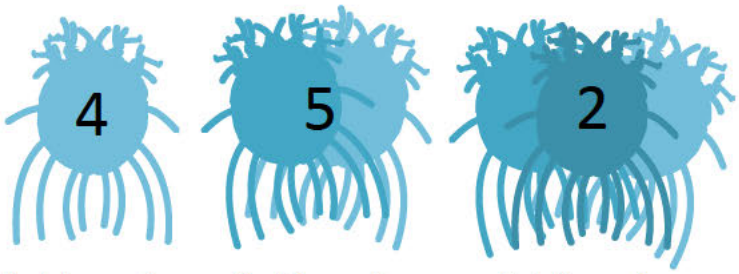
Crusted Scabies clients according to original place of residence

Region	Total clients end Q2 FY22, *n*	Clients per 1000
East Arnhem	48	4.54
West Arnhem	24	3.61
Darwin*	37	1.54
Darwin Urban	*14*	
Top End West	*10*	
Top End Central	*13*	
Katherine	46	3.88
Total Top End	155	2.92
Central‡	45	2.11
Total NT	200	2.68



*Darwin Region includes Darwin Urban, Top End West and Top End Central
‡Central Region includes Alice Springs and Barkly

Crusted Scabies clients notified in Q2 FY22 by grade:

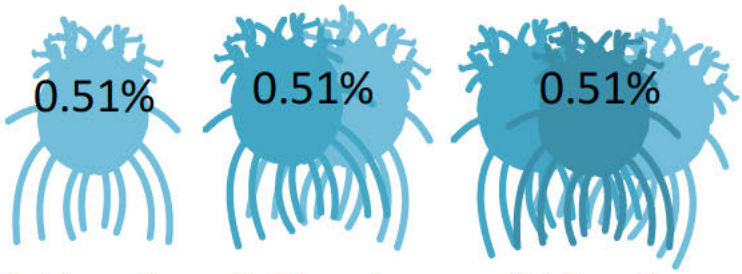


Grade 1 cases = 4
10x infectivity

Grade 2 cases = 5
100x infectivity

Grade 3 cases = 2
1000x infectivity

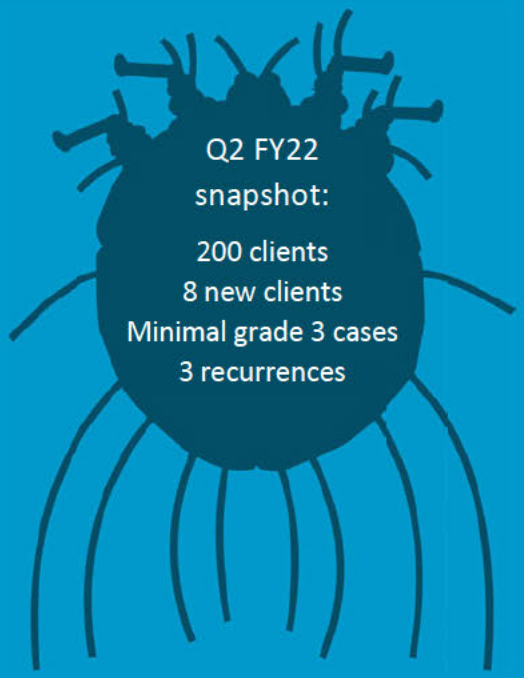
Crusted Scabies recurrence in Q2 FY22 by grade:



Grade 1 recur = 1
1 of 196 = 0.51%

Grade 2 recur = 1
1 of 196 = 0.51%

Grade 3 recur = 1
1 of 196 = 0.51%



Further information on Crusted Scabies (CS) recurrences in Q2 FY22

Client	Notified cases of CS, *n*	Time since previous CS case	Previous time between CS cases (where >2 cases, average)
#1	*3*	*3 years 0 months*	*2 years 8 months*
#2	*4*	*1 year 7 months*	*1 year 2 months*
#3	*8*	*7 months*	*9 months*

Of the three clients with Crusted Scabies recurrences in Q2 FY22, two completed treatment in hospital with clinical resolution of scabies and one client took their own leave from hospital prior to discharge.

s47F

s47F Of the eight new cases, four completed treatment, with clear documentation on discharge from hospital. Two clients discharged against medical advice prior to completion and two cases had no discharge summary issued on their discharge to indicate if treatment was completed. Conversations around the documentation of treatment completion in discharge summaries will be again raised with relevant stakeholders in the coming months.

Further detail on the timelines for the recurrent clients above is provided in the Supplementary pages.

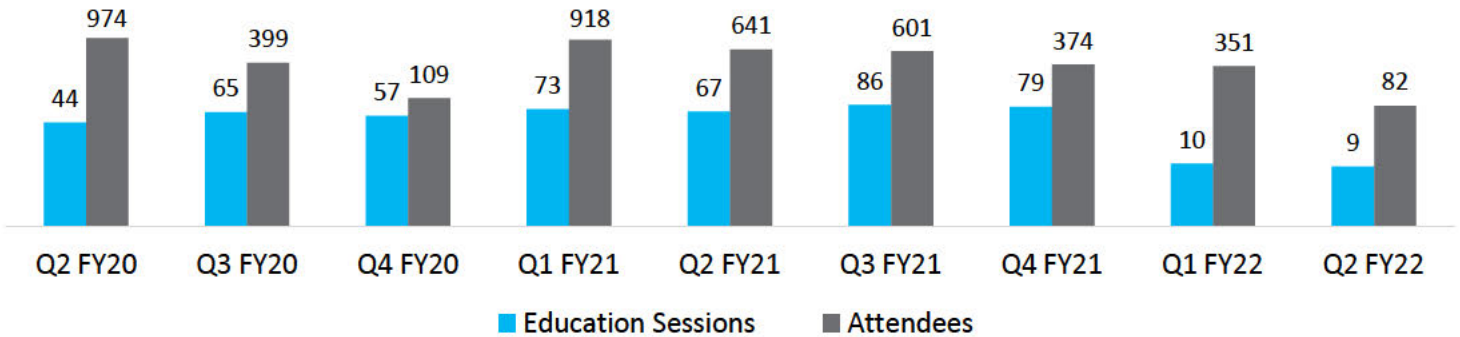
Crusted Scabies prevalence in the Northern Territory at end Q2 FY22 is 1 in 373

Utilisation of One Disease StoryTelling Tool in Q2 FY22

- 42 non-bounce* sessions by 33 users.
- Average application usage time: 8 minutes 17 seconds per session.
- Most common language: English. Other languages utilised: Kimberley Kriol, Murrinh Patha, Yolngu Matha, Anmatyerr, East Side Kriol.
- Most commonly accessed pages: Women's Story, Lyclear application game, Household Lyclear game, Men's Story, Scabies Free Bedroom Story.

*A non-bounce session is a session where the user engaged with site content beyond the homepage (rather than exiting from the homepage or the first page visited with no further interaction, which is called a "bounce").

Trends in One Disease Crusted Scabies education sessions and audiences, *n* ($\log^2$)



Note: Due to COVID-19, Q4 FY20, Q1 FY22 and Q2 FY22 found engagement with communities and services limited, with some education sessions provided remotely. Session and attendance numbers are therefore reduced.

Last modified: 18 January 2022

ONE DISEASE

One Disease – Q2 FY22 Supplementary Recurrences Timelines

CDC notified Crusted Scabies episode

Crusted Scabies episode (not notified)

Skin check documented: NAD

Skin check documented: abnormal; nil scabies

Skin check documented: abnormal; scabies

Skin check scheduled, refused by client

Scabies medication provided

Acronyms/shorthand: took own leave (TOL), discharged against medical orders (DAMA), Crusted Scabies (CS), treatment (tx), Katherine District Hospital (KDH), Gove District Hospital (GDH), Royal Darwin Hospital (RDH), Tennant Creek Hospital (TCH), Alice Springs Hospital (ASH), query (?), Top End Health Service (TEHS), Central Australia Health Service (CAHS), Clinical Information System (CIS), Primary Care Information System (PCIS), negative test results (-ive), positive test results (+ive), Shared eHealth Record (SeHR), Emergency Department (ED).

s47F

One Disease Program Reporting
Q3 FY22: January – March 2022

ONE DISEASE

Key Performance Indicator:
Eliminate Crusted Scabies as a public health concern in the Northern Territory by attaining a recurrence rate of Northern Territory Crusted Scabies clients less than 5% of the total cumulative cases.

Organisational Goal:
Educate and enable patient self-management to eliminate Crusted Scabies as a public health concern across Australia by 2022.

Overall Aim:
For Crusted Scabies to be easily managed within existing primary health-care systems and ultimately eliminated as a public health problem in Australia.

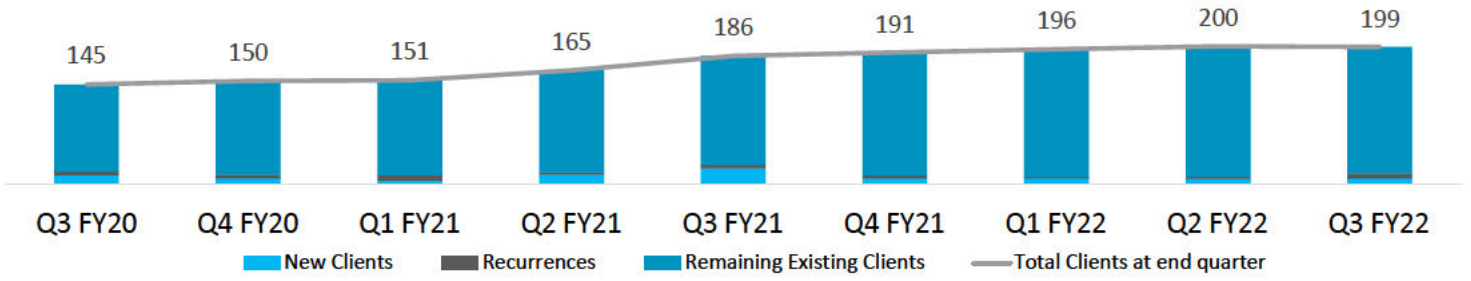
Recurrences Q3 FY22:

3.5%

7 clients of 200 (total clients at end of Q2 FY22) had a recurrence of Crusted Scabies in Q3FY22.

In Q3 FY22, from 1 January to 31 March 2022, 16 CDC notifications were advised. Of the 16 CDC notifications attributable to Q3 FY22, 9 were new clients and 7 were recurrent clients. s47F s47F s47F In total, 199 unique clients were listed at Q3 FY22 end.

Trends in Northern Territory Crusted Scabies Cases Q3 FY20 – Q3 FY22

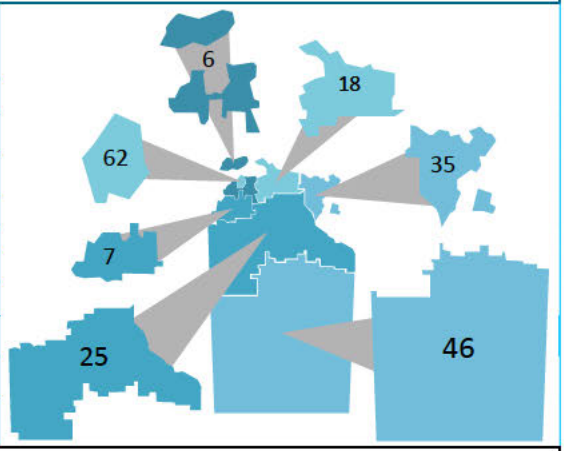


	Q3 FY20 (Jan 1 – Mar 31, 2020)	Q4 FY20 (Apr 1 – Jun 30, 2020)	Q1 FY21 (Jul 1 – Oct 30, 2020)	Q2 FY21 (Oct 1 – Dec 31, 2020)	Q3 FY21 (Jan 1 – Mar 31, 2021)	Q4 FY21 (Apr 1 – Jun 30, 2021)	Q1 FY22 (Jul 1 – Sep 30, 2021)	Q2 FY22 (Oct 1 – Dec 31, 2021)	Q3 FY22 (Jan 1 – Mar 31 2022)
Total Crusted Scabies clients	*145*	*150*	*151*	*165*	*186*	*191*	*196*	*200*	*199*
CDC notifications	*19*	*14*	*15*	*18*	*28*	*13*	*12*	*11*	*16*
Recurrent Crusted Scabies clients	*6*	*5*	*8*	*4*	*5*	*4*	*2*	*3*	*7*
New Crusted Scabies clients	*13*	*9*	*5*	*14*	*23*	*9*	*9*	*8*	*9**

Regional Crusted Scabies Client Statistics

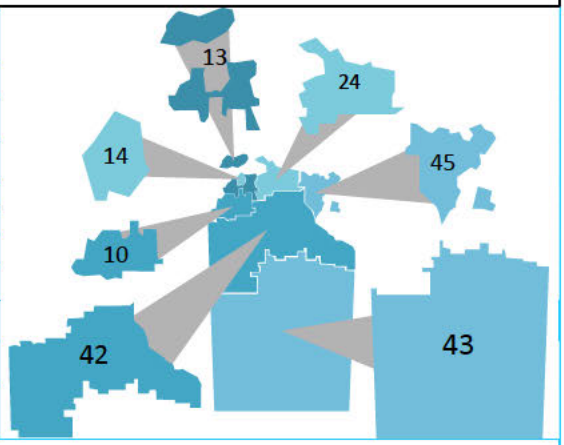
Crusted Scabies clients according to current location of residence

Region	Indigenous population, *n*	Total clients end Q3 FY22, *n*	Clients per 1000	New clients Q3 FY22, *n*	Recurrent clients Q3 FY22, *n*
East Arnhem	*10,582*	*35*	*3.31*	*2*	*2*
West Arnhem	*6,652*	*18*	*2.71*	*0*	*1*
Darwin*	*24,074*	*75*	*3.12*	*4*	*3*
Darwin Urban		*62*		*3*	*3*
Top End West		*7*		*1*	*0*
Top End Central		*6*		*0*	*0*
Katherine	*11,862*	*25*	*2.11*	*2*	*1*
Total Top End	*53,170*	*153*	*2.88*	*8*	*6*
Central‡	*21,376*	*46*	*2.15*	*0*	*0*
Total NT	*74,546*	*199*	*2.67*	*9*	*7*



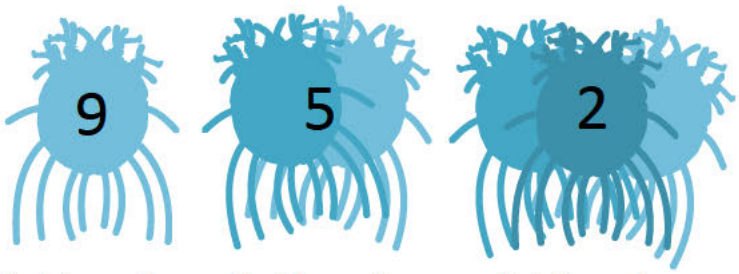
Crusted Scabies clients according to original place of residence

Region	Total clients end Q3 FY22, *n*	Clients per 1000
East Arnhem	*48*	*4.54*
West Arnhem	*24*	*3.61*
Darwin^	*40*	*1.66*
Darwin Urban	*16*	
Top End West	*11*	
Top End Central	*13*	
Katherine	*44*	*3.71*
Total Top End	*156*	*2.93*
Central‡	*43*	*2.01*
Total NT	*199*	*2.67*



^Darwin Region includes Darwin Urban, Top End West and Top End Central
‡Central Region includes Alice Springs and Barkly

Crusted Scabies clients notified in Q3 FY22 by grade:

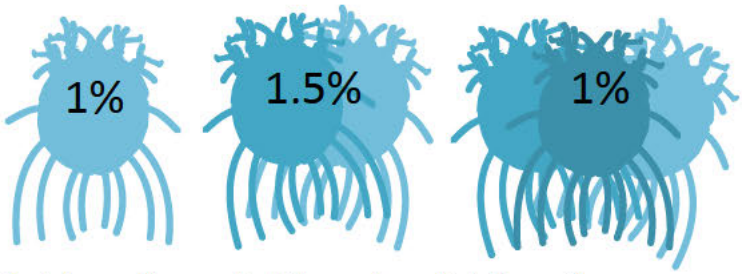


Grade 1 cases = 4
10x infectivity

Grade 2 cases = 5
100x infectivity

Grade 3 cases = 2
1000x infectivity

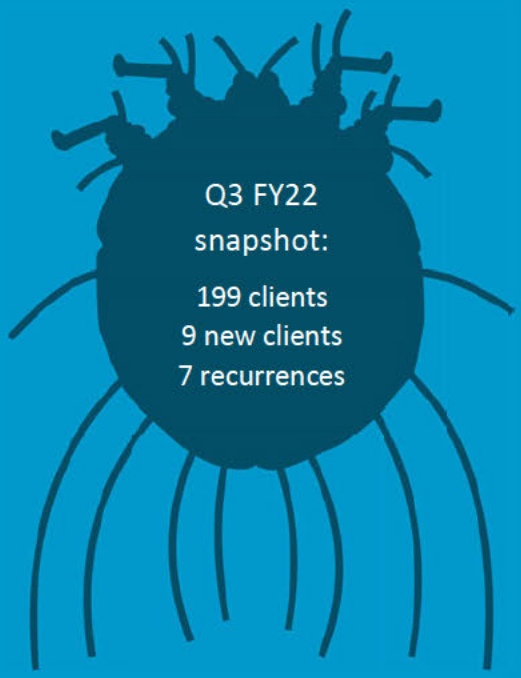
Crusted Scabies recurrence in Q3 FY22 by grade:



Grade 1 recur = 2
2 of 200 = 1%

Grade 2 recur = 3
3 of 200 = 1.5%

Grade 3 recur = 2
2 of 200 = 1%



Further information on Crusted Scabies (CS) recurrences in Q3 FY22

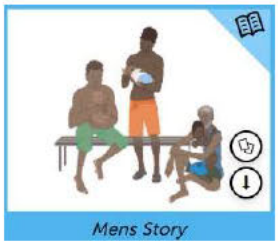
Client	Notified cases of CS, *n*	Time since previous CS case	Previous time between CS cases (where >2 cases, average)
#1	*3*	*2 years 0 months*	*1 years 4 months*
#2	*6*	*10 months*	*8 months*
#3	*2*	*4 years 10 months*	*N/A*
#4	*3*	*1 year 7 months*	*1 year, 9 months*
#5	*9*	*5 months*	*7 months*
#6	*2*	*10 months*	*N/A*
#7	*7*	*6 months*	*10 months*

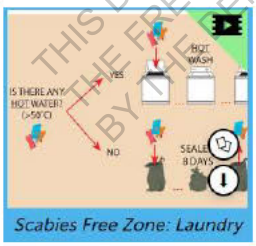
Of the 7 clients notified with a Crusted Scabies recurrence in Q3 FY22, four completed documented treatment according to hospital protocol, two were completing treatment at time of reporting, and one client did not complete treatment and has not re-presented for medical care. s47F
s47F

Further detail on the timelines for the recurrent clients above is provided in the Supplementary pages.

One Disease StoryTelling Tool in Q3 FY22 Analytics

- 123 people accessed the tool
- Most common language: English (70.3%) Other languages accessed included: Arrernte, Central Arrernte, Anindilyakwa
- Most commonly accessed pages: Men's Story, Scabies Free Laundry, Women & Babies Story, School-Aged Children, Interactive-Story Treatment

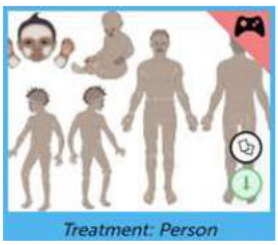

Mens Story



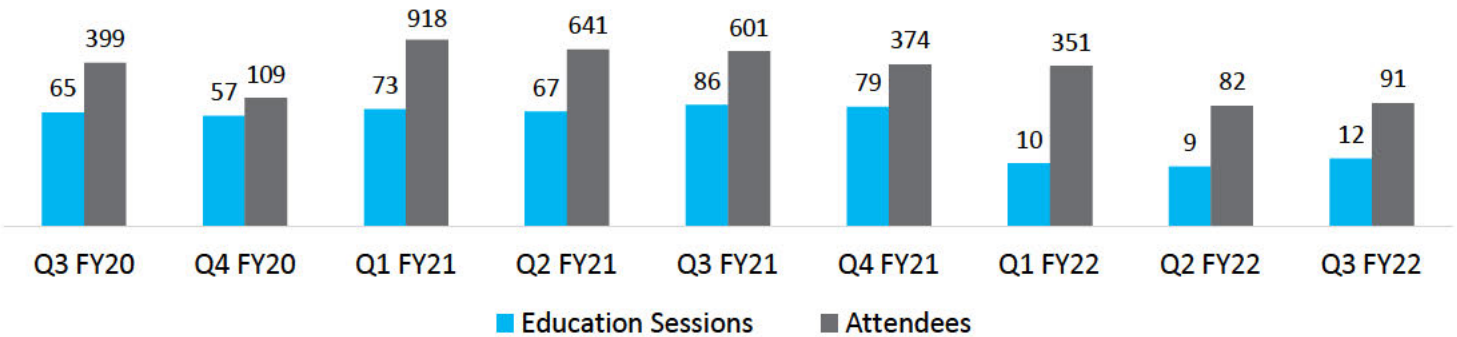
Scabies Free Zone: Laundry


Women & Babies Story


School Aged Children Story


Treatment: Person

Trends in One Disease Crusted Scabies education sessions and audiences, *n* (log²)



Note: Due to COVID-19, Q4 FY20, Q1 FY22, Q2 FY22 and Q3 FY22 found engagement with communities and services limited, with some education sessions provided remotely. Session and attendance numbers are therefore reduced.

Last modified: 8 April 2022

ONE DISEASE

ONE DISEASE

Q3 FY22 Supplementary Recurrences Timelines

Acronyms/shorthand

Took own leave **(TOL)**

Discharged against medical orders **(DAMA)**

Crusted Scabies **(CS)**, treatment **(tx)**

Katherine District Hospital **(KDH)**

Gove District Hospital **(GDH)**

Royal Darwin Hospital **(RDH)**

Tennant Creek Hospital **(TCH)**

Alice Springs Hospital **(ASH)**

Query **(?)**

Top End Health Service **(TEHS)**

Central Australia Health Service **(CAHS)**

Clinical Information System **(CIS)**

Primary Care Information System **(PCIS)**

Negative test results **(-ive)**

Positive test results **(+ive)**

Shared eHealth Record **(SeHR)**

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One Disease Program Reporting
Q4 FY22: April – June 2022

ONE DISEASE

Key Performance Indicator:

Eliminate Crusted Scabies as a public health concern in the Northern Territory by attaining a recurrence rate of Northern Territory Crusted Scabies clients less than 5% of the total cumulative cases.

Organisational Goal:

Educate and enable patient self-management to eliminate Crusted Scabies as a public health concern across Australia by 2022.

Overall Aim:

For Crusted Scabies to be easily managed within existing primary health-care systems and ultimately eliminated as a public health problem in Australia.

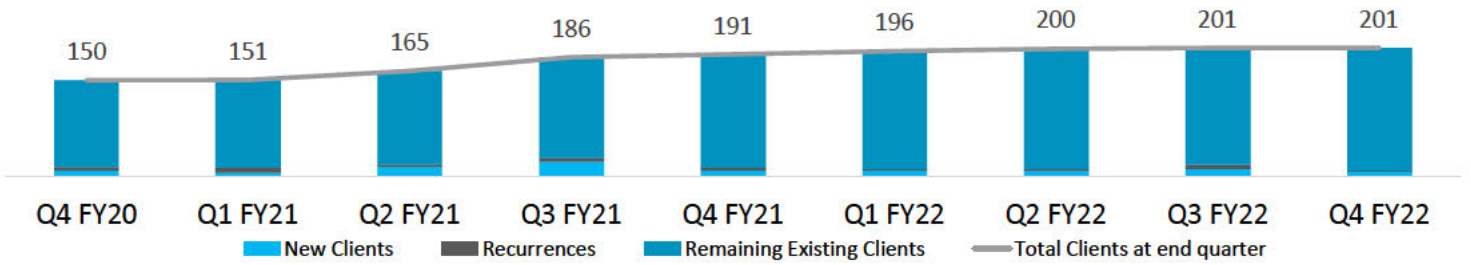
Recurrences Q4 FY22:

1.00%

2 clients of 201 (total clients at end of Q3 FY22) had a recurrence of Crusted Scabies in Q4 FY22.

In Q4 FY22, from 1 April to 30 June 2022, 9 CDC notifications were advised. Of the 9 CDC notifications attributable to Q4 FY22, 7 were new clients and 2 were recurrent clients. Two clients were notified late in Q3 FY22, which have been added retrospectively to the tables and graphs below. s47F In total, 201 unique clients were listed at Q4 FY22 end.

Trends in Northern Territory Crusted Scabies Cases Q4 FY20 – Q4 FY22



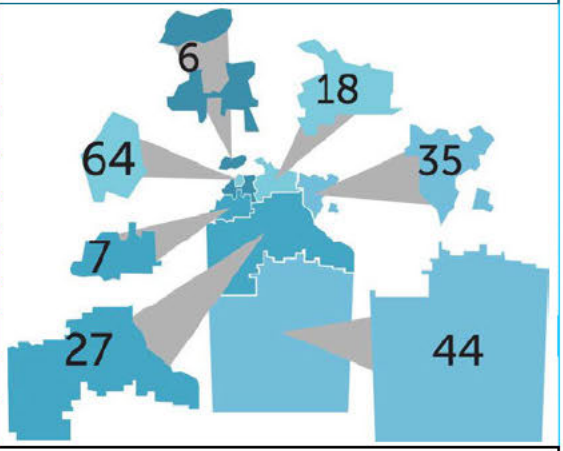
	Q4 FY20 (Apr 1 – Jun 30, 2020)	Q1 FY21 (Jul 1 – Oct 30, 2020)	Q2 FY21 (Oct 1 – Dec 31, 2020)	Q3 FY21 (Jan 1 – Mar 31, 2021)	Q4 FY21 (Apr 1 – Jun 30, 2021)	Q1 FY22 (Jul 1 – Sep 30, 2021)	Q2 FY22 (Oct 1 – Dec 31, 2021)	Q3 FY22 (Jan 1 – Mar 31 2022)	Q4 FY22 (Apr 1 – Jun 30 2022)
Total Crusted Scabies clients	*150*	*151*	*165*	*186*	*191*	*196*	*200*	*201**	*201*
CDC notifications	*14*	*15*	*18*	*28*	*13*	*12*	*11*	*18**	*9*
Recurrent Crusted Scabies clients	*5*	*8*	*4*	*5*	*4*	*2*	*3*	*7*	*2*
New Crusted Scabies clients	*9*	*5*	*14*	*23*	*9*	*9*	*8*	*11**	*7*

*These values adjusted to reflect retrospective CDC notifications

Regional Crusted Scabies Client Statistics

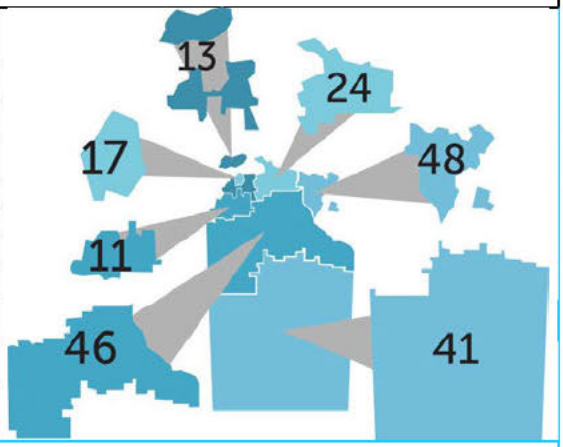
Crusted Scabies clients according to current location of residence

Region	Indigenous population, *n*	Total clients end Q4 FY22, *n*	Clients per 1000	New clients Q4 FY22, *n*	Recurrent clients Q4 FY22, *n*
East Arnhem	*10,582*	*35*	*3.31*	*1*	*1*
West Arnhem	*6,652*	*18*	*2.71*	*0*	*0*
Darwin*	*24,074*	*77*	*3.20*	*5*	*1*
Darwin Urban		*64*		*4*	*1*
Top End West		*7*		*1*	*0*
Top End Central		*6*		*0*	*0*
Katherine	*11,862*	*27*	*2.28*	*3*	*0*
Total Top End	*53,170*	*157*	*2.95*	*9*	*2*
Central‡	*21,376*	*44*	*2.06*	*0*	*0*
Total NT	*74,546*	*201*	*2.67*	*9*	*2*



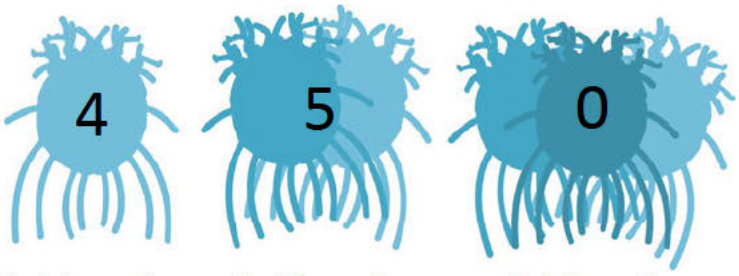
Crusted Scabies clients according to original place of residence

Region	Total clients end Q4 FY22, *n*	Clients per 1000
East Arnhem	*48*	*4.54*
West Arnhem	*24*	*3.61*
Darwin^	*41*	*1.70*
Darwin Urban	*17*	
Top End West	*11*	
Top End Central	*13*	
Katherine	*46*	*3.88*
Total Top End	*159*	*2.99*
Central‡	*41*	*1.92*
Total NT	*201*	*2.67*



^Darwin Region includes Darwin Urban, Top End West and Top End Central
‡Central Region includes Alice Springs and Barkly

Crusted Scabies clients notified in Q4 FY22 by grade:

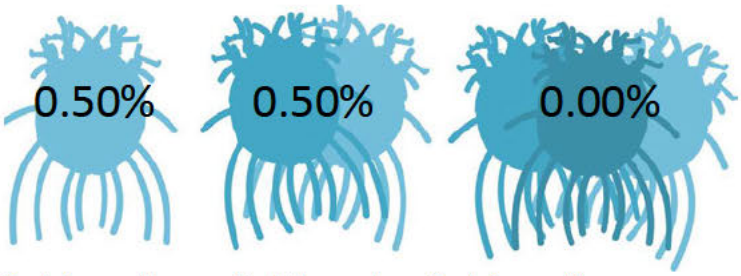


Grade 1 cases = 4
10x infectivity

Grade 2 cases = 5
100x infectivity

Grade 3 cases = 0
1000x infectivity

Crusted Scabies recurrence in Q4 FY22 by grade:



Grade 1 recur = 1
1 of 201 = 0.50%

Grade 2 recur = 1
1 of 201 = 0.50%

Grade 3 recur = 0
0 of 201

Further information on Crusted Scabies (CS) recurrences in Q4 FY22

Client	Notified cases of CS, *n*	Time since previous CS case	Previous time between CS cases (where >2 cases, average)
#1	*6*	*1 year 1 month*	*1 year 1 month*
#2	*2*	*2 years 2 months*	*NA*

Of the 2 clients with Crusted Scabies recurrences in Q4 FY22, both completed treatment in hospital with clinical resolution of scabies. s47F

s47F

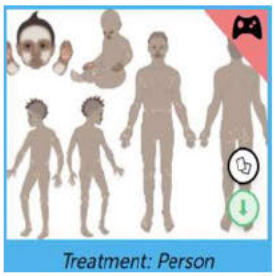
Client #2 may be considered a new episode rather than a recurrence as although their initial case was notified by CDC in 2018, retrospective review of the client's discharge summary from that episode indicate the Royal Darwin Hospital Infectious Diseases team downgraded the initial Grade 2 Crusted Scabies diagnosis to "non crusted scabies". If considering this person as a *new* client, recurrence rate for the quarter would in fact be 0.50%.

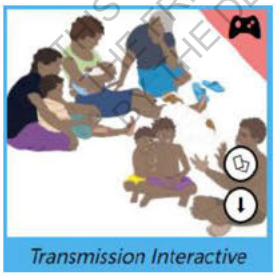
Further detail on the timelines for the recurrent clients above is provided in the Supplementary pages.

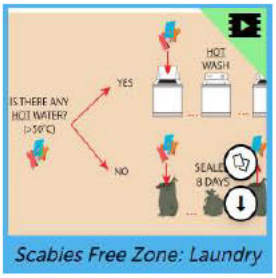
Crusted Scabies prevalence in the Northern Territory at end Q4 FY22 is 1 in 371

Utilisation of One Disease StoryTelling Tool in Q4 FY22

- 89 sessions by 80 users
- Most common language: English
- Other accessed languages: Murrinh Patha and Central Arrernte
- Most commonly accessed pages: Painting Lyclear, Scabies Transmission, Scabies Free Zone Laundry, Men's Story, Women and Children's Story


Treatment: Person


Transmission Interactive

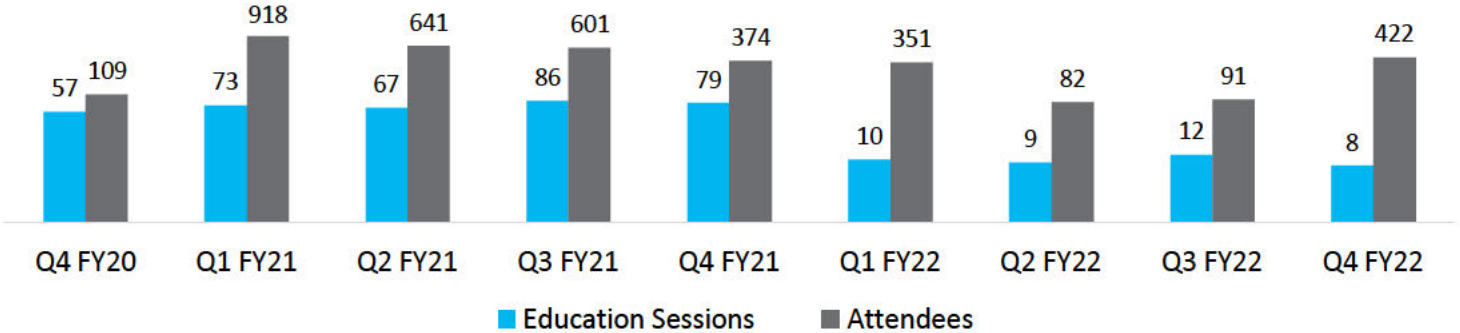


Scabies Free Zone: Laundry


Mens Story


Women & Babies Story

Trends in One Disease Crusted Scabies education sessions and audiences, *n* (log^2)



Note: Due to COVID-19 restrictions and One Disease wind-down - Q1 FY22 through Q4 FY22- found engagement with communities and services limited, with some education sessions provided remotely. Session and attendance numbers are therefore reduced.

Last modified: 18 July 2022

ONE DISEASE

ONE DISEASE

Q4 FY22 Supplementary Recurrences Timelines

Acronyms/shorthand

Took own leave **(TOL)**

Discharged against medical orders **(DAMA)**

Crusted Scabies **(CS)**, treatment **(tx)**

Katherine District Hospital **(KDH)**

Gove District Hospital **(GDH)**

Royal Darwin Hospital **(RDH)**

Tennant Creek Hospital **(TCH)**

Alice Springs Hospital **(ASH)**

Query **(?)**

Top End Health Service **(TEHS)**

Central Australia Health Service **(CAHS)**

Clinical Information System **(CIS)**

Primary Care Information System **(PCIS)**

Negative test results **(-ive)**

Positive test results **(+ive)**

Shared eHealth Record **(SeHR)**

s47F

s47F

One Disease Program Reporting
Q1 FY23: July – September 2022

ONE DISEASE

Key Performance Indicator:

Eliminate Crusted Scabies as a public health concern in the Northern Territory by attaining a recurrence rate of Northern Territory Crusted Scabies clients less than 5% of the total cumulative cases.

Organisational Goal:

Educate and enable patient self-management to eliminate Crusted Scabies as a public health concern across Australia by 2022.

Overall Aim:

For Crusted Scabies to be easily managed within existing primary health-care systems and ultimately eliminated as a public health problem in Australia.

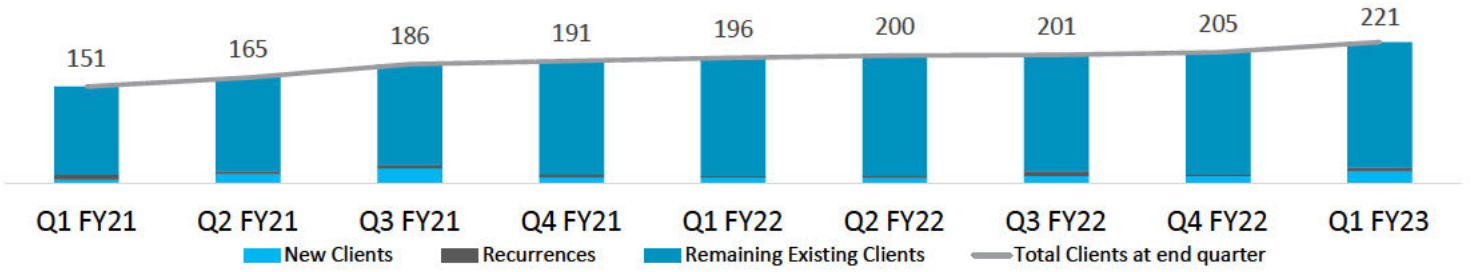
Recurrences Q1 FY23:

2.93%

6 clients of 205 (total clients at end of Q4 FY22) had a recurrence of Crusted Scabies in Q1 FY23.

In Q1 FY23, from 1 July to 30 September 2022, 28 CDC notifications were advised. Of the 24 CDC notifications attributable to Q1 FY23, 18 were new clients and 6 were recurrent clients. Four clients were notified late in Q4 FY22, which have been added retrospectively to the tables and graphs below. s47F In total, 221 unique clients were listed at Q1 FY23 end.

Trends in Northern Territory Crusted Scabies Cases Q4 FY20 – Q4 FY22



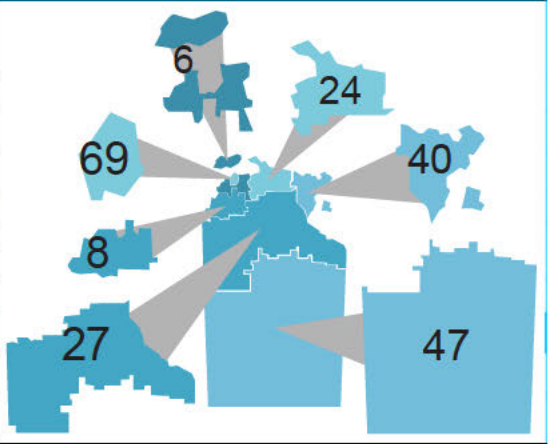
	Q1 FY21 (Jul 1 – Oct 30, 2020)	Q2 FY21 (Oct 1 – Dec 31, 2020)	Q3 FY21 (Jan 1 – Mar 31, 2021)	Q4 FY21 (Apr 1 – Jun 30, 2021)	Q1 FY22 (Jul 1 – Sep 30, 2021)	Q2 FY22 (Oct 1 – Dec 31, 2021)	Q3 FY22 (Jan 1 – Mar 31 2022)	Q4 FY22 (Apr 1 – Jun 30 2022)	Q1 FY23 (Jul 1 – Sep 30, 2022)
Total Crusted Scabies clients	*151*	*165*	*186*	*191*	*196*	*200*	*201*	*205*	*221*
CDC notifications	*15*	*18*	*28*	*13*	*12*	*11*	*18*	*13*	*24*
Recurrent Crusted Scabies clients	*8*	*4*	*5*	*4*	*2*	*3*	*7*	*2*	*6*
New Crusted Scabies clients	*5*	*14*	*23*	*9*	*9*	*8*	*11*	*11*	*18*

*These values adjusted to reflect retrospective CDC notifications

Regional Crusted Scabies Client Statistics

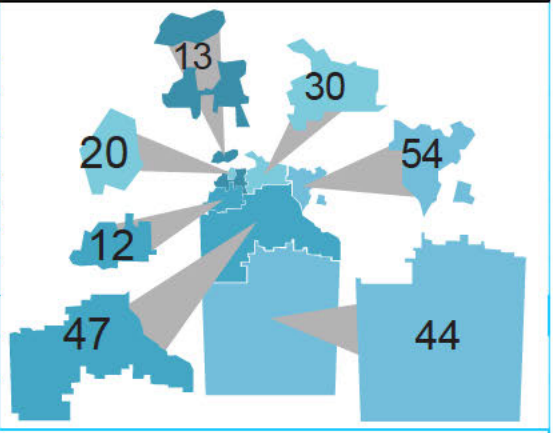
Crusted Scabies clients according to current location of residence

Region	Indigenous population, *n*	Total clients end Q1 FY23, *n*	Clients per 1000	New clients Q1 FY23, *n*	Recurrent clients Q1 FY23, *n*
East Arnhem	*10,582*	*40*	*3.78*	*4*	*2*
West Arnhem	*6,652*	*24*	*3.61*	*4*	*0*
Darwin*	*24,074*	*83*	*3.45*	*5*	*3*
Darwin Urban		*69*		*3*	*0*
Top End West		*8*		*2*	*3*
Top End Central		*6*		*0*	*0*
Katherine	*11,862*	*27*	*2.28*	*1*	*1*
Total Top End	*53,170*	*174*	*3.27*	*14*	*6*
Central‡	*21,376*	*47*	*2.20*	*4*	*0*
Total NT	*74,546*	*221*	*2.96*	*18*	*6*



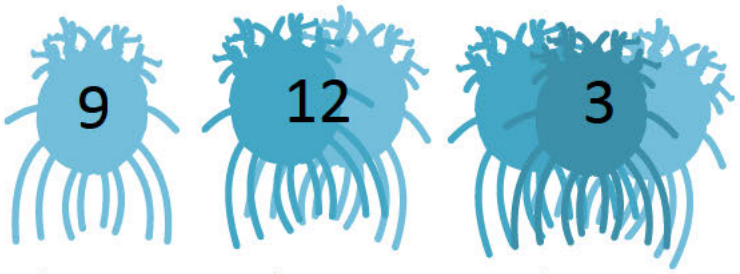
Crusted Scabies clients according to original place of residence

Region	Total clients end Q4 FY22, *n*	Clients per 1000
East Arnhem	*54*	*5.10*
West Arnhem	*30*	*4.51*
Darwin*	*45*	*1.87*
Darwin Urban	*20*	
Top End West	*12*	
Top End Central	*13*	
Katherine	*47*	*3.96*
Total Top End	*176*	*3.31*
Central‡	*44*	*2.06*
Total NT	*221*	*2.96*



*Darwin Region includes Darwin Urban, Top End West and Top End Central
‡Central Region includes Alice Springs and Barkly

Crusted Scabies clients notified in Q1 FY23 by grade:

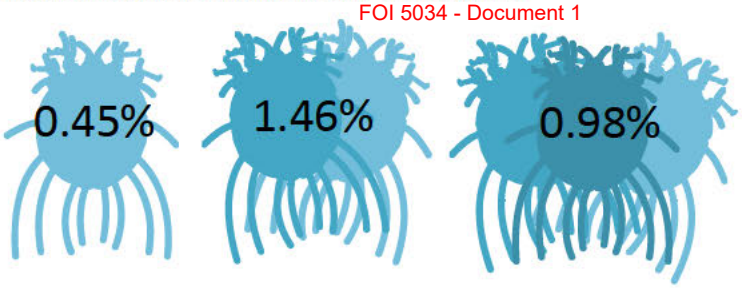


Grade 1 cases = 9
10x infectivity

Grade 2 cases = 12
100x infectivity

Grade 3 cases = 3
1000x infectivity

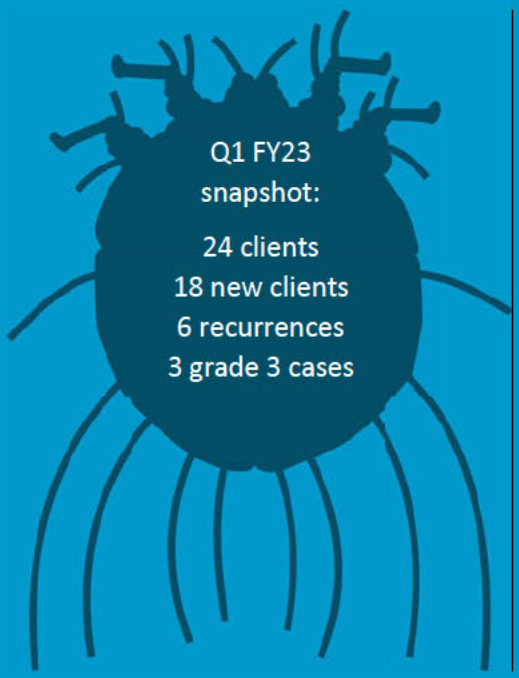
Crusted Scabies recurrence in Q1 FY23 by grade:



Grade 1 recur = 1
1 of 205 = 0.45%

Grade 2 recur = 3
3 of 205 = 1.46%

Grade 3 recur = 2
2 of 205 = 0.98%



Further information on Crusted Scabies (CS) recurrences in Q1 FY23

Client	Notified cases of CS, *n*	Time since previous CS case	Previous time between CS cases (where >2 cases, average)
#1	*2*	*5 years 4 months*	*NA*
#2	*7*	*11 months*	*12 months*
#3	*3*	*2 years 3 months*	*2 years 11 months*
#4	*2*	*4 years 1 month*	*NA*
#5	*2*	*1 year 6 months*	*NA*
#6	*2*	*5 years 6 months*	*NA*

In summary, most cases of Crusted Scabies have continued to be detected when at the lowest grades of infectivity and the recurrence rate is constantly under 5%.

Of the six clients with Crusted Scabies recurrences in Q1 FY23, two completed treatment in hospital,
s47F

Crusted Scabies prevalence in the Northern Territory at end Q1 FY23 is 1 in 337

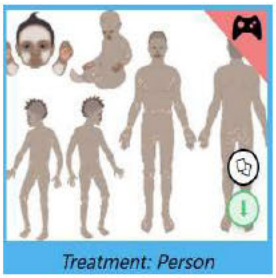
Utilisation of One Disease StoryTelling Tool in Q1 FY23

- 298 sessions by 293 users
- Most common language: English
- Other accessed languages: Wik Mungkan, Kunwinjku, Yolgnu Matha, Modern Tiwi, Warlpiri
- Most commonly accessed pages: Women & Babies Story, Mens Story, School Aged Children Story, Painting Lyclear Game, Scabies Free Bedroom


Women & Babies Story

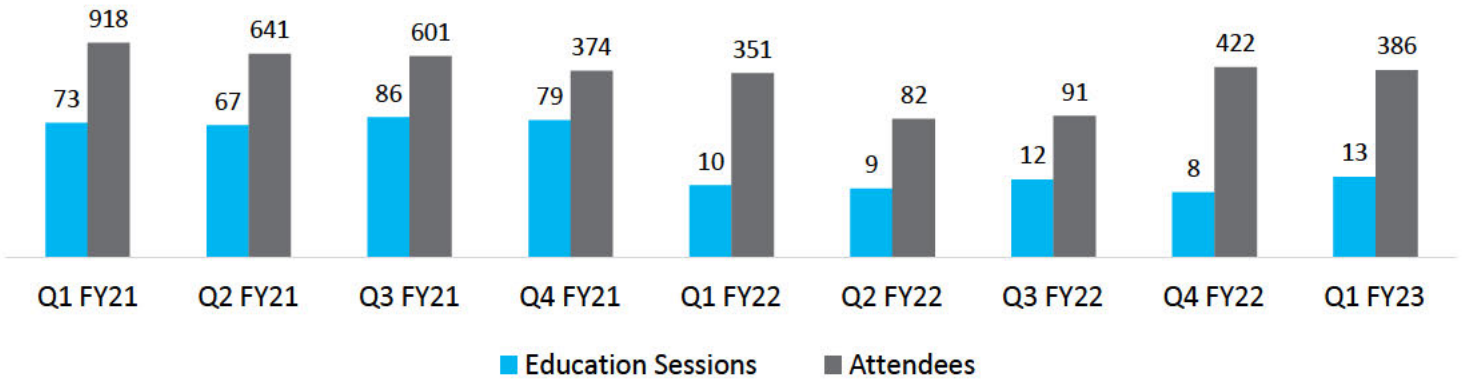

Mens Story


School Aged Children Story


Treatment: Person


Scabies Free Zone: Bedroom

Trends in One Disease Crusted Scabies education sessions and audiences, *n* ($\log^2$)



Last modified: 11 October 2022

ONE DISEASE

Q2 FY23: October– December 2022

This data was directly communicated by CDC staff – One Disease's Public Health Coordinator, who was responsible for the dashboard, left in October 22

Key Performance Indicator:

Eliminate Crusted Scabies as a public health concern in the Northern Territory by attaining a recurrence rate of Northern Territory Crusted Scabies clients less than 5% of the total cumulative cases.

Organisational Goal:

Educate and enable patient self-management to eliminate Crusted Scabies as a public health concern across Australia by 2022.

Overall Aim:

For Crusted Scabies to be easily managed within existing primary health-care systems and ultimately eliminated as a public health problem in Australia.

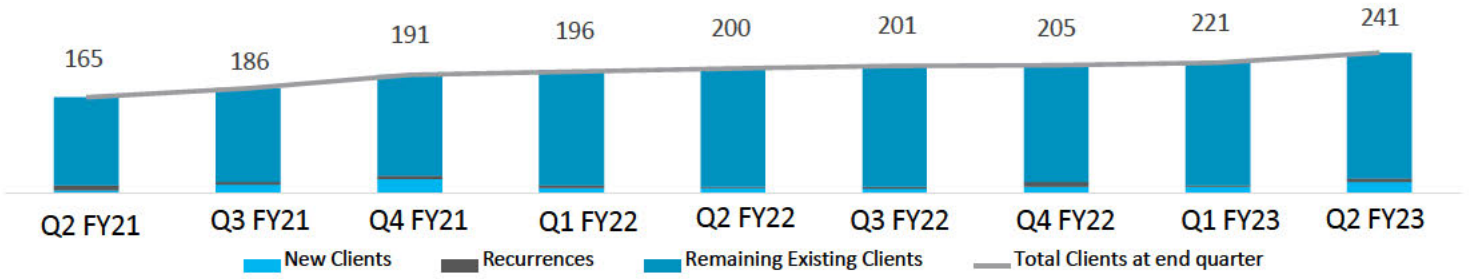
Recurrences Q2 FY23:

2.9%

7 clients of 205 (total clients at end of Q1 FY23) had a recurrence of Crusted Scabies in Q2 FY23.

In Q2 FY23, from 1 October to 22 December 2022, 20 CDC notifications were advised. Of these notifications, 13 were new clients and 7 were recurrent clients. Four clients were detected at Grade 3 level - the majority were detected when they were not as infectious - Grades 1 and 2. In total, 241 unique clients were listed at Q2 FY23 end.

Trends in Northern Territory Crusted Scabies Cases Q2 FY21 – Q2 FY23



	Q2 FY21 (Oct 1 – Dec 31, 2020)	Q3 FY21 (Jan 1 – Mar 31, 2021)	Q4 FY21 (Apr 1 – Jun 30, 2021)	Q1 FY22 (Jul 1 – Sep 30, 2021)	Q2 FY22 (Oct 1 – Dec 31, 2021)	Q3 FY22 (Jan 1 – Mar 31 2022)	Q4 FY22 (Apr 1 – Jun 30 2022)	Q1 FY23 (Jul 1 – Sep 30, 2022)	Q2 FY22 (Oct 1 - Dec 31, 2022)
Total Crusted Scabies clients	*165*	*186*	*191*	*196*	*200*	*201*	*205*	*221*	241
CDC notifications	*18*	*28*	*13*	*12*	*11*	*18*	*13*	*24*	20
Recurrent Crusted Scabies clients	*4*	*5*	*4*	*2*	*3*	*7*	*2*	*6*	7
New Crusted Scabies clients	*14*	*23*	*9*	*9*	*8*	*11*	*11*	*18*	13

*These values adjusted to reflect retrospective CDC notifications

UNSW CANBERRA

Public Service Research Group

Final Report for the *One Disease* Crusted Scabies Elimination Project

Karen Gardner and Miriam Glennie

The Public Service Research Group, Business School,

University of New South Wales Canberra

30 April 2022

Contact
Dr Karen Gardner
s47F

Acknowledgements

We would like to acknowledge *One Disease* CEO, Michelle Dowden and members of the *One Disease* team, Alessandra Superina, Meg Scolyer, Irene O'Meara, Geoffrey Angeles, Hannah Woerle, Stacey Foster, Genevieve Dodds who have provided many kinds of assistance to us in the collation of data for this report and for help in earlier evaluation with organising site visits, interviews and data collection. This work would not have been possible without them.

Citation

Gardner, K., Glennie M. Final Report for the *One Disease* Crusted Scabies Elimination Project: Public Service Research Group, Business School, University of New South Wales Canberra. April 2022

Table of Contents

i. Executive summary

This final report draws on data from our earlier evaluation (Part 1 and 2), together with program data compiled by *One Disease*, to provide an analysis of program strategies and key achievements in building system capacity for elimination of crusted scabies in the NT.

Results show that *One Disease* (OD), has achieved the legitimacy required to work in remote NT communities, and through establishing partnerships with the NT Health Department, Aboriginal Community Controlled Health Services (ACCHs) and community organisations, has worked to strengthen surveillance systems, improve treatment and follow-up and mentor novel ways of working to support individuals and communities to engage with health messages for the prevention and management of scabies and crusted scabies.

The single disease focus and deep sectoral knowledge of the *One Disease* team has enabled the program to respond quickly to changes in its environment, and to draw on and incorporate evidence from evaluation and research more broadly into new strategies. This has created an agility in implementation. While early work focused heavily on crusted scabies including on detection and provision of case management support not routinely available in the health system to individuals; subsequent work has focused on broader community education/ health promotion on scabies in an effort to reduce scabies prevalence and break the cycle of transmission between people with simple and crusted scabies.

Evidence from the 2016-18 evaluation (Gardner et.al 2018) suggests that intensive support and case management together with staff training and development of hospital treatment pathways informed by CARPA guidelines (Central Australian Rural Practitioners. Association Inc Standard Treatment Manual, 7th Edition), achieved improvements in hospital treatment completion and reductions in the number of recurrences. Audit data showed the program had also increased follow-up in the community. A cost of illness study conducted as part of the evaluation showed that for every episode of crusted scabies prevented, the health care system could expect to save $31,209.20 (Campbell et. al 2022).

Community education and engagement strategies developed in the latter stages of the program drew on novel methods for engaging communities in the production as well as consumption of health messages and services which can serve as models of participatory production. They showed widespread reach into communities. Many of these initiatives have resulted in the production of culturally relevant, local language resources focused on visual and oral communication that are utilised by remote community health services and will remain publicly available via the Australian Indigenous HealthInfoNet website.

The strategies described in this report are evidence of significant effort in building relationships between parts of the health system to increase flows of information across boundaries that have historically impeded continuity of care (hospitals and primary care and communities); raised the profile of crusted scabies and built community capacity through education to promote health seeking and to overcome normalisation of scabies amongst practitioners. Together with data provided by *One Disease* to its Board that shows reduced severity at diagnosis over time, it is reasonable to conclude that education has been a key success for *One Disease*.

Many legacy resources will continue to be available that can be embedded into service use and used by communities into the future. Mandatory notification of crusted scabies in the NT provides the framework for an ongoing focus on crusted scabies and planned Mass Drug Administration (MDA).

ii. 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
Corona Virus Disease	COVID-19
CS	Crusted Scabies
GP	General Practitioner
KPI	Key Performance Indicator
MDA	Mass Drug Administration
MOU	Memorandum of Understanding
NfP	Not-for-profit
NT	Northern Territory
OD	One Disease
PCIS	Primary Care Information System
PHC	Primary Health Care
QoL	Quality of Life

1. Final report

1.2 Overview of scope

As set out in the Evaluation Framework June 2020 (see pg 45) the intended objective of the final round of evaluation was to assess the impact of *One Disease's* multi-faceted, systems-based approach to crusted scabies elimination on patients, communities and the health system. The evaluation was to be underpinned by the World Health Organisation's framework for monitoring and evaluation for health system strengthening to consider indicators of both health system capacity (inputs, processes and outputs) and health system performance (outcomes and impacts). To understand intended and actual implementation, the evaluation planned to use an interventional implementation science approach based on Normalisation Process Theory to explore contextual influences on implementation, and consider potential sustainability into the future.

The ongoing impacts of COVID-19 on travel to remote communities in the Northern Territory and the related demands on health services, have prevented the evaluation team from collecting data required to conduct the final evaluation of the *One Disease* program, as set out in the June 2020 Evaluation framework. This means that the team has been unable to obtain audit data, nor interview, focus group or survey data that would enable an assessment of the extent of change and whether it is attributable to the program.

As a result of these insurmountable constraints, it was necessary to renegotiate the Final Evaluation Agreement. As agreed to, and subsequently set out in the Variation Agreement (29/03/2022), the evaluation team has worked to produce this report documenting key strategies implemented by *One Disease* and considering how these strategies have contributed to the development of the NT health system for people with Crusted Scabies, since the program was first implemented in 2016.

We draw on data from our earlier evaluation (Part 1 and 2), together with program data compiled by *One Disease*, to provide an analysis of program strategies and key achievements in building system capacity for elimination of crusted scabies in the NT. Where available, earlier evaluations of program impact have been drawn upon and One Disease program data have been used to consider the reach of particular initiatives. Data accessed for each of these phases is presented in Table 1 below.

Table 1: Evaluation phases and associated data collections

Evaluation phase	Data
First evaluation - impact assessment - recurrences and new cases - cost of illness - acceptability - Quality of Life pilot	• Audit of patient records • Interviews with healthcare providers • Program material (eg. Elimination plan, hospital care pathway) • Discussions with One Disease staff
Second evaluation - reach and acceptability of small grant program - case detection strategies	• Program material (e.g. small grant applications and recipients' final reports) • Summary data from survey of small grant recipients • Discussions with One Disease staff
Final summary report - overview of key strategies and reach - reach and acceptability of media strategies	• Program material (e.g. health promotion videos, hospital bedside chart) • Reach and engagement data from mass media advertising • Annual reports • Board reports • Discussions with One Disease staff

In addition to the primary objective of program evaluation, it was expected that outcomes of the evaluation may generate secondary benefits, by contributing to the evidence base on public health approaches to crusted scabies (CS) control and to guide future intervention strategies in remote Aboriginal communities in the Northern Territory (NT). Although the evaluation has not been possible in its intended form, outcomes from preliminary analysis of programme activity from the current evaluation phase, in addition to summative analysis of the *One Disease* programme across the six-year period are being used to develop the public health evidence base.

Analyses from this phase of evaluation have led to three academic papers, all of which are co-authored with *One Disease* staff. These include:

- a case study of *One Disease's* novel, highly participatory approach to health promotion via its crowdsourcing COVID-19 prevention messaging campaign (paper accepted);
- an invited editorial on the importance of considering disease stigma when planning and implementing disease mapping campaigns, using *One Disease's* community prevalence surveys to illustrate (paper under development); and
- a perspective paper on how not-for-profit (NfP) organisations can use a systems-based approach to health system change, reflecting on *One Disease's* program as a whole (paper under development).

These new, co-authored contributions to evidence are in addition to the 6 academic papers (4 published; 2 forthcoming), one book chapter and 7 conference papers produced in earlier evaluations. See Appendix 1 for a full list.

1.3 Background

Not-for-Profit (NfP) organisations make important contributions to disease control programs across the world. In settings with very limited health infrastructure, NfP organisations directly support disease control via the provision of health services such as vaccination, medication and surgical intervention. In settings with existing health infrastructure, NfPs more often support disease control indirectly, by contributing to health system capacity building via advocacy, education and partnerships (Cairncross et al 1997).

NfPs play a particularly important role in the control of neglected tropical diseases (NTDs), which mostly impact vulnerable populations that face high barriers to healthcare access. Internationally, not-for-profits working in disease control have used influencer, educator and mentoring roles to attempt to build capacity within systems for disease prevention and control, as well as to reduce disease stigma (eg. UK leprosy control organisation LEPRA). As organisations that lack formal power and a defined role in the established health system, NfPs must work to establish credibility and secure legitimacy within their contexts, at the same time preventing system dependency to ensure their impacts on the broader system can be sustained upon withdrawal.

In Australia, the NfP *One Disease*, began working with health services in the NT in 2010 to enhance regional efforts to reduce the impact of crusted scabies as a public health problem in remote communities of Arnhem Land through establishing a joint initiative with the Miwatj Aboriginal Health Corporation and the NT Government Department of Health, known as the East Arnhem Scabies Control Program (EASCP) (Lokuge et al., 2014).

From 2016 rollout of the case management approach piloted under the EASCP, together with a broader systems approach to strengthening prevention, improved detection, treatment completion, and better follow-up in the community was initiated. This culminated in the development of an Elimination Plan and coincided with the introduction of a mandatory notification system for crusted scabies in March 2016 in the Northern Territory. Mandatory notification signalled government and community buy-in, at the same time increasing opportunities for more accurate estimates of disease burden and extending resources for facilitating a sustainable treatment system (Quilty, Kaye, & Currie, 2017).

The *One Disease* Elimination plan focused on breaking the cycle of transmission and reinfection between those with crusted and simple scabies with the ultimate goal to eliminate crusted scabies from remote Australia by 2022. The Elimination plan has the following objectives:

- To improve detection and diagnosis of crusted scabies
- To prevent recurrence of crusted scabies and ensure that treated clients live in a scabies free zone
- To explore and destigmatise crusted scabies so that clients and families feel comfortable seeking care from health professionals
- To develop a sustainable model of coordinated care that can be replicated in other diseases in remote Aboriginal and Torres Strait Islander communities

The program provides the opportunity for reform in health care and also to build the evidence base for system-wide approaches to the detection, management, treatment and elimination of other NTDs.

1.4 Context of the *One Disease* program

Crusted Scabies is a hyper-infestation of the ectoparasite Sarcoptes scabiei var. hominis, the same mite that causes simple scabies. People with crusted scabies are highly infectious core transmitters of scabies, known to cause scabies outbreaks and contribute to scabies endemicity (Hassan 2020; Currie, 2015), making early detection of crusted scabies an important component of scabies control. The cycle of reinfection between people with crusted and simple scabies, underpins the proposition that the control of crusted scabies is a crucial step in addressing scabies (Engelman, 2019; Feldmeier, 2009; Worth, 2012).

In remote Aboriginal communities in the NT of Australia, scabies control programs have been implemented intermittently since the 1990s and have achieved significant short-term reductions in scabies prevalence, but such programs are complex to implement and their impacts have been difficult to sustain (Carapetis et al., 1997; Dowden 1999; Wong et al., 2001; Wong et al., 2002). Achieving treatment completion at the level of community coverage required, as well as a lack of resources for ongoing monitoring, detection and treatment, and inadequate community engagement has impeded efforts to sustain short-term benefits (Dowden 1999; Carapetis, Connors, et al 1997; Currie, Connors et al 1994; Wong, Amega et al 2002). Despite the availability of effective treatments for scabies and crusted scabies, interventions in the NT have not changed the burden of disease from scabies in 25 years (Karimkhani et.al 2015).

Risk factors for transmission in the NT include overcrowding, poor living conditions and mobility between communities. 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 of skin diseases.

Stigma and shame associated with having crusted scabies can make patients reluctant to seek care and there has not been active case detection for crusted scabies beyond contact tracing. Extended treatment periods of 3-4 weeks in a hospital isolation ward away from community is also difficult for

many patients. At the commencement of the *One Disease* program it was common for patients not to complete hospital treatment.

In addition, the high prevalence of scabies in remote communities has led to a culture of acceptance of scabies and skin sores - the so-called normalisation of skin conditions -which has led to a reluctance among providers to treat (Thomas et al., 2017)

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.

Notwithstanding these gaps in knowledge, there is widespread agreement that the priority in the control prospects for scabies is dependent on accurate definitions of target and priority populations with appropriate community-based control measures that not only treat the disease but also address the underlying social determinants of poverty (WHO, 2012).

A recent framework for scabies control proposed (1) mapping of disease burden; (2) delivery of interventions; and (3) establishing an appropriate monitoring and evaluation framework (Engelman et.al 2021). Like other studies before it, the framework notes that community engagement, human resources and training, access to medications, integration with other NTDs, safety and cost are key to success (Engelman et al., 2013; Hay et al., 2012, 2014). Government and community buy-in to these programs in the form of resources and expertise is needed.

Recent evidence from systematic review indicates that programs which incorporate effective treatments together with control measures such as health promotion, screening and environmental interventions can sustain scabies reductions; however, how the appropriate combination of strategies can be implemented and sustained remains unclear (May, Tong etal 2019).

Insights from Henderson (1987) on eradicating small pox highlighted the importance of embedding strategies within existing health services and structures, and drawing on local leaders such as teachers and village elders to mobilise community engagement. This perspective is echoed in John Hargrave's work on eliminating leprosy from remote Aboriginal communities, which was achieved in the decades following the introduction of effective multidrug therapy via active case detection and community health promotion with trained local Aboriginal health workers (Hargrave 1977).

According to May (2009) complex interventions are embedded in health service contexts when people are able to work, individually and collectively, to normalise new practices as part of people's knowledge and usual practice, and integrate them into service routines, social roles and institutional structures. Implementing complex interventions involves the broader relational work that is needed to change attitudes, improve procedures and build expertise to strengthen system capacity (May 2009).

Approaches to strengthening system capacity for disease control involve multiple interventions (education, prevention, support for treatment, community engagement) that act across multiple dimensions of the health system (individual, household, organisation, system) and target more than one intervention point at any one time. Such approaches necessarily involve a degree of tailoring or flexibility in implementation and coordinated effort with local communities, individuals and organisations, guided by evidence on the impact of strategies (Klepac 2015).

1.5 *One Disease* program implementation

Since 2016, *One Disease* has worked, at varying times, with all primary health care (PHC) NT Government clinics, 4 of 5 Aboriginal Community Controlled Health Service organisations (ACCHS) in the NT Top End, and the three public hospitals (Royal Darwin, Gove and Katherine) as well as remote communities, affected families and individuals.

Implementation is via a small team consisting of a program director, community and public health nursing and support staff, administered via a Memorandum of Understanding (MOU) between *One Disease* and the Department of Health and via Partnership agreements between *One Disease* and ACCHS. The *One Disease* /NT Health MOU commits the parties to work together in partnership to eliminate crusted scabies as a public health concern and sets out the principles and agreed actions for doing so.

Like other NfPs operating within established health settings, *One Disease* has had to establish legitimacy by defining its role and securing credibility among providers as well as implementing concrete strategies for change. The first evaluation in 2016-2018 found that *One Disease* had been widely adopted in the NT Top End by PHC services (both government and community controlled) and the two major hospitals. The first evaluation also found that the program was acceptable to stakeholders and had resulted in improved treatment and reduced recurrences (Gardner etal 2018). An early focus on education and support for hospital treatment completion was highly regarded by stakeholders interviewed as was the collaborative approach to service delivery and respectful two way learning with community. Audit data showed the program had improved treatment completion, increased follow-up in the community and indicated promising reductions in the number of recurrences. A cost of illness study conducted as part of the evaluation showed that for every episode of crusted scabies prevented, the health care system could expect to save $31,209.20 (Campbell et. al 2022).

Despite these successes, however, the evaluation also concluded there are significant challenges in moving towards elimination of crusted scabies in remote Aboriginal and Torres Strait Islander communities when scabies remains endemic. Household overcrowding is a significant impediment in communities with high prevalence of simple scabies, as treated crusted scabies individuals easily become re-infected. 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, elimination of crusted scabies will be difficult.

Since the first evaluation reported in July 2018, the *One Disease* program has continued to grow, adapting to changes in the contextual environment and responding to emerging evidence to implement new strategies across the health care system in pursuit of elimination. In particular a strong focus on working with communities to develop novel strategies to engage individuals in prevention and improve their knowledge of crusted scabies and its treatment; as well as to mobilise community interest in participating in MDA when scabies prevalence rises above 10% prevalence. Table 2 below sets out the key strategies *One Disease* has implemented over the life of the program to achieve its goals and to contribute to strengthening the public health notification and treatment systems.

Table 2: Strategies contributing to the public health notification (surveillance; test; trace; scabies free household) and service delivery systems for detection; prevention; treatment; follow-up.

System	One Disease strategy	Activities	Achievements	Actors and sectors involved
Surveillance	Improve state level data capture on crusted scabies patients	Partner with the Centre for Disease Control to develop a set of items for enhanced data capture; support development of IT database for enhanced data capture and management	Enhanced data capture system available for input and data management	Government
	Increase community level surveillance capability	Community-based, house-to-house sampling of scabies prevalence in community to determine when Mass Drug Administrations for scabies should be undertaken	2 community wide surveys (Maningrida and Galiwin'ku) 1 planned follow-up MDA (late-April, Maningrida)	Primary healthcare Aboriginal health workers
	Increase household level knowledge about scabies	SCAN app	Developed and piloted a mobile app enabling individuals to access information about skin health including scabies infections, and provides indications when a clinical skin check should be sought. A request has been received from practitioners at the Telethon Institute in the Kimberley to use the scan app in remote communities in WA.	Community
	Improve understanding of the impact of crusted scabies on quality of life	Develop a picture based survey tool for evaluating quality of life for Aboriginal people with Crusted Scabies drawing on existing QoL and dermatological scales	Developed and piloted a world-first tool, administered through a conversation technique.	
Prevention	Increase community knowledge, awareness and motivation for scabies prevention	Mass media information and education campaigns	*Scabies awareness campaign* Ads reached 98,176 Facebook users	Community

			TV, Radio, Bus ads also reached large numbers of communities *COVID-19 prevention campaign* Ads reached 91,295 Facebook users	
	Increase communication capability in primary healthcare and Aboriginal health workforce	Develop and tested storytelling tool to support skin workers to tell the story of scabies	iPads with storytelling tool distributed to Aboriginal health workers in one large remote community. Published on OD website with 16 website views	
	Increase health workforce capability in diagnosis and treatment of crusted scabies	Education and outreach sessions, including formal workshops and instruction, and informal education and information sessions	2021: 305 Education Sessions reaching more than 2500 attendees 2020: 212 Education Sessions reaching more than 2205 attendees 2019: 250 Education Sessions reaching more than 2400 attendees 2018: not reported 2017: 121 Education Sessions reaching more than 1570 attendees	Primary healthcare Hospitals Community organisations
	Increase health workers knowledge of scabies and crusted scabies	Developed skin health e-learning modules for inclusion in AHW training	Module published on Remote Area Health Corps website.	Registered training organisations
	Increase community knowledge about scabies prevention	Award of small grants to community and/or health organisations to conduct a local Scabies Free Zones project	38 community level scabies prevention projects completed	Primary healthcare Community organisations
Treatment	Improve information capture and patient management during hospital treatment	Developed and supported trial of hospital bedside care chart	Developed and trialled hospital bedside chart, received approval from form committee; possible implementation May-June 2022	Hospitals
	Increase hospital treatment completion	Supporting people with CS to attend	Increase in hospital treatment completion	Hospitals

		hospital and complete treatment through visits, liaison with family members and general support		Patients and their families
	Increase community knowledge about scabies treatment	Develop local language health promotion videos in partnership with community members about two doses of Lyclear cream at 7 day interval	Distributed scabies treatment information campaigns via multiple mass media outlets (e.g. Facebook, TV, Radio) Provided scabies treatment education to households, community groups and clinic staff	Community
	Secure government funding for Ivermectin as a first line treatment for scabies	Advocate for Ivermectin as a first-line treatment for Aboriginal and Torres Strait Islanders via submission to Pharmaceutical Benefits Scheme	Successful in supporting change in Pharmaceutical Benefits Scheme funding	Government
Follow-up	Improve patient follow-up following hospital discharge	Electronic care plans		Primary healthcare

Surveillance

Case detection

The first evaluation (Gardner et al 2018) of the *One Disease* elimination program illustrated the strategies to-date for improving the detection and diagnosis of crusted scabies (Goal 1 in Elimination Plan) had largely been implemented as expected. *One Disease* supported improvement in diagnosis through involvement in developing the CARPA guidelines, which cover scabies and crusted scabies. In 2016, crusted scabies was made a notifiable disease in the Northern Territory (NT), which aims to improves detection, diagnosis and surveillance through a formalised disease definition, contact tracing and the registration of case data. To support improvement in detection, *One Disease* worked with the Centre for Disease Control (CDC) to develop an implementation model for contact tracing by local primary care health services, and entered a data sharing agreement that allows *One Disease* access to the CDC's crusted scabies disease register. OD has also worked together with CDC to develop a set of items for enhanced data capture and supported development of IT database for enhanced data capture and management

The introduction of contact tracing marks the first systematic use of active case finding for crusted scabies in the NT. Counter to passive case detection which relies on patient self-reporting, active case finding identifies patients in their homes or communities who had not self-reported to health services. Further improvement in case detection for crusted scabies is hampered by the lack of evidence about best practice.

To gauge alignment of *One Disease's* strategies with best practice in case finding, and enable program planning, a systematic review of active case finding for crusted scabies and leprosy was conducted. Leprosy shares many commonalities with crusted scabies, as another stigmatised, communicable, skin-related neglected tropical disease. Leprosy remains endemic in many regions around the world, and is the subject of frequent active case finding campaigns that are examined in academic research. Although now rare in Australia, leprosy had been endemic in remote Aboriginal communities in the 1950s-70s and active case finding involving Aboriginal health workers played an important role in disease elimination.

The systematic review sought to identify effective active case finding techniques for leprosy, and to discuss how the findings can be informative for active case detection of crusted scabies. In particular, it sought to investigate how active case finding campaign type and personnel influence detection rates, and the cost effectiveness of different active case finding methods. The systematic review, which has now been published (Glennie et al 2021), identified 15 studies that met the inclusion criteria; all examine leprosy detection in developing countries. Study heterogeneity precluded meta-analysis and no generalisable conclusions could be drawn about cost effectiveness or the comparative effectiveness of campaign designs.

It is difficult to assess the transferability of findings to crusted scabies in the Australian context given differences in setting and disease. However, the findings suggest that both contact tracing and community wide surveys are likely to find crusted scabies cases missed by passive case detection in endemic and/or highly marginalised communities, such as remote Aboriginal communities. This reinforces *One Disease's* focus on enabling contact tracing for crusted scabies. The effectiveness of any active case finding campaign would be impacted by the skill levels of screeners and their acceptability to community members. *One Disease* has recognised this necessity, and has supported capacity building in crusted scabies diagnosis, and engaging local Aboriginal health workers in contact tracing.

Improved data collection

Data capture is an essential component of public health surveillance systems, required to map the distribution of disease, understand the needs of affected populations and inform control activities.

- *One Disease* has partnered with the Centre for Disease Control to develop a set of items for enhanced data capture and supported development of IT database for enhanced data capture and management

- It has piloted a picture based survey to gather data on quality of life for people with CS. QoL is needed for assessing cost effectiveness which is a key component of scabies control frameworks (publication forthcoming)

- OD developed a survey and method for house to house sampling of scabies prevalence. A survey and method for house-to-house sampling of scabies prevalence in communities has also been developed and piloted in two communities. Results will help to determine when Mass Drug Administrations for scabies should be undertaken (>10% prevalence). An important and novel aspect of this work is its focus on empowering communities to engage with monitoring activities through better understanding of concepts and rationale. Together with education on scabies, crusted scabies and its treatment, these activities facilitate a greater understanding of transmission and build community and individual level confidence that cure is possible. At the individual level, this can be expected to stimulate uptake of testing and adherence to treatment, and at the community level reduced stigma.

Prevention

Health promotion strategies need to address community level knowledge and direct action toward addressing participants across distributed households and fluid dwelling occupancies to interrupt the transmission of neglected tropical diseases (Chisholm, Crammond et al. 2020). Direct community level engagement and education has been a core focus of *One Disease's* work. In both the first and second evaluations, *One Disease* was lauded for its participatory approach to health promotion. The organisation has implemented novel methods of community involvement in health communication that serve as models of participatory production; many of these initiatives have resulted in the production of culturally relevant, local language resources focused on visual and oral communication that are utilised by remote community health services and will remain publicly available via the Australian Indigenous HealthInfoNet website; for example:

- An online story telling tool available for healthcare workers to use with clients in information and education about scabies prevention and treatment.
- The Skin Checks Across the North (SCAN) App for Aboriginal and Torres Strait Islander people living in the Northern Territory, Western Australia and Queensland. The app helps users to better understand the current condition of their skin and encourages a visit to the clinic. It is available in English and Yolngu Matha, allowing Yolngu people to access the app in their own language. A request has been received from practitioners at the Telethon Institute in Western Australia to use the scan app in remote communities in the Kimberly.
- Educational Video 'Walking Together Working Together' in which people working across Kakadu and Arnhem Land share their perspectives on working collaboratively to improve health outcomes in their communities.

Additional models of participatory production include the small grant programme implemented to support local community involvement in the promotion of scabies free zones and a crowdsourcing campaign to support the production of local language COVID-19 prevention messages.

Small grants program

In 2018, *One Disease* established a small grants program to improve the engagement of local health and community workers in the promotion of scabies free zones. The program is part of the organisation's overarching strategy to improve local systems for crusted scabies prevention, support workforce capacity building, and is in line with a community development approach to health promotion.

The small grants program had a positive impact on engaging local health and community health workers in the promotion of scabies free zones. The program attracted applicants from a range of sectors and service categories, including primary healthcare, women's groups, general services Aboriginal corporations, childcare providers and an arts collective. Under the program, 38 grants were awarded to 28 providers across QLD, WA and the NT.

All grant recipients were to required attend a *One Disease* Healthy Skin Symposium and small grants workshops. Participation in these sessions improved the knowledge, confidence and motivation of recipients to engage in community action on scabies free zones. A total of 82% of providers (n=23) were able to successfully complete their projects. The health promotion activities funded through these grant projects include hygiene infrastructure and supplies, information sessions, the production and distribution of health promotion materials, hygiene education and activities, scabies treatment and skin checks. Collectively, these activities reached hundreds of individuals in over 40 Aboriginal and Torres Strait Islander communities across three states.

The findings demonstrate the positive impact of the small grants program on workforce engagement and stimulating community action. However, the results must be interpreted with caution given the small sample size, bias towards completed projects and context of lower than anticipated community uptake of the grant opportunity.

Crowdsourcing health messages

Health communication is a critical component of pandemic mitigation, but mainstream prevention messaging often lacks social, cultural and linguistic relevance to vulnerable populations. *One Disease* implemented a novel, highly participatory pandemic prevention communication campaign that engaged individuals in remote Aboriginal communities of the NT directly in prevention messaging via crowdsourcing, and distributed videos to remote area post-codes via targeted Facebook advertising. Facebook metrics, administrative campaign data and national statistics were used to assess campaign reach and engagement. The campaign illustrates how seeking unscripted COVID-19 prevention video messaging can support community ownership of pandemic messaging, rapid content generation, and a high level of Facebook user engagement. It also shows the effectiveness of targeting remote area post-codes via Facebook advertising both to reach the target audience, and to support quality improvement assessments to inform health communication decision-making in a low resource setting.

Treatment

Little is known about optimal strategies for supporting treatment completion or the efficacy of strategies for reducing recurrences of crusted scabies. Some investigations into factors supporting treatment completion in the case of other diseases such as tuberculosis and leprosy that also occur in resource poor communities and have demanding treatment regimes have shown a focus on addressing patient risk factors such as homelessness (Gomez et al 2019) as well as risk factors related to the provision of care itself, including variations in the way patients are managed by doctors (Pepito 2021) and whether or not social care is provided alongside treatment (Izzard 2021).

One Disease has taken a multi-pronged approach to supporting improved knowledge of treatment and treatment completion which were a key focus of the program during its first two years. Strategies have included targeting support and education to individuals and families, as well as working with clinical stakeholders and organisations on their procedures and care pathways to align with CARPA guidelines and to advocate in the policy arena. The different strategies shown below aimed to change the knowledge and expertise of stakeholders and to embed new practices into service pathways and to policy. Examples include:

- Supporting people with crusted scabies to attend hospital and complete treatment by providing visits, liaison with family members and general support.
- Developed and supported trial of hospital bedside care chart that aligned with CARPA. This was conducted in partnership with hospital staff and implemented through monthly meetings where issues and barriers could be identified, discussed and resolved.
- Local language health promotion videos were developed in partnership with community members about two doses of lyclear cream at 7 day interval.
- Advocate for Ivermectin as a first-line treatment for Aboriginal and Torres Strait Islanders via submission to Pharmaceutical Benefits Scheme

Follow-up

PHC electronic care plans for crusted scabies were developed and implemented into Clinical Information Systems (CIS) in both NT Health and ACCH CIS. At the time interviews were conducted for the first

evaluation 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 crusted scabies recall completed. Training on crusted scabies 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 *One Disease*, CDC, hospital and PHC centres were developing under the new arrangements, both *One Disease* and CDC notification processes.

1.6 Implementation challenges

Implementation will always be subject to multiple challenges that influence service capacity and readiness to engage with new initiatives. Workforce turnover and staff shortages, geographical remoteness and high levels of disease burden are known challenges that place great demands on services in remote communities. The first evaluation found that *One Disease* staff had a deep knowledge of the NT health sector which enabled them to engage and work successfully with many providers to influence change in practices. Over time this knowledge and experience has also enabled *One Disease* to tailor implementation strategies and to coordinate effort at different times to target different audiences.

This has been important in the face of additional challenges posed by the onset of COVID-19 in 2020 to the operation of health services. Community closures and limits on travel to remote communities also meant that *One Disease* staff could not carry out many of its planned activities over an extended period in 2020-21. This led to an enhanced focus on working directly with communities during this period to develop online resources that could be used by community members and health centre staff and through developing novel strategies such as crowdsourcing to engage communities in developing their own health messages (details above). Not only has this focus resulted in the production of many resources that will be available following the completion of *One Disease* program, it has also facilitated novel methods for engaging communities in production as well as consumption of health messages and services, that can be a model for future practice.

1.7 Conclusions

COVID-19 related delays and restrictions on travel to communities has prevented the collection of data for a final evaluation as originally planned, to assess the *impact* of the program on the health system, communities and individuals.

This short report, drawing on data from earlier evaluation and reports from *One Disease,* shows that the organisation has achieved the legitimacy required to work in remote NT communities, and through establishing partnerships with the NT Health Department, ACCHs and community organisations, has worked to strengthen surveillance systems, improve treatment and follow-up and mentor novel ways of working to support individuals and communities to engage with health messages for the prevention and management of scabies and crusted scabies.

The single disease focus and deep sectoral knowledge of the *One Disease* team has enabled the program to respond quickly to changes in its environment, and to evidence from evaluation and research more broadly. This has created an agility in implementation. While early work focused heavily on crusted scabies including on detection and provision of case management support not routinely available in the health system to individuals; subsequent work has focused on broader community education and health promotion on scabies in an effort to reduce scabies prevalence and break the cycle of transmission between people with simple and crusted scabies.

Evidence from the first evaluation (2016-18) suggests that intensive support and case management together with staff training and development of CARPA informed hospital treatment pathways, achieved improvements in hospital treatment completion and led to reductions in recurrences. Audit

data showed there were also greater levels of follow-up in the community. Program data on community education and engagement strategies in the latter stages of the program show widespread reach into communities.

The strategies described in this report are evidence of significant effort in building relationships between parts of the health system to increase flows of information across boundaries that have historically impeded continuity of care (hospitals and primary care and communities); raised the profile of scabies and built community capacity through education to promote health seeking and to overcome normalisation of scabies and skin conditions amongst practitioners. Together with data provided by *One Disease* to its Board that shows reduced severity at diagnosis over time, it is reasonable to conclude that education has been a key success for *One Disease*.

Many legacy resources will continue to be available that can be embedded into service use and used by communities into the future. Mandatory notification of crusted scabies in the NT provides the framework for an ongoing focus on crusted scabies and planned MDA.

1.8 References

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1.9 Appendix 1 Project publications

Peer reviewed journal articles

Glennie M, Dowden M, Grose M, Scolyer M, Superina A, Gardner K. (2022) Engaging remote Aboriginal communities in COVID-19 public health messaging via crowdsourcing. *Frontiers in Public Health* 2022 E**rror! Hyperlink reference not valid.**doi.org/10.3389/fpubh.2022.866134

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Glennie M, Gardner K, Dowden M, Currie BJ (2021) Active case detection methods for crusted scabies and leprosy: A systematic review. PLoS Negl Trop Dis 15(7): e0009577.

Van der Linden N, van Gool K, Gardner K, Dickinson H, Dowden M, Regan D, Viney R.(2019) Modelling scabies: a systematic review to inform the design of a transmission model for evaluating the cost-effectiveness of scabies interventions*, PLoS Neglected Tropical Diseases*

Forthcoming

Van der Linden N, van Gool K, Gardner K, Lawripa, Woerle H, O'Meara I, Scolyer M, Dowden M, Regan D, Viney R. Measuring health-related quality of life in Aboriginal and Torres Strait Islander Australians with Crusted Scabies: a pilot project (Under development)

Agostino J, van Gool K, Campbell M, Dickinson H, Glennie M, Dowden M, Gardner K Impact of a Crusted Scabies elimination program in the NT Australia (Under development)

New

an invited editorial on the importance of considering disease stigma when planning and implementing disease mapping campaigns, using *One Disease's* community prevalence surveys to illustrate (paper under development)

a perspective paper on how not-for-profit (NfP) organisations can use a systems-based approach to health system change, reflecting on *One Disease's* program as a whole (paper under development).

Book Chapter

Dickinson H; Gardner K; Dowden M; Van der Linden N. 2020, 'Driving Change Across Boundaries: Eliminating Crusted Scabies in Northern Territory, Australia', in Nugus P (ed.), Transitions and Boundaries in the Coordination and Reform of Health Services Building Knowledge, Strategy and Leadership, Springer Nature

Reports

Gardner, K., Glennie M. Final Report for the *One Disease* Crusted Scabies Elimination Project: Public Service Research Group, Business School, University of New South Wales Canberra. April 2022

Gardner K, Glennie M. *Part 2 Evaluation: One Disease, Crusted Scabies Elimination Program*, University of New South Wales Canberra. July, 2020

Gardner K, Van Gool K, Agostino J, Renehan C, Van der Linden N, Viney R, Dickinson H. *Evaluation of the One Disease, Crusted Scabies Elimination Program*, University of New South Wales. August, 2018

Conference presentations

Gardner K. Improving systems for eliminating crusted scabies in Indigenous communities in the Northern Territory Australia. CHARM Conference August 2021 Canberra.

Dowden M, Scolyer M, Superina A, Grose M, Glennie M, Gardner K Crowdsourcing for local language, video-based COVID-19 prevention messaging to remote Aboriginal communities PHAA 2020

Campbell M, van Gool K, van der Linden N, Gardner K, Dowden M, O'Meara I, Woerle H, Scolyer M, and Viney R. A cost of illness model for crusted scabies in indigenous communities in the Northern Territory. Paper presented to HSRAANZ 4-6 December 2019 Auckland NZ.

van der Linden N, Van Gool K, M, Campbell M, Mulhern B, Viney R, Gardner K Woerle H,, O'Meara I, Dowden M. Assessing the impact of crusted scabies on quality of life in Indigenous communities in the Northern Territory: a pilot study. HSRAANZ Forum – the Pros and Cons of PROMs and PREMs. Sydney University 26 Nov 2018.

Dowden M, Gardner K, O'Meara I, Scolyer M, Woerle H, Agostino J, Van Gool K, Van der Linden N, Renehan C, Campbell M, Dickinson H Eliminating crusted scabies in Northern Territory: a systems based quality improvement approach PHCRIS Conference, Melbourne 2018

Dickinson H, Gardner K, Dowden M, ,Woerle H, Colyer M, O'Meara I. Driving change across boundaries: Eliminating crusted scabies in Northern Territory, Australia OBHCE Conference, Canada June 2018

Dowden M, Scoyler M, Omeara M, Woerle H, Gardner K. Eliminating crusted scabies in remote communities in Australia: a systems based quality improvement approach. HSRAANZ 2017

UNSW CANBERRA

Public Service Research Group

UTS

2. Evaluation of the One Disease Crusted Scabies Elimination Project: First report

The Public Service Research Group, Business School, University of New South Wales Canberra The Centre for Health Economics Research and Evaluation, University of Technology Sydney The Medical School, The Australian National University, Canberra

August 2018

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Acknowledgements
Many people have contributed to this report. In addition to those named as authors, others who have made particular contributions include:

- Michelle Dowden who linked the Evaluation team to essential contacts and resources in the NT
- Irene O'Meara, Meg Scolyer and Hannah Woerle who helped to organise site visits and interviews for the Evaluation team and undertook collection of patient level data, in addition to their normal workloads and within tight timeframes.
- Laura Thomas who conducted some literature review work for the evaluation

Thanks to the staff in participating services, who gave generously of their time for interviews and patients who answered quality of life questions, without whom this project would not have been possible.

Citation
Gardner, K., Van Gool, K., Van Der Linden N., Agostino J., Campbell M., Dickinson H., Renehan C., Viney R. Evaluation of the One Disease Crusted Scabies Elimination Project: Public Service Research Group, Business School, University of New South Wales Canberra. June 2018

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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2.1 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.

2.2 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.

2.3 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.

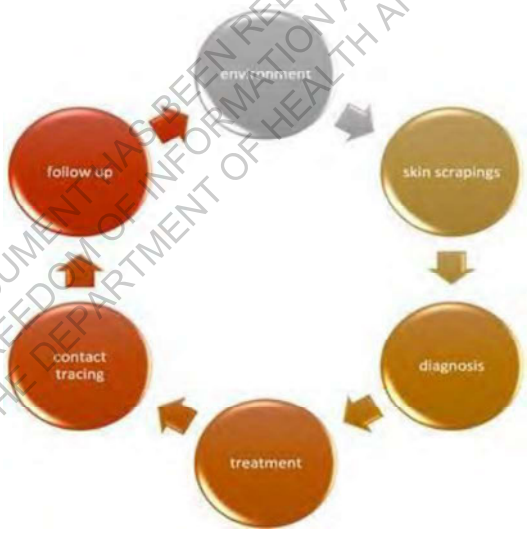
While this evaluation does not address the issue of elimination, it aims to contribute insights into program implementation, impact and cost in order to inform future efforts in the roll-out of the program to WA and QLD, and these could be expected to underpin future work that will be required to inform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

2.4 *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.

2.5 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

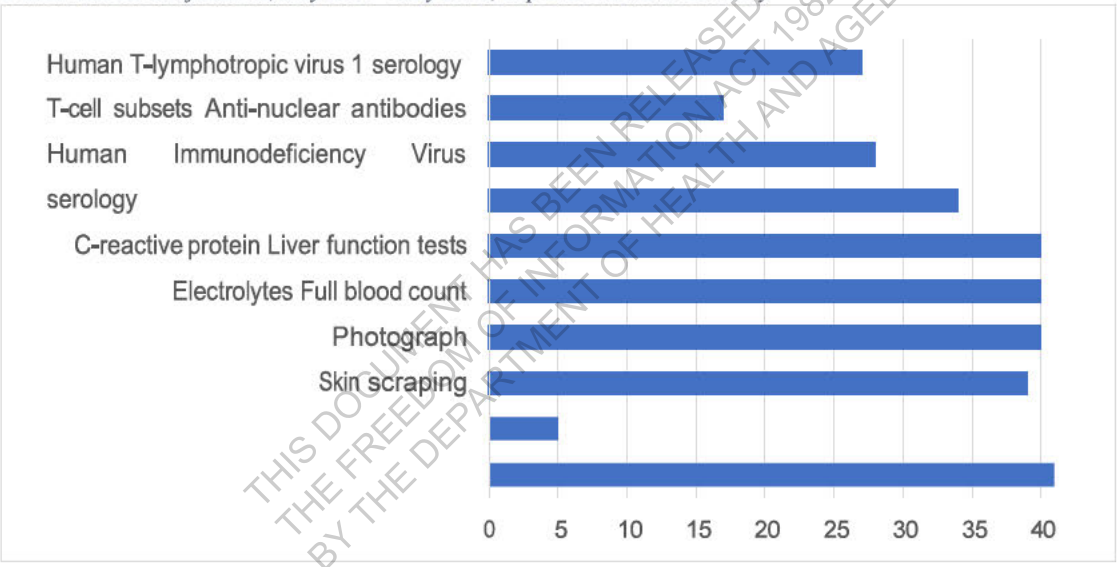
Category of homelessness	n	%
Not homeless	21	50
Improvised dwelling	6	14
Temporary with others	5	12
Boarding house	7	17
Other temporary lodging	3	7

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.

2.6 Cost-of-illness

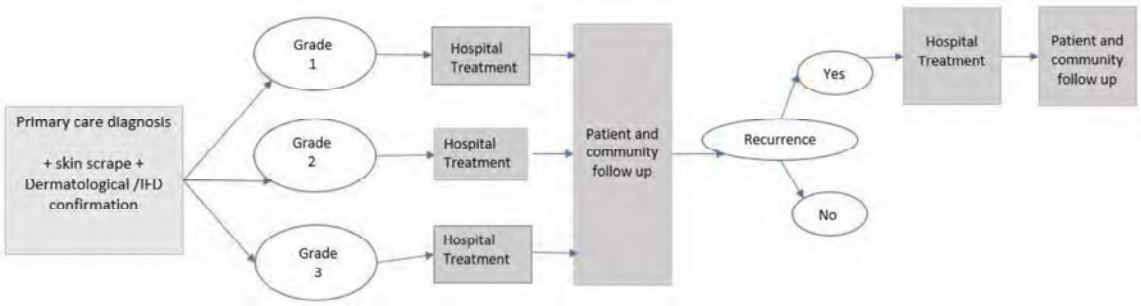
The aim of this section is to provide estimates of the annual costs associated with managing and treating CS. We developed a cost-of-illness (COI) model that calculates the expected average cost of treating one patient diagnosed with CS over a one-year period. This expected cost is then multiplied by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

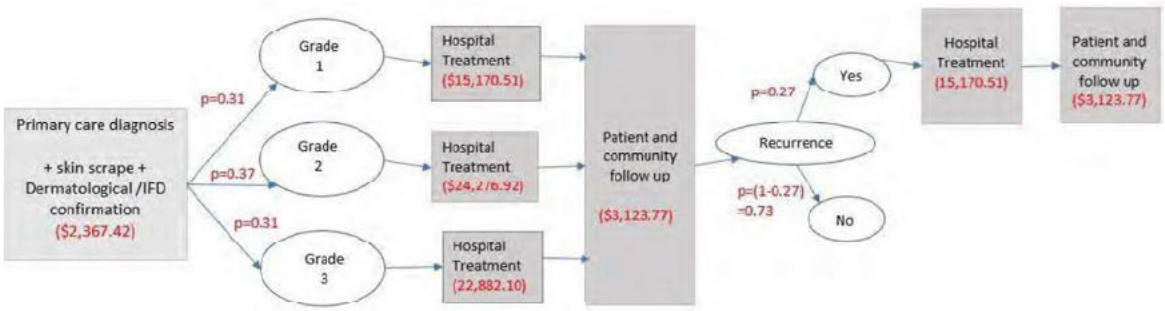
Table 19 indicates that the highest average cost per patient is associated with the hospital treatment phase which also varies across crusted scabies grade, with Grades 2 and 3 being the higher average cost per patient ($24,276.92 and $22,882.10, respectively) and Grade 1 the lowest ($15,170.51). There 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.

2.7 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.

Health Care

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.

One Disease

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.

Response

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.

Health care

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

One Disease

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.

2.8 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.

2.9 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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3. Phase 2 Report on the Crusted Scabies Elimination Program

Prepared for One Disease

June 2020

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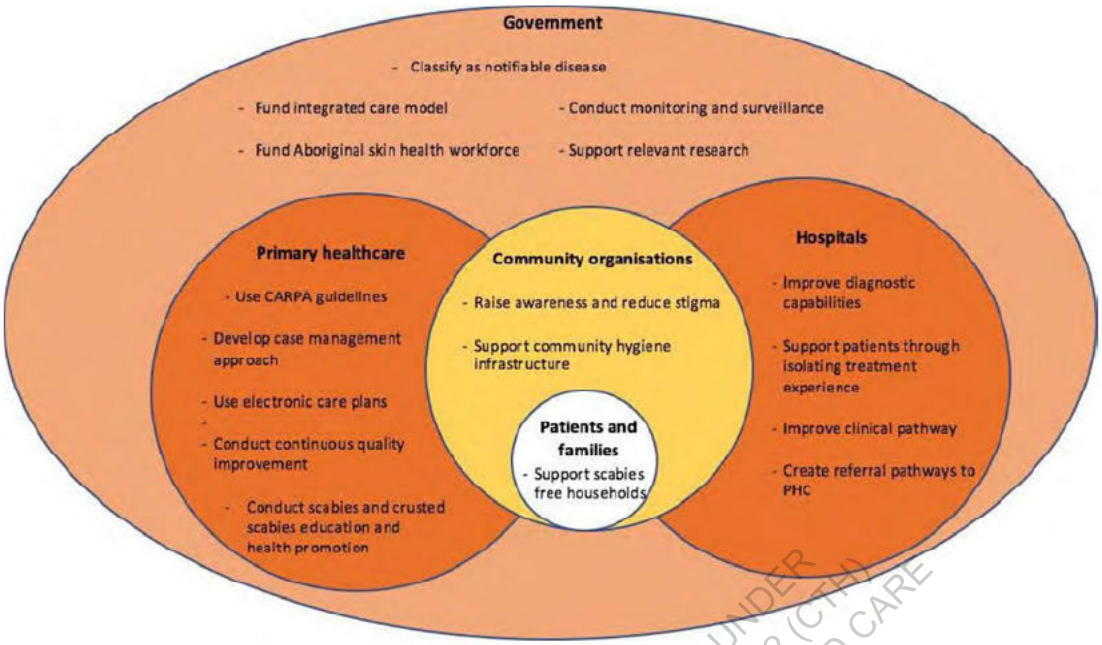
3.1 Introduction

This report presents work conducted as part of the second phase of evaluation of the One Disease Crusted Scabies Elimination Project. Phase 2 of the evaluation as originally planned required adjustment in response to the emergence of restraints on data collection caused by the COVID-19 pandemic. As a result four key areas of work were requested from the Evaluation team to assist One Disease in the development of program strategies leading into the final part of the program.

- A systems map outlining key elements of an integrated approach to the prevention and control of crusted scabies
- Systematic review on case finding
- Review of the educational grant program activities
- Evaluation framework for the final phase evaluation of the CS Elimination program

3.2 Integrated approach to prevention and control of crusted scabies



Government
- Classify as a notifiable disease to support standardised disease definition and surveillance
- Fund integrated care model to ensure continuity of care is provided across disease lifecourse
- Conduct monitoring and surveillance to track transmission and prevalence
- Fund Aboriginal skin health workforce to support local diagnosis, treatment and prevention
- Support relevant research to advance knowledge of best practice

Hospitals
- Support patients through treatment to reduce feelings of isolation and increase treatment completion
- Establish clinical pathway to facilitate care and discharge to the community
- Create referral pathways to PHC to ensure ongoing patient care

Primary healthcare
- Use CARPA guidelines to follow best practice
- Improve diagnostic capabilities to ensure accurate diagnosis
- Develop case management approach to ensure routine treatment and support for patients
- Use electronic care plans to enable timely follow-up
- Conduct continuous quality improvement to capture accurate data and promote improvement in delivery of care in accordance with CARPA guidelines
- Conduct scabies and crusted scabies education and health promotion to increase awareness and encourage health-seeking behaviour

Community organisations
- Raise awareness to reduce stigma
- Support community hygiene infrastructure to enable scabies free zones

Patients and families
- Support scabies free households by treating the entire household for scab

3.3 Active case detection methods for crusted scabies and leprosy: a systematic review

Background to systematic review

The first evaluation (Gardner et al 2018) of the One Disease elimination program illustrated the strategies to-date for improving the detection and diagnosis of crusted scabies (Goal 1 in Elimination Plan) had largely been implemented as expected. One Disease supported improvement in diagnosis through involvement in developing the CARPA guidelines, which cover scabies and crusted scabies. In 2016, crusted scabies was made a notifiable disease in the Northern Territory (NT), which improves detection, diagnosis and surveillance through a formalised disease definition, contract tracing and the registration of case data. To support improvement in detection, One Disease worked with the Centre for Disease Control (CDC) to develop an implementation model for contract tracing by local primary care health services, and entered a data sharing agreement that allows One Disease access to the CDC's crusted scabies disease register.

The introduction of contact tracing marks the first systematic use of active case finding for crusted scabies in the NT. Counter to passive case detection which relies on patient self-reporting, active case finding identifies patients in their homes or communities who had not self-reported to health services. Further improvement in case detection for crusted scabies is hampered by the lack of evidence about best practice.

To gauge alignment of One Disease's strategies with best practice in case finding, and enable program planning, a systematic review of active case finding for crusted scabies and leprosy was conducted. Leprosy shares many commonalities with crusted scabies, as another stigmatised, communicable, skin-related neglected tropical disease. Leprosy remains endemic in many regions around the world, and is the subject of frequent active case finding campaigns that are examined in academic research. Although now rare in Australia, leprosy had been endemic in remote Aboriginal communities in the 1950s-70s and active case finding involving Aboriginal health workers played an important role in disease elimination.

The systematic review sought to identify effective active case finding techniques for leprosy, and to discuss how the findings can be informative for active case detection of crusted scabies. In particular, it sought to investigate how active case finding campaign type and personnel influence detection rates, and the cost effectiveness of different active case finding methods. The systematic review is presented below and has been submitted for publication in an academic journal. It identified 15 studies that met the inclusion criteria; all examine leprosy detection in developing countries. Study heterogeneity precluded meta-analysis and no generalisable conclusions could be drawn about cost effectiveness or the comparative effectiveness of campaign designs.

It is difficult to assess the transferability of findings to crusted scabies in the Australian context given differences in setting and disease. However, the findings suggest that both contact tracing and community wide surveys are likely to find crusted scabies cases missed

by passive case detection in endemic and/or highly marginalised communities, such as remote Aboriginal communities. This reinforces One Disease's focus on enabling contact tracing for crusted scabies. The effectiveness of any active case finding campaign would be impacted by the skill levels of screeners and their acceptability to community members. One Disease has recognised this necessity, and has supported capacity building in crusted scabies diagnosis, and engaging local Aboriginal health workers in contact tracing. Further details about the review's findings, including barriers to and enablers of campaign implementation, and detailed discussion about findings' application to the NT can be found in the full review below.

Introduction

Crusted scabies is endemic in remote Aboriginal communities in the Northern Territory (NT) of Australia. Stigma, high barriers to healthcare access, and poor clinical awareness due to its rarity in the general Australian population, all contribute to late stage diagnosis, high mortality rates and on-going disease transmission (Gardner et al 2018). Caused by *Sarcoptes scabiei*, the same mite that causes simple scabies, crusted scabies is a severe, progressive and debilitating form of scabies that occurs in individuals whose immune systems are unable to control mite replication (Walton et al 2004), leading to crusting of the skin due to mite loads of up to a million or more (Currie 1995). Secondary bacterial skin infections associated with scratching, can lead to lymphadenopathy, post-streptococcal glomerulonephritis and rheumatic heart disease, bacteremia with sepsis and death (Feldmeier 2008). Historically crusted scabies had a 5-year mortality rate of up to 50% (Roberts 2005). Remote Aboriginal communities carry an estimated prevalence rate of 24/10,000, (May et al., 2016), compared with an estimated rate of < 0. 1/10000 in the general Australian population (unpublished data, OZBUG communication).

In 2016, crusted scabies was upgraded to a notifiable disease in the NT, which creates an imperative for a more systematic approach to disease control (Quilty et al 2017). Despite this heightened imperative and the clear barriers to healthcare access in remote Aboriginal communities, there is no systematic use of active case finding (ACF) to interrupt transmission and improve treatment outcomes. There is limited literature on active case detection for crusted scabies, which creates a challenge for designing appropriate campaigns and the need to look at comparable diseases for evidence based practice. Leprosy shares many commonalities with crusted scabies, as another stigmatised, communicable, skin-related neglected tropical disease that primarily effects vulnerable populations in resource poor settings. Caused by the bacillus, *Mycobacterium leprae*, leprosy causes skin lesions and nerve damage which can progress to debilitating physical deformity (Sasaki et al 2013; WHO 2006). Unlike crusted scabies, leprosy has long been a notifiable disease in most jurisdictions globally. While leprosy now has low prevalence (<1/10,000) in most tropical regions, pockets of endemicity remain in some countries (WHO 2016), mostly in communities marginalised by poverty, ethnicity, gender and/or age and facing barriers to healthcare access (Mangeard-Lourme et al 2017; Pedrosa et al 2018; Ezenduka et al 2012). ACF continues to play an important role in leprosy control in endemic regions (WHO 2020).

Leprosy is now rare in Australia, but had been endemic in remote Aboriginal communities in the 1950s-70s. There is a small grey literature about leprosy control in remote Aboriginal communities that illustrates active case finding played an important role in elimination programs (Lush et al 1998; Hargrave 1980). It highlights the important role of local Aboriginal health workers to support the cultural appropriateness and community acceptability as ACF

activity, as well as to maximise reach in remote geographies (Hargrave 1977). This review sought to identify effective ACF techniques for leprosy, and to discuss how the findings can be informative for ACF of crusted scabies. In particular, it sought to investigate how ACF campaign type and personnel influence detection rates, and the cost effectiveness of different ACF methods.

Method

Literature search: Systematic searches were conducted in MEDLINE, CINAHL, Scopus and the Cochrane Database for Systematic Reviews in October 2019 using a combination of search terms relating to active case finding in concert with the two review diseases. Search results were limited to English language papers from the past 20 years (1999 to 2009). See Appendix 1 for a full list of search terms and results. All search results were exported into EndNote for processing and screening.

Inclusion and exclusion criteria: To be included in the review studies had to examine an ACF campaign, with one of the two review diseases as the sole or primary campaign target. Included studies needed to report outcome data on the detection rates of the campaign and a relevant comparison such as baseline (pre-campaign), local prevalence rate (PR), or the detection rate of a concurrently conducted detection method. These criteria led to the exclusion of papers in which ACF is conducted as part of a control program but the ACF activity is not subjected to an effectiveness evaluation through comparison to other case detection methods and outcomes.

Data extraction, summary and risk of bias assessment: Data was extracted on the ACF campaign setting (community characteristics and country), ACF strategy type, campaign time frame, personnel, method and use of laboratory evidence (typically skin smear) in diagnosis (if not reported recorded as 'no'). Outcome data extracted were detection and/or prevalence rates (both campaign and comparison). Disease stage at diagnosis was not sought. Due to heterogeneity in campaign type, reporting and setting, a meta-analysis was not performed.

The relevance of the comparative detection or prevalence rate to the study setting impacts the risk of bias in assessment of outcome effect. A significant difference between the campaign and comparator rates will confirm a positive (or negative) effect of ACF in general. However, if the comparative rate has low relevance, the difference may conflate variations in prevalence with campaign effectiveness. For example, comparing the detection rate of a study conducted in a high prevalence area to the national prevalence rate in a low prevalence country will inflate the campaign effect size. To assess this risk of bias at the study level, a grading system was developed to rate the relevance of the comparison rate; the grades are identified in the data table (Table 1) and are:

- Low: location and timeframe of low relevance (e.g. national PR with regional sample NCDR for campaign)
- Moderate: location moderately relevant and/or comparator rate format and/or timeframe not relevant (e.g. PR rate with NCDR)
- High: location, timeframe and comparator rate format relevant (e.g. NCDRs of two concurrently conducted campaigns).

It is important to note that assessment against the comparator rate may not be the objective of included studies, but may rather serve as context. There is no evidence that studies selectively

report less relevant comparator rates; when these are used it is presumed to reflect the availability of prevalence data.

Results

The search yielded 511 unique results after removal of duplicates. All papers were screened at the title and/or abstract level and 50 papers were selected for full text review. Of these, 13 met the criteria for inclusion. Reference lists of selected papers were screened for additional resources, which yielded two additional papers, bringing the total included references to 15. This filtering process is presented in Figure 1 below.

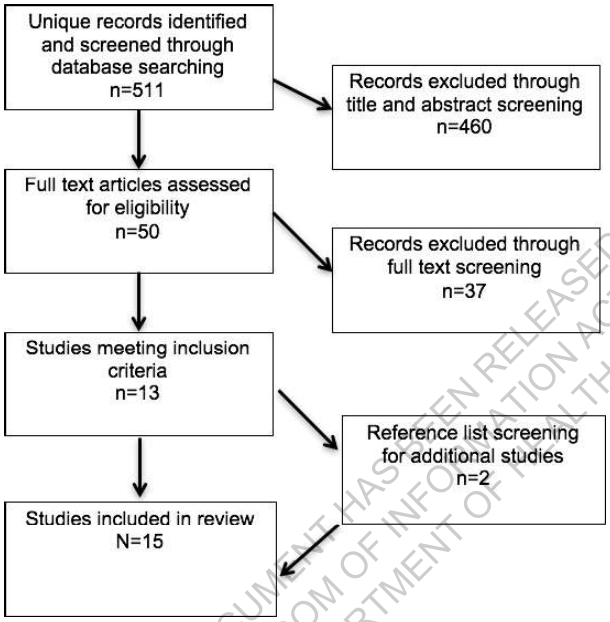


Figure 1. Eligibility flow chart

Study characteristics

All included studies report on case detection campaigns for leprosy. The search yielded only four studies including the term "crusted scabies", but none met the inclusion criteria. The papers included in the review draw on studies of leprosy ACF from nine countries, with five from India and three from Brazil (the two countries with largest leprosy numbers globally [WHO 2015]), and the remaining mostly from Asia and Africa. There are no studies from developed countries. Community screening is the most commonly reported detection method, used solely or in concert with contract tracing, in all but three studies which examine contact tracing only.

Not all targeted data extraction points were available in all studies, and extracted data was not uniform. When only detection numbers were reported, the new case detection rate (NCDR) or prevalence rate (PR) (whichever appropriate) was calculated manually. A summary of the included studies is presented in Table 1 below. Heterogeneity in reporting of both campaign implementation and outcome data inhibit standardization in summation for this review.

First author Country Year	ACF method	Sample	Delivery period	Personnel	Method description	Laboratory evidence	Outcomes	Screening accuracy	Comparability to outcome measure
Davoodian Iran 2009	Contact tracing	One large city 145 index cases, 509 contacts screened, 20 suspects referred	Not reported	Screening by leprosy nurses from leprosy clinic Referred for diagnosis in local dermatology centre	Index cases from records one leprosy clinic (1972-2004); skin examination household contacts, education and self-referral neighbours	Yes	NCDR 21.7/10,000 household, 14.3 neighbour National PR <1/10,000	15% with clinical signs confirmed with laboratory evidence	Low
De Souza Dias Barzil 2007	Community screening	4x100m2 zones in one endemic urban municipality 538 index cases mapped, 512 suspects referred	2 weeks per zone	Screening by community and primary healthcare workers Referred for diagnosis in primary healthcare centre under supervision visiting leprologist	Index cases from national registry (1998-2002) geo-referenced for density mapping; door to door screening in high density zones	No	Baseline PR 5.4/10,000; 9.4/10,000 in year of campaign of which 50% identified during campaign	20% suspects confirmed	Moderate

Ezenduka Nigeria 2012	Contact tracing, community screening, traditional healers incentive	10 randomly selected communities (5 high prevalence, 5 low) in two northern states	1 year	Screening by trained health workers and traditional healers Referred for diagnosis is leprosy treatment	Three concurrent programs: 1) Skin examination of household contacts; 2) Rapid village survey consisting mass communication and education campaign and skin examination of self-reporting individuals in public area of village; 3) Skin examination and	No	Household contract tracing most cost effective at US$142/case detected, traditional healer incentive US$192/case and rapid survey $313/case	Suspect numbers not reported	High

				centre by specialists	referral by traditional healers				
Fürst Cambodia 2018	Contact tracing	National Screened 1463 index cases from 2001-2011(67% traced) plus 24,603 contacts	4 years	Screening and diagnosis team consisting leprologists from national gov and French non-profit, district and local health workers Research partnership Cambodian government, CIOMAL and Novartis Foundation	Traced and re-screened index cases, household contacts and neighbours to 200m radius; screening, diagnosis and MDT commencement same day by mobile team	No	NCDR higher at household level 25.1/1,000 than neighbour 8.7/1,000 National passive NCDR rate same period 1/10,000	Suspect numbers not reported	Low
Ganapati India 2001	Community screening	Three municipal wards (slums in megacity)	1 month	Youth community volunteers (mixed gender) and supervising paramedicals	Community-wide screening	Yes	PR 4.2/10,000; state PR 6.6/10,000. 2 cases skin smear positive. US$20/NCD, US$322/skin smear positive	Suspect numbers not reported	High

Gillini Nepal 2018	Community screening	Two high prevalence districts	1 month	Screening by trained local volunteers	Door to door screening	No	NCDR 5.4/10,000 National PR <1/10,000 526 new cases in campaign year up	Suspect numbers not reported	Low

				centre by specialists	referral by traditional healers				
Fürst Cambodia 2018	Contact tracing	National Screened 1463 index cases from 2001-2011(67% traced) plus 24,603 contacts	4 years	Screening and diagnosis team consisting leprologists from national gov and French non-profit, district and local health workers Research partnership Cambodian government, CIOMAL and Novartis Foundation	Traced and re-screened index cases, household contacts and neighbours to 200m radius; screening, diagnosis and MDT commencement same day by mobile team	No	NCDR higher at household level 25.1/1,000 than neighbour 8.7/1,000 National passive NCDR rate same period 1/10,000	Suspect numbers not reported	Low
Ganapati India 2001	Community screening	Three municipal wards (slums in megacity)	1 month	Youth community volunteers (mixed gender) and supervising paramedicals	Community-wide screening	Yes	PR 4.2/10,000; state PR 6.6/10,000. 2 cases skin smear positive. US$20/NCD, US$322/skin smear positive	Suspect numbers not reported	High

Gillini Nepal 2018	Community screening	Two high prevalence districts	1 month	Screening by trained local volunteers	Door to door screening	No	NCDR 5.4/10,000 National PR <1/10,000 526 new cases in campaign year up	Suspect numbers not reported	Low

				Referred for diagnosis at local health centre Program supervision two Japanese non-profits and WHO			from 302 previous year. US$534/additional case compared with PCD. Partial records indicate roughly 50% suspects sought diagnosis		
Kumar India 2015	Community screening	Tribal colonies of one district	2 weeks	Screening by village health nurses and trained volunteers	Door-to-door screening. Suspects brought to health centre for diagnosis by nurse.	No	Campaign community prevalence rate 24.6/10,000, pre-campaign community prevalence rate 9.8/10,000. District prevalence rate 0.84/10,000. 34% of confirmed cases reported having noticed their skin lesions. 74% treatment completion one-year post campaign.	21% suspects confirmed	Moderate

				Referred for diagnosis at local health centre Program supervision two Japanese non-profits and WHO			from 302 previous year. US$534/additional case compared with PCD. Partial records indicate roughly 50% suspects sought diagnosis		
Kumar India 2015	Community screening	Tribal colonies of one district	2 weeks	Screening by village health nurses and trained volunteers	Door-to-door screening. Suspects brought to health centre for diagnosis by nurse.	No	Campaign community prevalence rate 24.6/10,000, pre-campaign community prevalence rate 9.8/10,000. District prevalence rate 0.84/10,000. 34% of confirmed cases reported having noticed their skin lesions. 74% treatment completion one-year post campaign.	21% suspects confirmed	Moderate

Mangeard-Lourme India 2017	Contact tracing, community screening	One district	6 months	Leprologist + local health workers; personnel from British non-profit, and trained local health workers.	Index cases identified from leprosy register (n=1,414); contact tracing to household (n=5,091) and neighbour (n=54,129), community wide screening of high risk groups (Scheduled Tribes) (n=26,340). Suspects escorted for diagnosis at primary healthcare centre by	Yes	Study campaign identified 303% more cases than the government ACF in the same district. PR for screened population 37.5/10,000. Local PR 0.73/10,000; ANCDR 13.94/100,000.	100% suspects confirmed	Moderate

					government medical offer and non-profit team.		90% of diagnosed new cases commence treatment at six months post campaign. High risk community screening yielded highest new and cases but contact tracing yielded highest female percentage.		
Moura Brazil 2013	Contact tracing	Two highest prevalence neighbour-hoods in one endemic municipality of megacity	1 month	4 doctors, 6 med students and 1 nurse	Index cases invited at treatment centres, household and neighbours of accepting index cases invited to participate; Household visits by mobile healthcare team consisting doctors, medical students, nurses and social worker. All participants received information/education, verbal questionnaire and skin exam. Suspects referred to healthcare centre for diagnosis.	Yes	Local PR 3.5/10,000 Household NCDR 290/10,000, neighbour NCDR 210/10,000	24% suspects confirmed	Moderate

Pedrosa Brazil 2018	Community screening	277 randomly selected public schools in one city	2.5 years	Trained leprosy technicians	Information and invitation through open seminar, children for whom consent (parents/guardians) obtained received skin examination by trained leprosy technicians at school; suspects and guardians referred to local healthcare centre for diagnosis.	Yes	Local PR 1.1/10,000 total, 0.68/10,000 in children. 11.58/10,000 study PR (participants aged <15 years) Contact tracing at household and neighbour level of NDCs yielded seven additional cases from 196 contacts.	Suspect numbers not reported	Moderate

							Grandparents the most common contact (28.6%) identified with current or past leprosy history.		
Rao India 2000	Community screening	Hilly tribal area in one highly endemic state	6 days	Trained (1-3 days) healthcare workers, female community workers and other voluntary workers	Mobile health team met village leaders for cooperation, then conducted door-to-door information/education and screening. Households given visit card which subsequently collected by confirmation team (medical officer and non-profit staff) who also performed diagnosis of suspects.	No	NCDR 3.9/10,000 compared with 8.6/10,000 is comparable format campaign with 150 day implementation	4% suspects confirmed leprosy	High
Schreuder Indonesia 2002	Community screening	Two endemic districts on main island	6 months	Mixed gender field workers	Rapid village survey (RVS): school + village information/education and voluntary screening of existing patients, their household contacts, suspects identified by village leaders and any additional self-reporting, suspects subsequently diagnosed by medical officer. Leprosy Elimination Campaign (LEC): information/education and	No	RVS PR 9.5/10,000, LEC PR 6.4/10,000 Local PR 5/10,000		High

					screening of self-reports.				
Shetty India 2009	Community screening	Two areas (one urban, one rural)	5 months + 2 months	Two person health worker teams (local,	Door-to-door screening. Consent gained from head of household to enter and	Yes	Campaign PR rural 6.72/10,000, urban 2.61/10,000.	80% rural suspects self-reported, 70% urban suspects.	Moderate

			missed households	mixed gender) trained (3 day)	from individuals before examination. Suspects 'guided to' healthcare centre for diagnosis		Local PR rural 1.37/10,000, local PR urban 0.9/10,000	100% of rural suspects diagnosed, 97% of urban suspects	
Tiendrebéogo Mali 1999	Community screening	Villages with populations over 1,000 in one health district	2 months	1 doctor, 2 nurses)	Passive and active CD implemented concurrently in randomly selected villages (similar sample size). Passive method: information/education by local nurse, referral of suspects/self-reports to local healthcare centre for examination, then to district healthcare centre for diagnosis by leprosy nurse. Active method: information/education by mobile team (1 doctor, 2 nurses), examination and diagnosis on site.	No	ACF 4.3/10,000, US$72/NCD. PCD (1 year) 1.5/10,000, US$36/NCD. National PR 1.37-2.11/10,000	Not reported	High
Utap Malaysia 2017	Community screening	Three highest prevalence Penan (ethnic minority) settlements	3x1 month	Doctor, medical officers, lab technician with previous health service visits to target communities	Community wide screening. Confirmed cases re-traced by medical officers.	Yes	NCDR 720/10,000 (n=6/83) Penans PR 5.5/10,000, rest of population PR 0.07/10,000	Not reported	Moderate

Detection methods

Twelve of the reviewed studies examined community screening methods targeting underserved communities and/or endemic regions. The dominant model of community screening uses door-to-door (door-to-door) visits by a small team of community health workers (CHWs) for information and education communication plus screening for clinical signs of leprosy, and referral of positive screened (universally referred to as 'suspects') to a local health centre for diagnosis. A number of studies reported alternate settings, including schools and village squares.

Six studies examined contact tracing campaigns, three of which using this method to identify high prevalence areas for targeted community screening. One study used the contact tracing for micro-targeting of geographies for screening, which is achieved by identifying and tracing index patients, then mapping their house location and using case clustering for highly localised community screening (De Souza Dias et al 2007). In the included studies, contact tracing was retrospective – identifying index patients through historical national and/or notifiable disease records and seeking out both the index and their contacts to either the household level, and in most cases, the neighbour level (Moura et al 2013; Davoodian et al 2009; Fürst et al 2018). Neighbour level tracing was only undertaken in densely populated urban areas.

Less than half of the studies report the criteria or case definition used for diagnosis. The WHO guidance for control leprosy in endemic countries states that diagnosis can be made on the presence of a skin lesion consistent with leprosy with definite sensory loss *or* a positive skin smear (WHO 2019). In non-endemic countries, laboratory evidence through skin smear (US CDC 2017) or nucleic acid testing (Australian Dept Health 2020) is required. Half the studies in this review reported using skin smears in diagnosis (Ganapati et al 2001; Davoodian et al 2009; Shetty et al 2009; Utap and Kiya 2017; Mangeard-Lourme et al 2017).

Detection personnel

Across studies, community screening campaigns was typically conducted by a small team (2-4) of community health workers and/or local volunteers/workers. Few studies provide any meaningful detail about the recruitment, training or remuneration (if any) of field or community workers/volunteers, or about roles and responsibilities during the campaign (i.e. information/education, skin examination). When the duration of training is reported, it is typically 1-3 days (Rao 2000). Most studies report whether the gender composition of the team is mixed or single sex. Female community health workers are used in some settings for cultural appropriateness (Rao 2000). One study reported using local recovered leprosy patients in community screening as a means to enhance community buy-in (Gillini 2018).

Numerous studies reported making contact with community leaders prior to commencing a community based campaign to gain support and raise awareness (Shetty et al 2009; Utap and Kiya 2017; Mangeard-Lourme et al 2017). This practice was most common in rural and village based community settings. In a few studies, the relationship (e.g. prior or on-going contact) between mobile health workers and the campaign community is reported (Utap and Kiya 2017; Mangeard-Lourme et al 2017). A minority of studies report whether consent was sought before entering a household or conducting a skin examination. Those that do tend to be more recent, and often involve a developed country implementation partner (e.g. Pedrosa et al 2018; Shetty et al 2009; Utap and Kiya 2017; Mangeard-Lourme et al 2017).

Campaign effectiveness

All but one reported ACF campaigns resulted in a higher detection rate than comparative passive detection methods – confirming that passive methods miss cases in high risk populations. Heterogeneity in both detection and comparator measures, however, inhibits a meta-analysis of outcomes. Similarly, heterogeneity in the scale, setting and personnel of the reviewed campaigns inhibits a comparative assessment of method design or effectiveness across studies.

Overall, findings suggest that contact tracing yields a higher NDCR than community screening, and that amongst community screening campaigns, those targeting marginalised ethnic groups yield the highest increase in detection or prevalence rate. One study (Rao et al 2000) compares its outcome data with an ACF campaign of similar design and scale but conducted over a much longer time frame (150 days compared with 6 days); it finds the longer campaign has a NCDR more than twice as high, suggesting rapid survey methods may be less effective but may be more efficient.

Two studies report on concurrent case detection campaigns, both African; these papers are also two of only three studies that assessed financial costs. The first, reported by Ezenduka et al (2012), is a comparison of three ACF methods in Nigeria: household contact tracing, targeted community screening, and a traditional healer incentive to encourage referral to local health centres. It finds household contact tracing has the lowest cost per new case detected at US$142/NCD compared to US$192/NCD in the traditional healer incentive and US$313/NCD for community screening. Tiendrebéogo et al (1999) find a community screening ACF campaign (US$72/NCD) cost twice as much per new case detected than PCD (US$36) but yielded a four times higher prevalence rate, and detected cases at an earlier disease stage (the costs/benefits of which are not quantified). The remaining cost comparison study, reported by Gillini et al (2018) on a campaign in Nepal, had a dramatically higher ACF cost than the African studies of US$534/NCD more than the passive method. The baseline cost of the passive method was not reported so total cost is not identifiable. The African studies used local personnel while the Nepalese study involved personnel from WHO and a Japanese non-profit which likely contributed to cost differences. Ganapati et al (2001) reported the cost per NCD for a case diagnosed through clinical examination (US$20) was less than 10% of the cost of case diagnosed through skin smear (US$322).

Seven of the community screening studies, particularly the Indian ones, report both the numbers of positive screened individuals ('suspects') and numbers diagnosed. There is a wide range in these numbers, from 4%-100%. On average only around 10-15% are confirmed with leprosy, in one study only 4% (Rao et al 2000). In the study reporting 4%, a chaser team of medical officers visited the homes of 'suspects' identified by community health workers/volunteers meaning 96% of positive screens were false positives. These findings illustrate poor diagnostic capacity amongst community screeners or an inappropriate disease definition for screening. In studies relying on 'suspect' self-report to local health centres for diagnosis, the proportion of 'suspects' who actually attended the health centre is rarely reported. In the few studies that do, attendance rates are roughly 50%. For example, in partial records from the Nepal campaign just under 50% of 'suspects' for which this data was captured attended health clinic (Gillini et al 2018). In these cases, the difference between suspect numbers and confirmed cases is partly a product of false positives, and partly suggestive of barriers to access. There were two exceptions, in which all or nearly all suspects were confirmed. In the first exception (Mangeard-Lourme et al 2017), consenting 'suspects' were escorted to the health center for diagnoses yielding a confirmation rate of 100%. This campaign is the only review study reporting both suspected and confirmed cases in which a leprologist

performed community-based screening. This study compared its outcome data with a recent local government ACF campaign in the area in which 13% of 'suspects' were confirmed. The second exception (Shetty et al 2009) used comparable methods to those yielding 10-15% confirmation rates (i.e. local community workers with three days training and suspect self-reporting), but reported at or near 100% confirmation of the ~80% of suspects who self-reported for diagnosis. More information is needed to identify whether the unusually high suspect confirmation rates for this campaign method reflects more effective community worker training or a disease definition leading to under-detection in screening.

Significantly, only two studies reported treatment outcomes; in these studies, one reported that 74% of cases had completed MDT one-year post campaign (Kumar et al 2015) and the other reported that 90% had commenced MDT by the end of the six month campaign period (Mangeard-Lourme et al 2017). The latter of the studies commented that entry to the national government leprosy register is triggered by commencement of MDT. As a result, those facing the highest barriers to access will not be recorded for subsequent patient follow-up or recognised for future targeted community screening.

Barriers and enablers

Five studies reported barriers to and enablers of ACF campaign effectiveness. De Souza et al (2007) found GIS an enabler in a context with few traditional address markers (e.g. street sign/number) in Brazil. Mangeard-Lourme et al (2017) found evidence of micro-clustering of leprosy cases in a district in India pointing to the value of geo-mapping for resource allocation/campaign targeting. Numerous studies reported the involvement of community volunteers as an enabler in gaining community support for the campaign (Rao et. al. 2000), including former leprosy patients in one study (Gillini et al 2018). However, the use of community workers/volunteers may represent a barrier to campaign effectiveness given low screening accuracy rates.

Lack of transport access, inadequate timeframes and long waiting times at the local health centre were reported barriers for both patients and community health workers that led to incomplete coverage of households and attendance of suspects in the Nepalese campaign (Gillini et al 2018). One study in India reported that the co-occurrence of numerous chronic skin ailments with leprosy was inhibiting proper diagnosis (Shetty et al 2009).

Two studies reported findings that evidence how low awareness would inhibit PCD effectiveness; in one Indian study, 45% of NDCs had visited a health centre in the past 1 to 2 years, most of which had done so for examinations of lesion(s) specifically (Shetty et al 2009). This illustrates poor diagnostic capability in local health services. Another Indian study found that only 34% of NDCs reported having noticed their skin lesion(s) prior to diagnosis demonstrating low community awareness which would impede patient self-reporting (Kumar et al 2015). Non-availability of MDTs a common barrier to treatment completion (Shetty et al 2009), which, if widely known, has the capacity to discourage self-reporting.

Discussion

These findings illustrate that ACF campaigns yield higher detection rates than PCD methods. This higher yield is most significant in contact tracing campaigns and in non-rapid community screening campaigns in highly marginalized, and more geographically remote populations. Two studies in India (Kumar et al 2015; Mangeard-Lourme et al 2017) and one in Malaysia (Utap and Kiya 2017) reporting ACF campaigns in rural or remote areas dominated by the most marginalised ethnic groups yielded detection rates up to 40-120 times that identified through

PCD in the same region. This confirms the importance of ACF campaigns in communities facing the highest barriers to healthcare access. These studies also report campaigns using more highly skilled community screeners and due to similarities in context, are the most relevant to crusted scabies detection in the NT of Australia.

Beyond higher detection yields, it is difficult to draw rigorous conclusions about the effectiveness of ACF methods in comparison with PCD methods with limited relevance on comparator detection rates, and few cost effectiveness studies. The lack of cost effectiveness studies is a significant empirical gap given the resource poor contexts in which leprosy occurs. Furthermore, there is inadequate data in this review from which to assess whether ACF campaigns result in better treatment outcomes or overall disease control; an additional significant empirical gap given the resource intensiveness of ACF campaigns.

Heterogeneity in reviewed campaign size and context inhibits accurate comparison of campaign design and effectiveness across studies. Outcome data suggest that contact tracing yields a higher detection rate than community screening. Caution must be used given the small sample size, however, this tentative finding aligns with existing evidence about both contact-based transmission and geographic clustering in leprosy (De Souza Dias et al 2007; Hoeven et al 2008) - evidence which has been used to mandate contact tracing for notifiable diseases including leprosy and crusted scabies. In the only ACF cost comparison study, contact tracing was found to be more cost effective than community screening (Ezenduka et al 2018). All contact tracing ACF campaigns in this review are retrospective, which depends on the existence of a national or notifiable disease register. This is not the case in many countries. In Australia, leprosy has long been a notifiable disease but crusted scabies has only recently become notifiable in a single jurisdiction (NT).

A key weakness of the dominant model of community screening is its reliance on ‘suspect’ self-report to local health centres for formal diagnoses. In relying on ‘suspect’ self-report in ACF, most of the barriers to PCD effectiveness will be similarly prohibitive. Social stigma and poor healthcare access due to barriers such as limited time, transport and finances will impede self-reporting, and local health services may suffer from poor resource conditions (Gillini et al 2018). Additionally, high rates of false positive screening by community health workers may impede suspect self-reporting by creating community skepticism about campaign effectiveness.

Increasing the accuracy of local prevalence rates through ACF can be an end in itself, as this can be used for future resourcing targeting. However, ACF that is not integrated with treatment (both healthcare access and MDT availability) will likely have limited impact on disease control, making resource allocation for this activity questionable. More longitudinal research is needed to assess the impact of ACF campaigns on disease control over time.

Implications for the Australian context and review limitations

The findings suggest an ACF program to capture missed cases of crusted scabies in Australia would likely be effective given the marginalisation of remote Aboriginal communities and significant barriers to healthcare access amongst this population. The cost effectiveness is not clear given the dearth of cost studies and low applicability of existing ones to the NT. As all studies reported in this review are in developing country contexts and communities with significantly higher population densities than remote northern Australia, the transferability of

particular models is limited. However, the review illustrates a number of findings that may inform ACF program design in Australia.

As crusted scabies is now a notifiable disease in the NT, contact tracing is a mandated component of disease control making some of the findings from contact tracing campaigns for leprosy relevant. This review points to the value of tracing to the neighbourhood level, not just the household. GIS mapping may also be useful for micro-targeting given the very low population density and given the absence of traditional address systems/markers in many remote Aboriginal communities.

A limitation of the literature covered in this review for the Australian context is the centrality of the household as the campaign target. Household centric strategies will miss the most hard-to-reach individuals: the homeless and highly mobile. Recent research found that a high proportion of crusted scabies patients are homeless (Gardner et al 2018). Any ACF campaign designed for the NT would require consideration of how to capture individuals outside a household system.

There is limited information from which to draw conclusions about the likely acceptability of review ACF campaigns in Aboriginal communities. Only a few studies discuss the process of consent – an issue that would be very important in the Australian context. Cultural sensitivity was supported in some studies through the use of community workers/volunteers, including former patients, and making contact with village elders/leaders to gain support prior to community outreach. The aligns with the grey literature about leprosy control in remote Aboriginal communities in the 1950s-70s. This literature presents Aboriginal health workers as integral to leprosy control and ACF (Hargrave 1977, 1980).

The poor screening accuracy of community health workers/volunteers identified in this review highlights the importance of diagnostic skilling in ACF teams. Lack of healthcare provider awareness in low prevalence areas is known to inhibit early detection of leprosy (US HRSA 2019) and may similarly impact case detection for crusted scabies. There is limited evidence from this review about how laboratory testing can be managed in leprosy ACFs as only a minority of studies reported using them. Re-tracing cases subsequently confirmed through laboratory testing can pose logistical and resource challenges. The role of new diagnostics need consideration for both leprosy and crusted scabies ACF. Molecular detection using nucleic acid amplification techniques such as polymerase chain reaction (PCR) to detect *M. leprae* has been used on skin and nasal swabs (Devita et al) and also shows promise for diagnosis of scabies (Fraser et al 2018). Development of sensitive and specific point-of-care rapid diagnostics using antigen or nucleic acid detection would be a major advance for ACF in both leprosy and scabies. Recent innovations in non-invasive diagnostic techniques such as video dermatoscopy (Micali et al 2016) may also aide the accuracy of community based screening in the identification of crusted scabies. Further research is required to assess the effectiveness of these technological advances in ACF programs.

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Appendix 1. Search terms

1"crusted scabies" OR "Norwegian scabies"
2 leprosy OR "hansen's disease"
3 “case find*” OR “case detect*” OR “contact trac*” OR “contact screen*” OR “contact investig*” OR “clinical audit” OR “community screen*”
1 AND 3
2 AND 3
1 AND 2 AND 3

	1 AND 3	2 AND 3	1,2 AND 3
CINAHL	27	1	28
Scopus	487	3	490
MEDLINE	323	3	326
Cochrane	0	0	0

Appendix 2. Glossary

ACF	active case finding
CHW	community health worker
door-to-door	door to door
healthcare centre	healthcare centre
healthcare centreW	healthcare worker
information/education	information and education communication
NCD	new case detected
NCDR	new case detection rate
MDT	multidrug therapy
PCD	passive case detection
PR	prevalence rate

3.3 Engagement of local health and community workers through a small grants program

In 2018, *One Disease* established a small grants program to improve the engagement of local health and community workers in the promotion of scabies free zones. The program is part of the organisation's overarching strategy to improve local systems for crusted scabies prevention, support workforce capacity building, and is in line with a community development approach to health promotion. This section evaluates the small grants program by addressing the question:

> *What is the impact of the small grants program on engaging local health and community workers in the promotion of scabies free zones, and what type of health promotion activities did it fund?*

Summary

The small grants program had a positive impact on engaging local health and community health workers in the promotion of scabies free zones. The program attracted applicants from a range of sectors and service categories, including primary healthcare, women's groups, general services Aboriginal corporations, childcare providers and an arts collective. Under the program, 38 grants were awarded to 28 providers across QLD, WA and the NT.

All grant recipients were required attend a *One Disease* Healthy Skin Symposium and small grants workshops. Participation in these sessions improved the knowledge, confidence and motivation of recipients to engage in community action on scabies free zones. A total of 82% of providers (n=23) were able to successfully complete their projects. The health promotion activities funded through these grant projects include hygiene infrastructure and supplies, information sessions, the production and distribution of health promotion materials, hygiene education and activities, scabies treatment and skin checks. Collectively, these activities reached hundreds of individuals in over 40 Aboriginal and Torres Straight Islander communities across three states.

The findings demonstrate the positive impact of the small grants program on workforce engagement and stimulating community action. However, the results must be interpreted with caution given the small sample size, bias towards completed projects and context of lower than anticipated community uptake of the grant opportunity.

Methods

Data for this component of the evaluation were collected from grant program documentation, including funding conditions, grant applications, completion reports, documentation for the accompanying workshops, Healthy Skin Symposiums, in addition to discussions with *One Disease* staff and aggregated survey data from two surveys conducted by *One Disease* over the course of the program. The first of these surveys sought feedback from workshop and Symposium attendees; this survey yielded 16 responses (response rate unknown). The second survey is a post-program survey of all grant recipients. The survey yielded nine responses from

23 complete projects (none from incomplete), representing a response rate of 39% from the providers who completed their project.

We aimed to assess the impact of the small grants program on the knowledge, confidence, motivation and action of grant recipients as indicators of workforce engagement. Data were extracted for synthesis from grant applications and completion reports. Data were: provider type, community, community partners, project activities, completion status, lessons learned, and any additional comments relating to implementation or impact. We analysed provider type and community to assess program uptake and reach. The involvement of additional community partners was analysed to assess the extent of further community mobilisation in grant implementation. Project activities were classified into health promotion activity categories to describe the range of activities undertaken. Completion status was analysed to assess the completion rate and reasons for non-completion. Lessons learned and additional comments were analysed from self-reported insights into barriers and enablers, capacity building and community impact.

Aim and conditions of small grants program

The Small grants program was one component of *One Disease's* overarching strategy to support workforce engagement and capacity building for crusted scabies elimination. Key objectives of this strategy are to:

- provide Crusted Scabies education to local health workers, people with Crusted Scabies, their families, and the wider community.
- create Scabies Free Zones
- create knowledge bases within remote communities so that people can manage this disease themselves.
- embed Crusted Scabies elimination strategies within existing health service systems.
- develop an approach for effective long-term care coordination for people with this condition.

The small grants program was established to provide grants of up to $5,000 (plus GST if applicable) for local health and community organisations to conduct community-based projects promoting scabies free zones. The grants were offered in the NT, QLD and WA, with up to $100,000 (plus GST) available in each state. To be eligible for a grant, projects were required to:

- Work directly with remote Indigenous communities to provide them with information/education on ways to create and maintain scabies free zones within household environments.
- Identify culturally appropriate, creative and relevant ways to communicate the information.

The program aimed to engage organisations with on-going service relationships with Indigenous communities, and who those who tend to be advocate for Aboriginal peoples' wellbeing. As such, to be eligible for a grant, organisations were required to fit one of two categories:

- Non-profit incorporated community health organisations who service Indigenous communities in either the NT, QLD, or WA.

- Organisations who service the NT, WA or QLD's communities registered with the Office of Registrar of Indigenous Corporations.

Project exclusions were:

- Equipment only without a justified educational component
- Interstate projects
- Subsidy of ongoing administrative costs
- Professional development of staff including training
- Travel and transportation costs
- Applications for projects already completed
- General fundraising, religious or political party activities
- Research

All grant recipients were required to attend a two-day workshop and education session hosted and funded by *One Disease.* Projects were to be completed within 12 months and funding was provided retrospectively at the completion of the projects and submission of final report. Several reporting options including a short-written report, a poster presentation, or digital clip were made available. Successful applicants were required to work together with *One Disease* on matters such as joint publicity, for example to advertise successful projects in its Annual report, website and/or social media channels.

Implementation of the grant program

The grants were advertised as an open call for applications across each state. This advertising yielded a smaller number of applications than available grants. In consideration of this outcome, *One Disease* decided not to extend any additional open calls for applications, but rather to extend invitations directly to a small number of providers with whom *One Disease* has a working relationship. Additionally, providers operating across multiple communities were allowed to submit one application per community in contrast to the original grant specifications of only one application per organisation.

Applications were assessed by a panel of *One Disease* staff. Selection was based on applicants meeting all grant requirements including project objectives and provider type. In a small number of cases, *One Disease* staff engaged with applicants to amend their project design to be deemed suitable for award. A total of 38 out of 39 applications were accepted from 28 providers. Of these, 21 were from the NT, 14 from QLD and 3 from WA.

To support workforce capacity building and enhance the likelihood of successful project implementation, grant recipients were required to attend a small grants workshop, hosted and funded by *One Disease* in concert with a Health Skin symposium. Six sessions were held – one in both WA and QLD, and four in the NT. These educational sessions aimed to improve grant recipients' knowledge about scabies and crusted scabies, improve recipients' confidence in implementing a healthy skin project and bolster their motivation to support the development of scabies free zones in their communities.

Grant conditions had specified a 12-month implementation timeframe. However, the activities of numerous recipients were interrupted by factors beyond their control, including COVID-19 related restrictions. In such circumstances, recipients were afforded extensions on project timelines.

As of 30 June 2020, $127,875 had been acquitted against the grant program, with another $5,000 expected in September upon completion of one grant offered an extended implementation timeframe.

Workforce engagement

The grants program engaged individuals from a diverse range of organisations operating in both health and non-health sectors. The organisations can be categorised into three groups:

- health service providers (mostly primary care services)
- Aboriginal corporations (non-medical entities providing a range of community services such as housing, employment, outreach)
- local community organisations (consisting mostly of women's support services and childcare/family support services).

The 28 providers awarded a grant service over 40 communities across the three states. Of the 28 providers awarded a grant, 23 completed their project. The provider types of these organisations are presented in Figure 3.1 below.

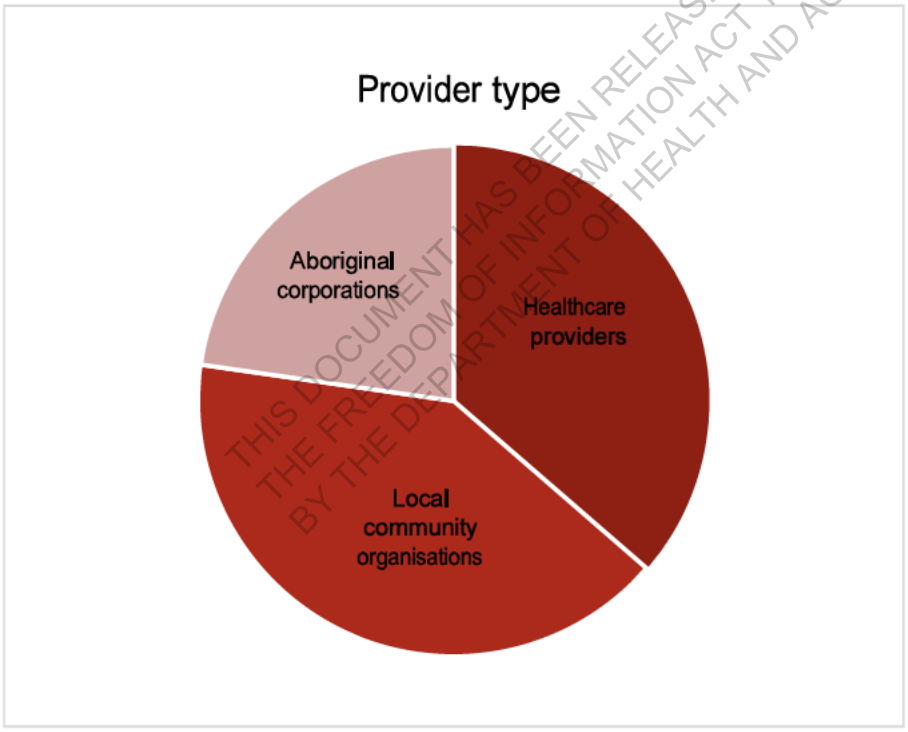

Figure 3.1. Provider type for completed projects

The five providers who did not complete their project consisted of healthcare and childcare providers. Non-completion was primarily due to conflicting priorities around resources, both human – in terms of staff release for project activity, and financial – in terms of the retrospective payment system.

Knowledge, confidence and motivation

Data from both the post-workshop and -symposium feedback survey and post-program survey was analysed to assess the knowledge, confidence and motivation of recipients to undertake health promotion for scabies free zones. Knowledge was assessed in post-workshop feedback survey by asking respondents to rate their knowledge about: 1) the detection, diagnosis and treatment of crusted scabies, and 2) preventing recurrent scabies. There were 16 responses from grant recipients, all of which rated their knowledge in these domains as either 'good' or 'excellent' after attending the Symposium. In the QLD workshop, the feedback survey asked two additional questions about whether workshop participation increased participant's: 1) understanding of how my project should be shaped, and 2) creating and maintaining scabies free zones for my community. There were seven responses, all of which reported being satisfied or very satisfied.

Data from the post-program survey of grant recipients were analysed to assess change in recipients' confidence to implement their grant project and motivation to support the development of scabies free zones in their communities as a result of participating in the Healthy Skin Symposium. Data show that Symposium participation improved the implementation confidence of 55% of survey participants. These results are presented in Figure 3.2 below.

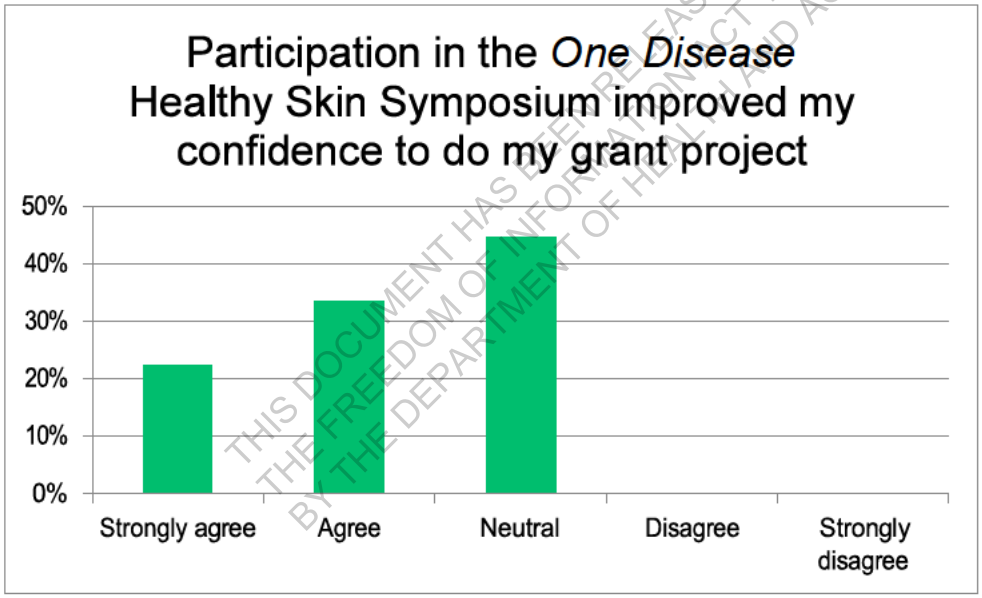

Figure 3.2 Grant project implementation confidence

Survey data show that over 70% of recipients experienced an increase in motivation to support the development of scabies free zones in their communities.

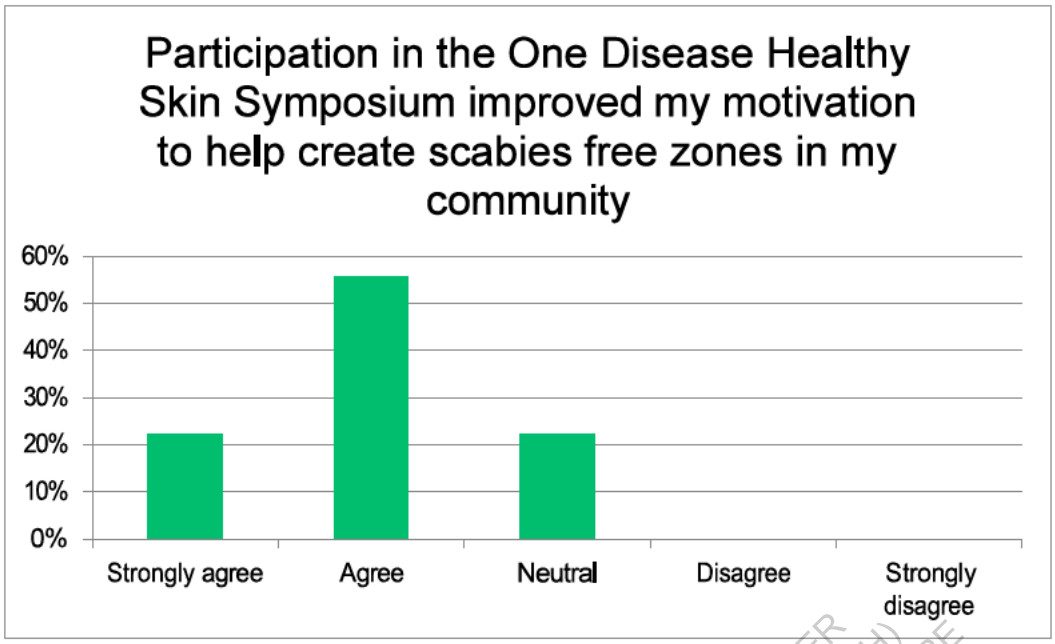

Figure 3.3 Scabies free zone motivation

Qualitative data drawn from project completion reports provide further evidence of local and community worker engagement. There were numerous positive commentary provided about program involvement, particularly regarding the opportunity to do something for community, and to connect with other local service providers. A number of reports expressed a desire for the program to continue, and/or for on-going engagement with *One Disease*.

Application and completion report data also demonstrate that the grant program engaged local health and community workers beyond the organisational representatives who submitted the application and/or attended the workshop and Symposium. More than half (54%) of the completed projects were implemented with involvement of community partners. In numerous projects, community wide initiatives were conducted using grant funding, which involved up to five-six community service organisations across a range of sectors. Additionally, a number of completion reports from health service providers described organisational capacity building activities within recipient organisations, with Symposium attendees running either formal or informal knowledge sharing sessions with colleagues upon return.

Action

Program documentation, particularly completion reports, were used to assess workforce action in health promotion for scabies free zones. Of the 28 providers awarded a grant, 23 completed their projects – which represents 82% of providers and 71% of projects. The action undertaken as part of the grant program represent six categories of health promotion activity:

- Hygiene infrastructure and supplies: this category includes the purchasing and installation of washing machines, provision of washing powders, soaps, cleaning products etc.
- Information sessions: this category involves verbal information provision to individuals or groups about scabies, crusted scabies and scabies free zones

- Health promotion materials: this category involves the production and/or distribution of health promotion materials such as booklets, posters, videos
- Hygiene education and activities: this category includes education about household or personal hygiene such as household cleaning or bush soap making, in addition to activities such as haircuts, skin and foot care
- Scabies treatment and scabies free zones: the category includes the provision of lyclear and ivemectin by health workers, and complete household cleaning (bedding, clothes etc.)
- Skin check: this category involves skin checks by health workers

Most projects involved activities across multiple categories. All projects involved either information sessions or the production and/or distribution of health promotion material, as projects were required to involve an educational element as a condition of grant award. The categories of activity undertaken in completed projects, along with the provider type, location, involvement of local partners, and reach (if reported) are presented in Table 3.1 below.

				Health promotion activity type						Reach		
State	**Community**	**Provider type**	**Comm. partner**	**Hyg. Infr/sup**	**Info session**	**Health prom**	**Hyg. edu**	**Scabies treat.**	**Skin check**	**Ind.**	**House-hold**	**Other**
NT	Alice Springs	HSP	Y			X						
NT	Maningrida	LCO	Y	X								
NT	Borooloola	LCO	Y	X	X			X		34 scabies treatment	2 received washing machine	
NT	Ramingining	LCO	Y	X	X					10 beds		
NT	Tennant Creek	HSP	Y		X	X				379 students		
NT	Baniyala,	AC	N			X						
NT	Nauiyu	AC	Y		X	X						2 bbq events
NT	Maningrida	LCO	Y			X						120 calendars
NT	Karnte and Little Sisters	AC	N	X	X						16 households (80 ppl)	
NT	Larapinta, Trucking Yards	AC	N	X	X						8 households (55 ppl)	
NT	Warlpiri, Charles Creek	AC	N	X	X					90 ppl		
NT	Wadeye	AC	Y	X	X	X						
NT	Minjilang	LCO	N	X			X					
NT	Kyrbook Farm	LCO	Y	X			X					4-5 washing loads/day

NT	Gunbalanya	LCO	N	X	X		X					1-2 washing loads/day
NT	Twelve in Top End Central	HSP	Y		X	X			X			
WA	Broome	LCO	Y		X		X		X			
WA	Djarindijin	AC	Y	X	X						every household	
WA	Kalumburu	LCO	Y	X	X		X		X			90% community
QLD	Townsville	HSP	N			X						106 video views
QLD	Coen	HSP	N		X	X		X			3 (>6ppl each)	
QLD	Cairns	HSP	Y		X	X		X				
QLD	Mackay	HSP	Y		X	X			X			4 group info sessions; 762 skin screening sessions; 7 referrals to GP for treatment
QLD	Kowanyama	LCO	N	X	X	X		X				enough welcome packs for 1-2 years
QLD	Townsville	LCO	N		X		X			7 women		

QLD	Cairns and Thursday Island	HSP	N		X	X				60 children		
QLD	Cairns	LCO	N	X	X					~250 women and children per year		

Table 3.1 Summary of grant project location, provider types, use of community partner, activity type and reach

Both the completion report template and the post-program surveys required recipients to describe the impact of the projects on their community. In survey data, 8 of the 9 respondents agreed or strongly agreed that they had been able to increase awareness of scabies and crusted scabies in their community, and to improve community knowledge about scabies free zones. These findings are presented in Figures 3.4 and 3.5 below.

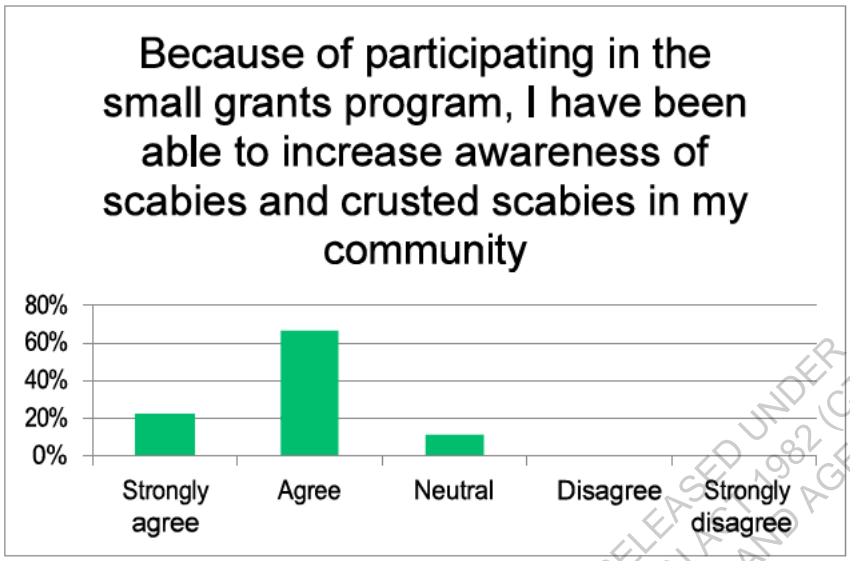

Figure 3.4. Increased community awareness of scabies and crusted scabies

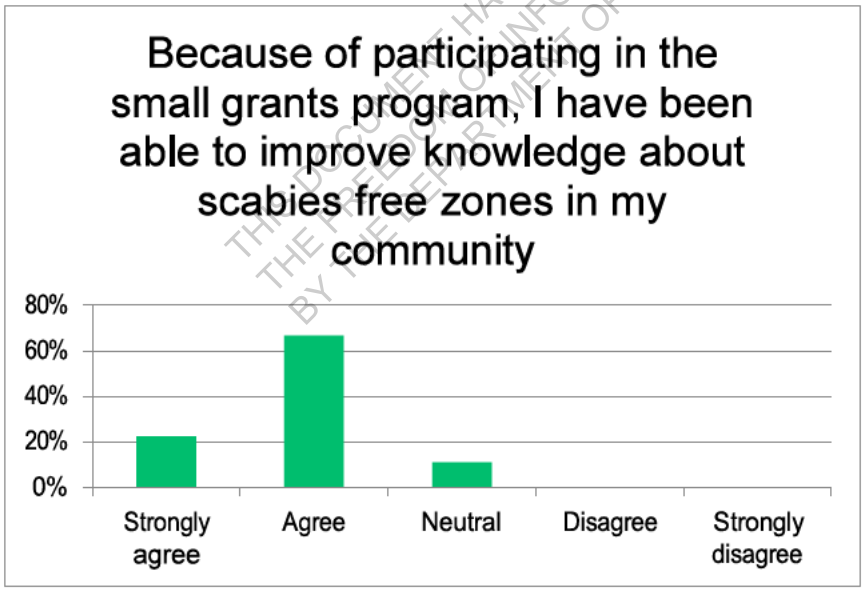

Figure 3.5. Increased community awareness of scabies and crusted scabies

Qualitative data from completion reports provides some further self-report data on the community impact of projects. One local community organisation had received informal feedback from the local health service provider that they were seeing reduced scabies prevalence. One health service provider reported an increase in community health seeking behaviour for scabies.

A number of recipients reported positive social impacts associated with the implementation of their grant project, with participants saying that they enjoyed connecting with other community members during project activity. One health service provider reported a perceived reduction in social isolation amongst community elders, who had come together during for project activities and reconnected with peers.

Using engagement and lessons learned for further work

A number of completion reports discussed additional or on-going work that the organisation is undertaking as a result of participating in the grant program. One health service provider received additional funds to translate the health promotion video they produced through the *One Disease* grant into four Indigenous languages. As a result of the knowledge gained from their participation in the Healthy Skin Symposium, one health service provider reported increased compliance with best practice for scabies treatment, and another reported increased testing for Group A strep. An emergency accommodation provider reported that the knowledge gained, in addition to the supplies purchased with their grant, have enabled them to become confident that they are preventing scabies transmission through centre bedding.

Completion reports required recipients to reflect on the lessons learned from project implementation to further support capacity building in the implementation of community projects. The most commonly reported learning was the need for flexibility and adaptability to accommodate community needs and maximise community engagement. Sorry Business, extreme weather events, poor local infrastructure and freight services for supplies, community unrest, shame about suffering from scabies and transience amongst household members were all cited as implementation challenges requiring adaptation of project plans and timelines. Underestimating costs was a project-related challenge for some. A number were impacted by COVID-19 related restrictions.

Nearly half of the completion reports expressed praise of, and gratitude for, support from *One Disease* and its staff. One noteworthy point of thanks was expressed to *One Disease* for minimising the administrative burden of grant application and reporting – noting that without such support, small and resource-poor local organisations are unable to engage with grant programs. A number of recipients reported using *One Disease* health promotion resources when engaging with community members, and some invited *One Disease* staff to conduct information sessions.

Despite generally positive experiences and an expressed motivation for continued work and engagement from some, it was recognised in a number of reports that it would be difficult to continue scabies education work and prevention after the grant project was completed due to time and resource limitations.

Discussion and limitations

The small grants program had a positive impact on the engagement of participating local health and community workers in the promotion of scabies free zones. Participation in the Healthy Skin Symposium and small grants workshops had a positive impact on the knowledge, confidence and motivation of recipients, and 82% of providers were able to successfully undertake community action in the promotion of scabies free zones.

There is some evidence of organisational capacity building in reports of knowledge sharing between workshop attendees and their colleagues. The high proportion (54%) of projects involving (at times multiple) community partners, which suggests that a small grants program can support the mobilisation of social networks for health promotion at the community level. There is also important, though limited, self-report evidence of improved treatment compliance amongst health service providers and creation of scabies free zones in emergency accommodation providers. Implementation lessons at both the *One Disease* and recipient levels highlight organisational capacity building through identification of the importance of flexibility and adaptability when undertaking community based project work.

The positive and reflective nature of most recipients' responses to the lessons learned section of the completion report template suggest a motivation to improve their ability to undertake community engagement work into the future. However, the sustainability of health promotion activity beyond a one-off grant program is unclear, given the resource poor setting of most recipient organisations. Longitudinal research would be needed to assess the whether the workforce engagement identified in this evaluation is sustained, and to evaluate the outcomes of project activities in communities.

Caution must be used in interpretation of these positive findings, given the small sample size of survey data, and the potential for bias in results because all survey and final report data relate to completed projects only. The findings must also be interpreted in the context of lower than expected uptake, given that the open calls for applications yielded less than one third the number of applications as were grants available.

3.5 Final Evaluation Framework June 2020

Introduction

Purpose of the Evaluation Framework

This framework describes an approach to design of the final component of the evaluation of the One Disease Crusted Scabies (CS) Elimination project. It outlines objectives for this part of the evaluation and the methods by which information can be collected, analysed and reported. It is therefore intended to guide the development and conduct of the evaluation, including the timing of evaluation activities. It may also be used as a source of information for participants and those who have a stake in the evaluation and its findings. The framework is designed to evolve as the evaluation progresses and as new information, findings and perspectives come to light.
Earlier components of the evaluation were conducted under a partnership arrangement between One Disease and a research consortium led by the Public Service Research Group at the Business School University of New South Wales Canberra, comprising The Medical School at the Australian National University, The Centre for Health Economics Research and Evaluation (CHERE), University of Technology, Sydney and the Doherty Institute, University of Melbourne. This framework draws from that experience and builds on earlier evaluation and research findings.

Background and context

Since the 1990s, scabies control programs have had significant impacts on reducing the prevalence of scabies in remote Aboriginal communities in NT of Australia, but such programs are complex to implement and their impacts difficult to sustain (Carapetis et al., 1997; Dowden 1999; Connors etal 2001; Wong et al., 2001; Wong et al., 2002). Achieving treatment completion at the level of community coverage required, as well as a lack of resources for ongoing monitoring, detection and treatment has impeded efforts to sustain short term benefits (Dowden 1999; Carapetis, Connors, etal 1997; Currie, Connors etal 1994). Despite the availability of effective treatments for scabies and CS, interventions in the NT have not changed the burden of disease in 25 years (Karimkhani et.al 2015).

Control programs have historically targeted scabies, (not crusted scabies) and models include those that target individuals, their contacts or whole communities at once. They include mass community administration of drugs, for example ivermectin or benzyl benzoate lotion, without implementing a community based program or education to complement this (Kearns, 2015; Haar, 2014) as well as programs that combine active screening regimes and annual treatment days with health education initiatives and environmental interventions (Wong, 2001; Wong, 2002). Recent evidence from systematic review indicates that programs which incorporate effective treatments together with control measures such as health promotion, screening and environmental interventions can sustain scabies reductions (May 2019). Such programs are yet to be applied in crusted scabies.

The cycle of reinfection between people with crusted and simple scabies, underpins the proposition that the control of CS is a crucial step in addressing scabies (Engeleman 2018; One Disease, 2016; Feldmeier, 2009; Worth, 2012). Evidence from one study of 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, 2015).

There is widespread agreement that the priority in the control and by extension elimination prospects for crusted scabies is dependent on accurate definitions of target and priority populations with appropriate community-based control measures that not only treat the disease but also address the underlying social determinants of poverty (WHO, 2012). 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). However, evidence regarding the the appropriate combination of strategies required remains unclear (May, Tong etal 2019)

One Disease approach to Crusted Scabies

Improving the detection, management, treatment and follow up of crusted scabies and breaking the cycle of transmission and reinfection between those with crusted and simple scabies, and is the subject of the One Disease systems based elimination initiative. In 2011 One Disease established a joint initiative with the 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. Results indicated that usual follow-up and chemoprophylaxis for patients returning from hospital to endemic areas was inadequate, leading to recommendations for active monitoring and wider adoption of a preventive case management approach (Lokuge et al., 2014).

From 2016 a focus on rollout across the NT of the case management approach together with support for prevention (education, stigma reduction, improved detection, treatment completion, and scabies free homes) 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.

An evaluation of the program from 2016-2018, assessed the extent to which the program had achieved reductions in the number of recurrences and new cases, the cost of illness in the NT as well as the barriers and enablers to implementation and the extent to which the program had been sustained and could be replicated in other places. The evaluation found that the OD program had been widely adopted in the Top End by PHC services (both government and community controlled) and the two major hospitals, was acceptable to stakeholders and had resulted in improved treatment, reduced recurrences, and lower costs (Gardner etal 2018). Audit data showed the program had improved treatment completion, increased follow-up in the community and indicated promising reductions in the number of recurrences. A cost of illness study conducted as part of the evaluation showed that for every episode of CS prevented, the health care system could expect to save $31,209.20.

Despite these successes however, the evaluation also concluded there are significant challenges in moving towards elimination of crusted scabies in remote Aboriginal and Torres Strait Islander communities. Household overcrowding which is a major determinant of scabies transmission is a significant impediment in communities with high prevalence of simple scabies, as treated individuals easily become re-infected. New roles that support care integration and continuity across the prevention and treatment spectrum, in a culturally secure

manner, and enhanced data collection systems to monitor and track treatment outcomes are essential for embedding a systematic response. It was strongly argued the program cannot be implemented without the Aboriginal health workforce who are central to engaging communities and families in prevention and self-management. Effective action requires coordinated intervention from practitioners, communities, individuals and households, guided by evidence on the impact of strategies for achieving population-level improvements in prevention and treatment, and reductions in recurrences and new cases among individuals.

Since the evaluation reported in July 2018, the program has continued to grow, adapting to changes in the contextual environment and responding to emerging evidence to implement new strategies across the health care system in pursuit of elimination. At the time of writing major strategies have included.

- BUILDING CAPABILITY FOR CASE DETECTION
    - Promoting the use of data from recall and reminder systems for CS in systems based CQI programs; in-service training of health workers and individuals
- MONITORING AND SURVEILLANCE
    - Working with NT Govt towards an enhanced dataset for CS
- EDUCATION AND WORKFORCE CAPACITY DEVELOPMENT
    - Community education and health promotion to improve health literacy among individuals and families
    - Inservice training for hospital nurses, primary health care and community providers
    - Curriculum for skin health incorporated into Aboriginal health worker training (RAFF model)
    - Story telling tool for health and non-health professionals such as in aged care, child care etc
- COMMUNITY MOBILISATION AND HEALTH PROMOTION
    - Social media and other strategies to raise community awareness and reduce stigma
- TREATMENT COMPLETION
    - Social support for people in hospital to complete treatment
    - Hospital pathway and discharge planning to ensure referral to scabies free homes and PHC for follow up care
- SECONDARY PREVENTION AND FOLLOW UP
    - PHC care coordination model to prevent recurrences
- HEALTHY ENVIRONMENTS
    - Scabies free zones

A final round of evaluation is proposed by One Disease to test the extent to which this systems based approach to eliminating crusted scabies has achieved reductions in the number of new cases and prevented recurrences in patients over time and to assess the impact of program strategies on patients, communities and the health system system, including the impact of scabies free households on the transmission of CS at the household level. Outcomes of the evaluation may be used to develop the evidence base for public health approaches to CS scabies control and to guide future intervention strategies in remote Indigenous communities in the NT and other Australian states.

Approach to the evaluation

Evaluation Questions

Four distinct areas of evaluation are proposed. These are: 1) program implementation and adaptation over time 2) impacts on service systems and delivery of health care 3) impacts on patient experiences and outcomes 4) Impact of health promotion strategies on awareness, attitudes, and prevalence at the community level.

The focus of evaluation is on providing a detailed analysis of the program's development, implementation and impact. Key overarching evaluation questions are:

What is the impact of a multi-faceted systems based approach to crusted scabies elimination on patients, communities and the health system?

1. How has the program developed over time and to what extent have program strategies been implemented as planned?
2. What have been the impacts on health system development?
3. What have been the impacts on patient experience and outcomes?
4. How have community health promotion strategies (scabies free zones, social media and other strategies) impacted awareness, attitudes and prevalence at the community level?

Evaluation participants

The following are groups of participants in the evaluation study:

- People over the age of 18 with crusted scabies who are participating in the CS Elimination program. People with Crusted scabies are those who have a diagnosis of Crusted Scabies, documented laboratory report, evidence of scabies mites or eggs by microscopy of a skin scraping and documentation verified by an infectious disease physician or dermatologist. Crusted Scabies was made a Notifiable Disease in the Northern Territory (NT) under the Notifiable Diseases Act NT in January 2016. Crusted Scabies is notifiable by laboratory on detection of scabies mites and verified by an infectious disease physician or dermatologist. Those with recurrent CS have two or more incidences.

- Households and families of people returning from hospital following treatment for crusted scabies

- Key informants are community controlled and government-provided primary health care and key hospital providers, policy officers, One Disease program staff as well as other stakeholders such as local Indigenous community based workers

Overarching analytical framework and analysis

Data collection and analyses for individual evaluation components will draw on appropriate methods and theories. The results of each data collection will be analysed separately, and the results synthesised to answer the evaluation questions. The methods will be designed and the findings structured to facilitate this synthesis, and the research team will meet after each round of data collection to discuss the emerging results. Wherever possible data sources will be triangulated to provide confirmation and further detail study findings.

The evaluation will use an interventional implementation science approach to explore contextual influences and implementation. Normalisation Process Theory (NPT) will be used to underpin our approach to Area 1 analysis and guide investigation of the contextual factors that helped or inhibited progress. NPT is a sociological theory concerned with the social

organization and dynamic work processes of implementation, of making practices routine (embedding) and of sustaining them in their social and organisational contexts (integration). NPT conceives implementation as the process of bringing a new set of practices into action, to embed these in everyday work and integrate them into organisational structures and processes. NPT investigates:

- Process problems: how to make new ways of thinking, acting and organizing in health care routine
- Structural problems: how to integrate new systems of practice into existing organizational and professional settings.
- Dynamic elements of context: what are the barriers and enablers to implementation in different contexts

We will consider the program's development and adaptation over time, potential of the program model to improve care and outcomes (the extent to which the program elements align with recognised features of coordinated systems-based models for disease elimination); its workability in different contexts including observable barriers and enablers; and the extent to which new practices for detection and management were embedded in everyday work and integrated into service systems.

The World Health Organisation's framework for monitoring and evaluation for health system strengthening will underpin the approach to assessment of program impacts and patient outcomes. This framework considers both indicators of health system capacity (inputs, processes and outputs) and health system performance (outcomes and impacts). Data collection across these domains enables better understanding of the causes of an indicator result in the context of the resources and processes of the PHC service, and therefore helps identify how best to strengthen the program.

Inputs & processes	Outputs	Outcomes	Impacts
One Disease Strategies **Health workforce, service organisation, and** policy context	**Intervention access and service readiness** Systems in place and used • Recall system for CS • Care planning template • Notification system Episodes of care for CS patients • Aboriginal health worker/health practitioners • Community nurse • One disease staff • General practitioner **Intervention quality, safety and efficiency** Care following treatment guidelines. For each suspected case, are there: • Skin scrapings • Photographs • Bloods as per guidelines • Review by dermatologist/ID physician • Time from referral to review • Time from referral to initiating treatment	**Coverage of interventions** Medications prescribed/provided for each CS case (vs. predicted as per guidelines) Medications prescribed/provided to family of CS case Evidence of chemical treatment of CS case house **Prevalence risk behaviours & factors** Data from One Disease • community screening activities • implementation of Scabies free households	**Improved health outcomes & equity** New episodes of CS Recurrent episodes of CS Hospitalisations for CS Total presentations with scabies in community

Quantitative and qualitative data will be combined to provide as comprehensive a picture as possible of the CS Elimination strategy - its development, implementation, impacts and achievements. Where possible sources will be triangulated to provide confirmation and further details of findings. Quantitative data will be used where it is available, but in some cases it may be limited or coverage may be incomplete.

Evaluation schedule

One Disease advises the evaluation is to be conducted over the period July 2020 - June 2023. The focus and direction of evaluation may change in response to early learnings or external factors, such as changes that may arise in relation to travel due to COVID_19. The evaluation will adapt to these changes, and the plan has deliberately built in flexibility to adapt evaluation approaches in the latter stages if required.

Ethics

Ethics approval will need to be obtained prior to the commencement of data collection from Human Research Ethics Committees at the partner universities and from Aboriginal and Torres Strait Islander committees. Governance approvals obtained from NT Health Department will also be required. Finalisation of the Framework and the specific data collection arrangements will determine the approach to ethics and if necessary, several applications covering different parts of the evaluation may be submitted to ensure the evaluation can proceed in a timely fashion and as soon as possible. The final Evaluation framework will form the basis for the ethics submission.

Our experience suggests that obtaining ethics approvals may take as long as 3-6 months during which time preliminary literature review work and data capture frameworks will be developed and agreed with One Disease. Feedback to One Disease on this phase of work will be provided at the conclusion of the six-month period and will form the basis for data collection, analysis and modelling.

Evaluation conduct

Regular meetings between the core One Disease team and evaluators, anticipated to be held on a fortnightly basis in the initial phases of evaluation, will be the vehicle for updates on any early risks, issues or findings. If information is considered of importance to a wider audience, dissemination and associated caveats will be decided at this meetings.

Data collection

2.7.1 Data collection principles

The following principles apply to data collection:

- Data collection will be considered as a partnership activity with the One Disease partners
- Wherever possible existing data available through One Disease will be used
- Qualitative data collection will be designed bearing in mind the existing reporting burden of participants and will aim to minimise that burden
- Requests for additional quantitative data will be made through One Disease

2.7.2 Data collection methods

Data collection methods will include:

Access to data collected by One Disease for the purposes of the CS Elimination strategy will be provided to the evaluation team

- Demographic data and data on episodes of care, care planning, pathology tests and treatment (once cleansed) for patients with CS enrolled in the program, extracted by OD staff from the shared medical record or an existing database such as Communicare or PCIS
- Population estimates in order to calculate incidence.
- Data collected by One Disease from community scabies screening activities, to estimate prevalence
- Data metrics from interactive web based or other health promotion activities to assess reach
- Qualitative data collected at region and service level through on-site interviews and focus groups, supplemented by phone interview and/or survey.

Data limitations

Data limitations will be clearly described in the evaluation reports. There are several quantitative data limitations identified that may impact on the extent to which the evaluation can draw conclusions systematically across all demonstrator sites. It should be noted that qualitative data collection will play a large role in helping understand the implementation process, barriers and enablers and the perceptions of those involved in the strategy. This data complements quantitative data.

Logic models

At the initial conception stage, an overarching logic model was developed for the CS Elimination strategy by the One Disease partners. Some assumptions underpinning the models and some of the planned activities have changed. This is normal in the implementation of a new initiative. For the evaluation, these program logics provide a picture of what the program was expected to deliver including activities, the anticipated context and supporting elements, as well as program outputs and desired outcomes.

Comparison Groups

The rigour of analysis will rely on the availability of before and after data, and on the construction of a feasible control group. Such a control group is important to the analytical validity of the CS Elimination evaluation. In particular, a suitable control group will strengthen the inferences on the causal impact of the strategy which is fundamental to Area 3. In non-experimental studies finding a suitable control group is always challenging. Our approach will combine principles of evaluation rigour whilst also remaining pragmatic about data availability. Our earlier evaluation of the program adopted a before and after approach to data collection to allow comparison of outcomes pre and post intervention. One Disease conducted an audit of patient records for those clients with a Northern Territory shared electronic health record who had an episode of CS after 1 July 2016. The 1st of July 2016 was determined to be the start date for the current OD program intervention. 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 prior.

Stakeholders

The following stakeholders will be engaged during the evaluation.

Role	Purpose of engagement	Method of engagement
Evaluation Reference Group - membership to be determined in consultation with One Disease team	Provide expertise, advice and support the conduct of the evaluation	Meeting contact as required
One Disease project team	Access existing quantitative and qualitative data Support access to ACCHS and State Government clinics and clinic data Receive advice, inform Qualitative data, access to demonstrator sites	Regular meetings Individual and group meetings
Identified sites GPs Aboriginal Health Workers Practice Nurses Practice Managers Care Navigators/CS Coordinators AMS teams	Data collection Information on evaluation Case studies	Individual and group meetings Email
Selected patients	Provide qualitative data for patient experience studies	Individual meetings
Regional services	Qualitative data collection	Individual and group meetings
State Government	Inform	Email/phone meetings

Timeline

Proposed timing of evaluation activities is set out in the table below. Ethics applications would begin in the latter half of 2020 in preparation for data collection to commence in 2021. Data collection and analysis for each area is staggered as shown in the Table with a final report due to One Disease in December 2022.

	2020		2021				2022			
	July-Sep	Oct-Dec	Jan-Mar	Apr-June	July-Sep	Oct-Dec	Jan-Mar	Apr-June	July-Sep	Oct-Dec
Ethics application and revisions										
Collation of program data										
Area 1										
Focus groups with key OD staff										
Healthcare provider interviews										
Healthcare data access and cleaning										
Data analysis and Area write-up										
Area 2										
Healthcare provider interviews										
Healthcare data access and analysis										
Data analysis and Area write-up										
Area 3										
Patient interviews										
Healthcare data access and analysis										
Data analysis and Area write-up										
Area 4										

Community survey										
Prevalence data access and cleaning										
Data analysis and Area write-up										
Draft report consultation										
Final report submission										20 Dec

Area 1 – Implementation

Area 1 addresses the processes of implementing the strategy and the perceptions and experiences of involved services and providers.

Area 1 Evaluation Questions

The key questions for this area of investigation are:

- How has the program developed over time and to what extent have program strategies been implemented as planned?
- What are the barriers and enablers to implementation in different settings and for different client groups?
- To what extent is the strategy aligned with principles and processes for disease elimination?

How has the program developed over time and to what extent have program strategies been implemented as planned?		
Secondary questions	**Data source**	**Collection Method**
How has the program been implemented over time?	Program data and Interviews	Interviews and document review
To what extent have program strategies developed and been implemented as planned?	Program data and Interviews	Interviews and document review
What are the barriers and enablers to implementation in different settings and for different client groups?	Program data and Interviews	Interviews and document review
To what extent is the strategy aligned with principles and processes for disease elimination?	One Disease documents and literature	Desktop review and Interviews

Area 1 - Available data

It is anticipated that the following data can be provided by One Disease:

- Number of enrolled patients, number of enrolled clients with care plans
- Demographics of patients
- Number of practices and other health services participating (at site and/or regional level)
- Some reports from care plans
- One Disease program reports and documents

Area 1 - Additional data to be collected

Qualitative data will be collected by the academic core team. The team will seek assistance in gaining access to specific health service staff and other stakeholders from the One Disease Project Leads.

Given the size of the project and number of participating services, data on implementation will be collected by the evaluation team at regional and state level (if appropriate) with key managers, providers, clinicians and service coordinators involved in implementation.

Key data sources include interviews and focus groups with staff at regional, state and service levels. Semi-structured interview templates for interviews will be developed. Interviews may be conducted face-to-face or by phone, unless opportunistic interviews are arranged at the time of site visits or other meetings.

Area 1 – Analysis

Normalisation Process Theory (NPT) will underpin our approach to Area 1 analysis. NPT is a sociological theory concerned with the social organization and dynamic work processes of implementation, of making practices routine (embedding) and of sustaining them in their social and organisational contexts (integration).

We will consider the program's development and adaptation over time, potential of the program model to improve care and outcomes (the extent to which the program elements align with recognised features of coordinated systems-based models for disease elimination); its workability in different contexts including observable barriers and enablers; and the extent to which new practices for detection and management were embedded in everyday work and integrated into service systems.

Area 2 Impact on health service systems and delivery of care
Area 2 addresses the impacts on health service systems and delivery of care.

Area 2 Evaluation Questions
What have been the impacts on health system development?

- What are the impacts on primary health care and hospital systems development?
- What are the impacts on primary health care and hospital activity such as length of hospital stay (LOS) and discharge, PHC follow up and care planning?
- To what extent has care followed best practice as outlined in the CARPA guidelines?

What are the impacts on health system development ?		
Secondary questions	**Data source**	**Collection Method**
Patient outcomes	Patient record and CDC data	Data request
What are the impacts on hospital systems and activity – length of hospital stay (LOS), readmissions	Hospital activity data Program data and Interviews	Data request Interviews and document review
What are the impacts on primary health systems and activity such as PHC follow up and care planning?	Primary care data Program data and Interviews	Data request Interviews and document review

Area 2 - Available data
For **Area 2** the following data reports will be analysed:

Data for enrolled patients

- ☐ Hospital admissions
- ☐ Hospital readmissions
- ☐ Electronic discharge summaries for GPs

Practice data

- ☐ Episodes of care for CS patients
- ☐ Pathology for CS patients
- ☐ Date of notification
- ☐ Date of infectious disease/dermatology review
- ☐ Medications prescribed for CS patients and household contacts
- ☐ Number of presentations for scabies
- ☐ Proportion of patients receiving CS Care plan

Area 2 - Additional data to be collected
Qualitative data will be collected by the academic core team. The team will seek assistance in gaining access to specific health service staff and other stakeholders from the One Disease Project Leads. Key data sources include interviews with PHC and Hospital staff and managers. Semi-structured interview templates for interviews will be developed. Interviews may be conducted face-to-face or by phone, unless opportunistic interviews are arranged at the time of site visits or other meetings.

Area 2 - Additional considerations

Rural/remote context

Unique rural service patterns will be factored in. For example, transfer of patients from smaller hospitals to referral hospitals and vice versa will be factored into the analysis of admissions and ED presentations so that a patient transferred between hospitals without going home is counted as one admission.

Sample size

The sample size will be the number of patients for whom data is available and can be used for the evaluation. The size of the sample will be considered in analysis and reported accordingly.

Data limitations

There are a number of limitations with data extracted from primary health care systems. However, the Northern Territory has the most advanced primary health care information system in Australia, and arguably the highest quality data. This notwithstanding, the quality of extracted data is dependent on the quality of data entry by primary health care staff. For example, medications may be dispensed but not recorded in the patient information system. Additionally, some of the proposed indicators are things not routinely entered into medical records (e.g. chemical treatment of house). At the commencement of the evaluation the team will review the proposed data elements to be extracted with the One Disease team to determine the validity and reliability of the extracted data.

Within hospital data, the major limitation is that there is no specific ICD-10 code for crusted scabies. Thus to enable data collection on hospital admissions/readmissions will require manual review of hospital files for CS patients.

Area 3 – Impact on patient experience and outcomes

Area 3 addresses patient experience and outcomes.

Area 3 Evaluation Questions

- What are the impacts on patient experiences and outcomes?

3. What are the impacts on patient experience and outcomes		
Secondary questions	**Data source**	**Collection Method**
What are the impacts on patient outcomes?	Patient record and CDC data	Data request
Did the CS strategy reduce recurrences and new cases of CS among individuals enrolled in the program?	Primary care and hospital data/ shared medical record	Data request
How do patients experience the program?	**Qualitative data**	**Interviews**
How have patients experienced the program and what has been their experience of health care?	Qualitative data	Interviews

Area 3 - Primary and secondary outcomes

It is anticipated the following individual level variables from audit of patient records conducted by One Disease staff for patients with CS and patients with recurrences of CS will be available to the evaluation team.

Demographics
Sex
Age
Aboriginal and Torres Strait Islander status
Main primary health care service Homelessness
Overcrowding
Co-morbidities

- Type I/II Diabetes Mellitus
- Chronic Kidney Disease
- Systemic Lupus Erythematosus
- Alcohol abuse
- Other substance abuse
- Human T-lymphotropic virus 1 (HTLV-1)

Initial investigations and treatment Date of initial assessment of suspected CS
Investigations performed

- Skin scraping
- Photos
- Bloods as per guidelines

Date of infectious disease/dermatology review Date treatment initiated
Place of treatment (community/hospital) Duration of initial treatment
Completed initial treatment

Follow-up treatment Number of episodes of care Evidence of family follow-up

Evidence of chemical treatment of home Care
plan in use
Recall system in use Recurrence
date

From Centres of Disease Control
Date of notification
Age, sex and Aboriginal and Torres Strait Islander status of patient Region of notification
Primary episode or recurrence
Contact name of date of birth and community

Area 3 - Available data
For **Area 3** the following data reports will be analysed:

Data for enrolled patients
- Hospital admissions
- Hospital readmissions
- Electronic discharge summaries for GPs

Practice data
- Episodes of care for CS patients
- Pathology for CS patients
- Date of notification
- Date of infectious disease/dermatology review
- Medications prescribed for CS patients and household contacts
- Number of presentations for scabies
- Proportion of patients receiving CS Care plan

Area 3 Additional Data
Patient interviews
Qualitative data will be collected by the academic core team. We will engage and train a local Aboriginal health worker to assist in the conduct of face to face interviews with clients. Interviews will explore the experiences of people with CS. It is anticipated that client groups with specific needs will be sampled, including for example, people with recurrences or who are homeless. Groups will be determined in consultation with One Disease team leads. Short semi-structured interview templates will be developed. The team will seek assistance in gaining access to clients with CS from the One Disease Project Leads.
One Disease will provide demographic data, data on episodes of care, care planning, and hospital or community based treatment extracted from an existing database (Communicare or PCIS of shared electronic record) as well as data from One Disease data systems on education and other support services received.
We will draw on case study methodology to explore the client in their local community environment, bringing together data from different sources on recurrences, living arrangements, travel and perceptions of care at different points of the treatment trajectory.

Area 3 - Additional considerations

Rural/remote context

Unique rural service patterns will be factored in. For example, transfer of patients from smaller hospitals to referral hospitals and vice versa will be factored into the analysis of admissions and ED presentations so that a patient transferred between hospitals without going home is counted as one admission.

Sample size

The sample size will be the number of patients for whom data is available and can be used for the evaluation. The size of the sample will be considered in analysis and reported accordingly.

Data limitations

There are a number of limitations with data extracted from primary health care systems. However, the Northern Territory has the most advance primary health care information systems in Australia, and arguably the highest quality data. This notwithstanding, the quality of extracted data is dependent on the quality of data entry by primary health care staff. For example, medications may be dispensed but not recorded in the patient information system. Additionally, some of the proposed indicators are things not routinely entered into medical records (e.g. chemical treatment of house). At the commencement of the evaluation the team will review the proposed data elements to be extracted with the PCIS team and ACCHOs to determine the validity and reliability of the extracted data.

Within hospital data, the major limitation is that there is no specific ICD-10 code for crusted scabies. Thus to enable data collection on hospital admissions/readmissions will require manual review of hospital files for CS patients.

Area 4 – Impact of community health promotion strategies on awareness, attitudes and prevalence at the community level

Area 4 investigates the impact of community health promotion strategies (scabies free zones, social media and other strategies) on awareness, attitudes and prevalence at the community level

Area 4 Evaluation Questions

4. What are the impacts of health promotion strategies on awareness, attitudes and prevalence at the community level		
Secondary questions	**Data source**	**Collection Method**
What is the impact of scabies free zones on prevalence of scabies at household level in selected communities?	Survey data	Data request
What is the reach and impact of social media strategies on awareness and attitudes to crusted scabies	Metrics from social media Qualitative data	Data request Survey and interviews Document review

Area 4 - Available data

As data availability from surveys conducted by One Disease to establish prevalance at the household level becomes known, exact items to be included in data analysis will be identified.

For **Area 4** the following data reports will be analysed:

- Pre and Post Survey data provided by One Disease on household prevalence
- Metrics data if available from any social media interventions

Area 4 Additional Data

Qualitative data will be collected by the academic core team. Key data sources include document review and interviews with One Disease staff, and community surveys. The team will seek assistance in gaining access to community members and other stakeholders and help with administration of retrospective cross sectional surveys from the One Disease Project Leads. Short surveys will assess knowledge, awareness and attitudes to crusted scabies prevention, treatment and creation of scabies free zones.

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Appendix A – Participating services

Health Service Provider	Site
Stage 1 NT Aboriginal Community Controlled Health Services (ACCHS)	
Miwatj	
	Galiwinku
	Gunyangara
	Nhulunbuy
	Yirrkala
Katherine West	
	Bulla
	Timber Creek
	Yarralin
	Amanbidji
	Nitjpurru
	Daguragu
	Kalkarindji
	Lajamanu
Sunrise	
	Manyallaluk
	Barunga
	Beswick
	Mataranka
	Jilkminggan
	Minyerri
	Bulman/Weemol
	Ngukurr
	Rittarangu
Wurli-Wurlinjang	
	Binjari
	Katherine
Danila Dilba	
	Darwin
Stage 1 Department of Health	
	Adelaide River
	Alyangula (Groote Eylandt)
	Angurugu
	Bagot
	Batchelor
	Belyuen (Delissaville)
	Borroloola
	Casuarina
	Gapuwiyak
	Gunbalanya (Oenpelli)

	Jabiru and Gagudju (Kakadu)
	Karama
	Katherine
	Maningrida
	Milikapiti (Snake Bay)
	Milingimbi
	Milyakburra (Bickerton Island)
	Minjilang (Croker Island)
	Nauiyu (Daly River)
	Nhulunbuy
	Numbulwar
	Palmerston
	Palumpa (Nganmarriyanga)
	Peppimenarti
	Pine Creek
	Pirlangimpi (Garden Point)
	Ramingining
	Robinson River
	Umbakumba
	Wadeye (Port Keats)
	Wagait Beach
	Warruwi (Goulburn Island)
	Woodycupaldiya
	Wurrumiyanga (Bathurst Island)
Stage 1 NT Aboriginal Community Controlled Health Services (ACCHS) (commencing in 2018)	
Central Australian Aboriginal Congress	
	Alice Springs
	Amoonguna
	Areyonga
	Mutitjulu
	Ntaria (Hermannsberg)
	Santa Teresa
	Wallace Rockhole
Anyinginyi	
	Corella Creek
	Mungkarta
	Tennant Creek
	Wogyala
	Areyonga
	Ntaria (Hermannsberg)
	Wallace Rockhole
Ampilatwatja HC	Ampilatwatja
Kintore Pintupi Homelands	Kintore
Urapuntja (Utopia) Clinic	Urapuntja
Stage 1 NT Government Health Services (commencing in 2018)	

	Ali Curung (Ale-Kerange)
	Alice Springs
	Aputula (Finke)
	Canteen Creek (Orwaitilla)
	Elliott
	Engawala (Alcoota)
	Epenarra (Wutunugurru)
	Haasts Bluff (Ikuntji)
	Harts Range (Atitjere)
	Imanpa (Mt Ebenezer)
	Kaltukatjara (Docker River)
	Kings Canyon (Watarrka)
	Lake Nash (Alpurrurulam)
	Laramba (Napperby)
	Mount Liebig (Amunturrngu)
	Ntaria (Hermannsburg)
	Nyirripi
	Orrtipa-Thurra (Bonya)
	Papunya
	Pmara Jutunta (Ti Tree 6 Mile)
	Tara (Neutral Junction)
	Tennant Creek
	Ti Tree (Nturiya)
	Titjikala (Maryvale)
	Ukaka
	Willowra
	Wilora (Stirling)
	Yuelamu (Mt Allan)
	Yuendumu
	Yulara

APPENDIX 3

ONE DISEASE

KEY ACHIEVEMENTS

2011

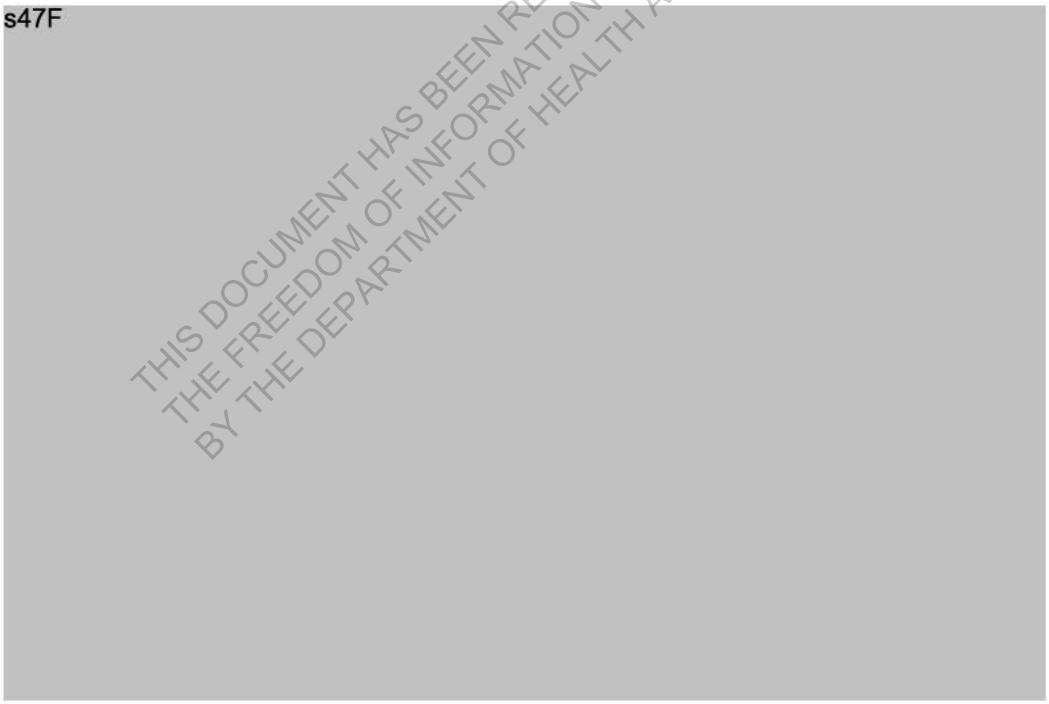
One Disease At A Time (ODAAT) is established by Dr Sam Prince to eliminate a preventable disease from Australia's Indigenous communities.

ODAAT develops the East Arnhem Scabies Control Program (EASCP) based on analysis and insights from local and international programs, including those from the Australian Indigenous communities of Galiwinku and Wadeye, and scabies programs in Panama, Central America.

The EASCP is the first program worldwide to focus on "core transmitters" - those with Crusted Scabies - to efficiently and effectively reduce simple scabies.

2012

Under the EASCP, the Crusted Scabies case management pilot program begins in Yirrkala, a small community in the Northern Territory's East Arnhem region. Six people with Crusted Scabies are identified and treated.



2013

ODAAT partners with Merck Sharp & Dohme and is successful in fast-tracking the submission to have Ivermectin approved to be prescribed as an orally administered treatment for scabies and Crusted Scabies by the Australian Therapeutic Goods Administration.

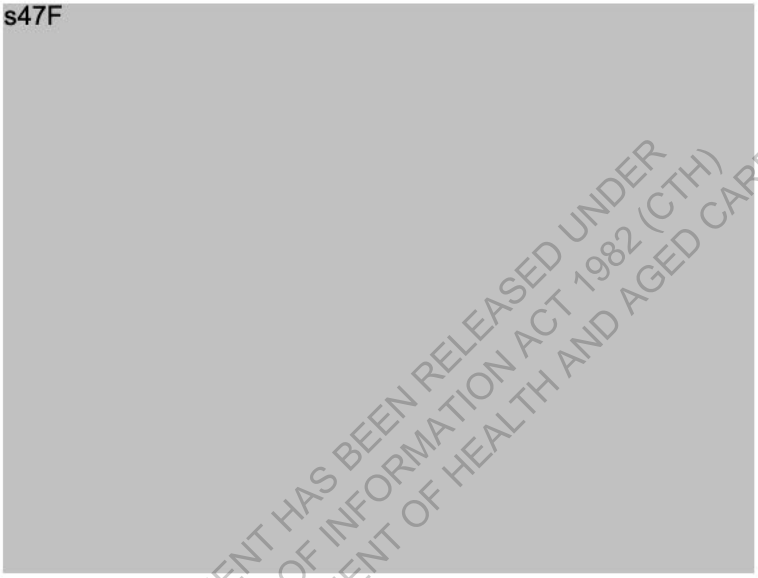
One Disease At A Time legally changes its name to One Disease.

2014

One Disease makes the crucial decision to focus efforts solely on Crusted Scabies after a greater understanding is attained of who needs the most immediate attention.

One Disease sets the following goal: To eliminate Crusted Scabies as a public health concern, through patient self-management, across the Northern Territory (NT) by the end of 2018 and in Australia by the end of 2022.

s47F



2016

One Disease begins to focus on using the Crusted Scabies recurrence rate as a key measure of its ongoing success in the field.

One Disease is one of a group of organisations that successfully advocate for the NT government to include Crusted Scabies as a notifiable disease in the NT, and therefore confirming it is a public health issue.

s47F

2017

One Disease conducts clinical audits of health services' clinical files to ensure confirmed Crusted Scabies cases meet the NT's new notifiability criteria. Of the 488 suspected cases, only 85 meet the criteria, indicating further health sector education is required.

One Disease develops the world-first Crusted Scabies Elimination Program, which is endorsed by the One Disease Advisory Board.

The elimination program has two goals:

1. Improving detection and diagnosis of Crusted Scabies

2. Preventing recurrences of Crusted Scabies in people who have been successfully treated by embedding local systems and ensuring those treated live in Scabies Free Zones

One Disease signs a new Memorandum of Understanding with the NT Department of Health in July 2017. The MOU states that the NT Department of Health will commit to collaborating with One Disease in eliminating Crusted Scabies.

One Disease establishes a video microscopy project to investigate whether new technology can be used to improve detection by shortening diagnosis time.

One Disease delivers 164 Crusted Scabies education sessions with a total of 1581 attendees.

Recurrence rate of Crusted Scabies in the NT is just under 10%.

s47F

2018

One Disease secures funding for two years from the Australian Government Department of Health through the Office of The Hon Ken Wyatt AM MP.

One Disease successfully negotiates the inclusion of recall and reminder prompts specifically for people being treated for Crusted Scabies, within the existing electronic patient systems of the NT. By mid-2018, 75% of One Disease's Crusted Scabies clients have a recall and reminder prompt set up in their health systems.

One Disease establishes and begins to run a two-year small grant program for organisations working with remote Indigenous communities in the NT, Western Australia (WA) & Queensland (Qld). Grants are awarded for local scabies and Crusted Scabies education projects, specifically on how to create Scabies Free Zones.

One Disease delivers 364 Crusted Scabies education sessions with a total of 3284 attendees.

Recurrence rate of Crusted Scabies in the NT is 3.3%.

s47F

2019

One Disease develops two new resources: a Renal Brochure and the Crusted Scabies e-Learning Module for Health Workers.

One Disease makes the decision to focus its efforts on Scabies Free Zone education in the NT due to the Crusted Scabies burden in this state.

One Disease begins hiring Indigenous community-based Healthy Skin workers to work directly with their communities to provide education on creating Scabies Free Zones.

37 organisations working with Indigenous communities across the NT, Qld and WA are supported with One Disease small grants to develop Scabies Free Zones projects.

An additional two years of funding is confirmed from the Australian Government Department of Health.

This funding is matched by the s47G who began supporting One Disease in 2011.

Recurrence rate of Crusted Scabies in the NT is 1.7%. One Disease celebrates its first quarter (June 2019 quarter) with a zero-recurrence rate.

s47F

2020

The advent of the COVID-19 pandemic leads One Disease to work quickly and develop a series of community driven handwashing and social distancing promotion short clips to help spread COVID-19 safe messages within Indigenous communities.

One Disease Scabies and Crusted Scabies Storytelling tool is completed and launched virtually in May 2020.

Due to pandemic-imposed travel restrictions, One Disease begins an intensive mass media campaign to increase understanding of scabies detection, treatment and prevention and the reach of our messages.

Crusted Scabies detection begins to be recorded by its grade:

Crusted Scabies Grade 1 (10x infectivity): 63% of clients (Mean 57%)

Crusted Scabies Grade 2 (100 x infectivity): 25% of clients (Mean 33 %)

Crusted Scabies Grade 3 (1000 x infectivity): 12% of clients. (Mean 10%)

One Disease writes the Crusted Scabies/scabies section of the Batchelor Institute Workbook for the unit: HLTAHW016 Assess clients physical wellbeing and the Charles Darwin University Skin Health Unit (as part of the Postgraduate Certificate in Primary Health Care).

A process is initiated with other stakeholders to prepare and submit a Pharmaceutical Benefits Scheme (PBS) submission to have Ivermectin included as a first-line treatment for scabies on the PBS.

The enhanced dataset for Crusted Scabies notifications within the notifiable diseases system of the Northern Territory Government Public Health Unit (Centre for Disease Control) is completed and becomes live.

Recurrence rate of Crusted Scabies in the NT is 3.03%.

2021

The SCAN (Skin Checks Across the North) app was completed for Aboriginal and Torres Strait Islander people living in the NT, WA and Qld. Its key aim is to help users work out if they may have scabies or another skin condition, and encourages a visit to their health clinic. It is available in English and Yolngu Matha.

2022

One Disease Podcast series "Scratching the Surface" is completed, consisting of eight episodes.

Ivermectin becomes available on the PBS as a first-line treatment for scabies for Aboriginal and Torres Strait Islander people.

Crusted Scabies recurrence rate is currently 2.9%.

s47F