Phase 2 Report on the Crusted Scabies Elimination Program

Prepared for One Disease

June 2020

Dr Karen Gardner
Dr Miriam Glennie

Contact Page

Client	One Disease
Title	Report on the Crusted Scabies Elimination Program
Contact Officer	Ms Michelle Dowden
University	Public Service Research Group, University of NSW, Canberra
Contact	Dr Karen Gardner
Business Address	School of Business, UNSW Canberra, PO Box 7916, Canberra, BC ACT, 2610
Telephone	02 6268 6253
Mobile	0424 247 376
Email	Karen.Gardner@unsw.edu.au Miriam.Glennie@unsw..edu.au

Preamble

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

This report contains the first three components of work.

Contents page

PART 1

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

PART 2

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.

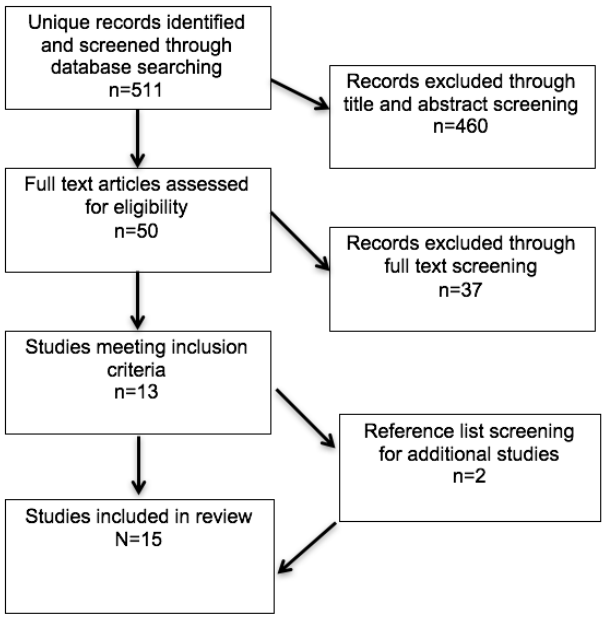

Figure 1. Eligibility flow chart

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	4x100m^2 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

				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 screening of self-reports.	No	RVS PR 9.5/10,000, LEC PR 6.4/10,000 Local PR 5/10,000		High
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.

Reference list

Cassell, J. A., Middleton, J., Nalabanda, A., Lanza, S., Head, M. G., Bostock, J., ... & Walker, S. L. (2018). Scabies outbreaks in ten care homes for elderly people: a prospective study of clinical features, epidemiology, and treatment outcomes. *The Lancet infectious diseases*, *18*(8), 894-902.

Currie BJ, Maguire GP, Wood YK. (1995). Ivermectin and crusted (Norwegian) scabies *Med J Aust*; 163: 559-560.

Devita, A., Ibrahim, F., Menaldi, S. L. S. W., Budianti, A., & Yasmon, A. (2019). Detection of Mycobacterium leprae using real-time PCR in paucibacillary leprosy patients with negative acid-fast bacilli smears. *Medical Journal of Indonesia*, *28*(4), 351-7

Davoodian, P., Dadvand, H., Raz-Nahan, M., Baghestani, S., Mahbubi, A., & Bageri, A. (2009). Case finding survey for leprosy in Iran: Bandar Abbas and Minab. *Leprosy Review*, *80*(4), 441-444.

De Souza Dias, M. C. F., Dias, G. H., & Nobre, M. L. (2007). The use of Geographical Information System (GIS) to improve active leprosy case finding campaigns in the Municipality of Mossoró, Rio Grande do Norte State, Brazil. *Leprosy Review*, *78*(3), 261-269.

Engelman, D., & Steer, A. (2018). Diagnosis, treatment, and control of scabies: can we do better? Lancet Infect. Dis., 18, 822-823. doi:10.1016/S1473-3099(18)30372-4

Ezenduka, C., Post, E., John, S., Suraj, A., Namadi, A., & Onwujekwe, O. (2012). Cost-Effectiveness Analysis of Three Leprosy Case Detection Methods in Northern Nigeria. *PLoS Neglected Tropical Diseases*, *6*(9).

Feldmeier, H., & Heukelbach, J. (2009). Epidermal parasitic skin diseases: a neglected category of poverty-associated plagues. *Bull World Health Organ*, 87(2), 152-159. doi: 10.2471/BLT.07.047308

Fürst, T., Cavaliero, A., Lay, S., Dayer, C., Chan, S., Smrekar, A., . . . Steinmann, P. (2018). Retrospective active case finding in Cambodia: An innovative approach to leprosy control in a low-endemic country. *Acta Tropica, 180*, 26-32.

Tamieka A. Fraser, Alynn Martin, Adam Polkinghorne, Scott Carver . Comparative diagnostics reveals PCR assays on skin scrapings is the most reliable method to detect Sarcoptes scabiei infestations. *Veterinary Parasitology* 251 (2018) 119–124.

Ganapati, R., Revankar, C. R., Pai, V. V., Bulchand, H. O., & Ajayan, N. (2001). Leprosy case detection through community volunteers - A low cost strategy [3]. *International Journal of Leprosy and Other Mycobacterial Diseases*, *69*(1), 37-39.

Gillini, L., Cooreman, E., Pandey, B., Bhandari, C., Vandelaer, J., Rayamajhi, R., . . . Kita, E. (2018). Implementing the Global Leprosy Strategy 2016-2020 in Nepal: Lessons learnt from active case detection campaigns. *Leprosy Review*, *89*(1), 77-82.

Hargrave, J. (1977). Leprosy and the Aboriginal health worker in the Northern Territory. *Aboriginal and Islander Health Worker Journal*, *1*(2), 4.

Hargrave, J. C. (1980). Current notes on leprosy control in the Northern Territory. NT Health.

Hay, R.J., Steer, A.C., Engleman, D., & Walton, S. (2012) Scabies in the developing world—its prevalence, complications, and management. *Clin. Microbiolol. Infect*. 18, 313-323. doi: 10.1111/j.1469-0691.2012.03798.x.

Hay, R.J., Johns, N.E., Williams, H.C., Bolliger, I.W., Dellavalle, R.P., Margolis, D.J., Naghavi, M. (2014). The global burden of skin disease in 2010: an analysis of the prevalence, complications and management. *J. Invest. Dermatol*. 134(6), 1527-1534. doi: 10.1038/jid.2013.446

Hoeven TA, Fischer EA, Pahan D, Richardus JH (2008) Social distance and spatial distance are not the same, observations on the use of GIS in leprosy epidemiology. Epidemiol Infect 136: 1624–7

Jeanneret, L. A., et al. (2007). "An outbreak of scabies: A forgotten parasitic disease still present in Switzerland." Swiss Medical Weekly 137(49-50): 695-699

Khan, A., et al. (2012). "Rapid control of a scabies outbreak at a tertiary care hospital without ward closure." American Journal of Infection Control 40(5): 451-455

Klepac, P., Funk, S., Hollingsworth, T. D., Metcalf, C. J. E., & Hampson, K. (2015). Six challenges in the eradication of infectious diseases. Epidemics, 10(Supplement C), 97-101. doi: https://doi.org/10.1016/j.epidem.2014.12.001

Kumar, M. S., Padmavathi, S., Shivakumar, M., Charles, U., Appalanaidu, M., Perumal, R., Somasekhar, Y. J. L. r. (2015). Hidden leprosy cases in tribal population groups and how to reach them through a collaborative effort. *86*(4), 328-334.

Lokuge, B., et al. (2014). "Crusted scabies in remote Australia, a new way forward: lessons and outcomes from the East Arnhem Scabies Control Program." Medical Journal of Australia 200(11): 644-648.

Lush, Douglas, John C. Hargrave, and Angela Merianos. "Leprosy control in the Northern Territory." *Australian and New Zealand journal of public health* 22.6 (1998): 709-713.

Mangeard-Lourme, J., Singh, A., Singh, R. K., Parasa, J., & de Arquer, G. R. (2017). Enhanced active case-finding, identifying leprosy cases missed by recent detection campaigns in Munger District, Bihar, India. *Leprosy Review, 88*(4), 452-462.

May, P., Bowen, A., Tong, S., Steer, A., Prince, S., Andrews, R., Carapetis, J. (2016). Protocol for the systematic review of the prevention, treatment and public health management of impetigo, scabies and fungal skin infections in resource-limited settings. Systematic Reviews, 5, 1626. doi: 10.1186/s13643-016-0335-0

Moura, M. L. N., Dupnik, K. M., Sampaio, G. A. A., Nóbrega, P. F. C., Jeronimo, A. K., do Nascimento-Filho, J. M., Nobre, M. L. (2013). Active Surveillance of Hansen's Disease (Leprosy): Importance for Case Finding among Extra-domiciliary Contacts. *PLoS Neglected Tropical Diseases, 7*(3).

Pedrosa, V. L., Dias, L. C., Galban, E., Leturiondo, A., Palheta, J., Jr., Santos, M., . . . Talhari, C. (2018). Leprosy among schoolchildren in the Amazon region: A cross-sectional study of active search and possible source of infection by contact tracing. *PLoS Neglected Tropical Diseases, 12*(2).

Quilty, S., Kaye, T.S., & Currie, B.J. (2017). Crusted scabies in northern and central Australia – now is the time for eradication. Med. J. Aust., 206(2), 96. doi: 10.5694/mja16.00809

Rao Rao, P. V., Bhuskade, R. A., & Desikan, K. V. (2000). Modified leprosy elimination campaign (MLEC) for case detection in a remote tribal area in the State of Orissa, India. *Leprosy Review, 71*(3), 377-381.

Roberts LJ, Huff am SE, Walton SF, Currie BJ. (2005). Crusted scabies: clinical and immunological findings in seventy-eight patients and a review of the literature. J Infect 50: 375-381.

Schreuder, P. A. M., Liben, D. S., Wahjuni, S., Van Den Broek, J., & De Soldenhoff, R. (2002). A comparison of rapid village survey and leprosy elimination campaign, detection methods in two districts of East Java, Indonesia, 1997/1998 and 1999/2000. *Leprosy Review, 73*(4), 366-375.

Shetty, V. P., Thakar, U. H., D'Souza, E., Ghate, S. D., Arora, S., Doshi, R. P., . . . Thakur, D. V. (2009). Detection of previously undetected leprosy cases in a defined rural and urban area of Maharashtra, Western India. *Leprosy Review, 80*(1), 22-33.

Tiendrebéogo, A., Sow, S. O., Traore, M., Sissoko, K., & Coulibaly, B. (1999). Comparison of two methods of leprosy case finding in the circle of Kita in Mali. *International Journal of Leprosy and Other Mycobacterial Diseases, 67*(3), 237-242.

Utap, M. S., & Kiyu, A. (2017). Active case detection of leprosy among indigenous people in Sarawak, East Malaysia. *Leprosy Review, 88*(4), 563-567.

US Health Resources and Services Administration (HRSA) (2019). National Hansen's disease (leprosy) program caring and curing since 1984, from: https://www.hrsa.gov/hansens-disease/index.html

Walton SF, Holt DC, Currie BJ, Kemp DJ. (2004). Scabies: new future for a neglected disease. Adv Parasitol; 57: 309-376. 4

World Health Organisation (WHO). (2012). Global report for research on infectious diseases of poverty. Retrieved Aug. 29, 2018, from: http://www.who.int/tdr/capacity/global_report/en/

Worth, C., Heukelbach, J., Fengler, G., Walter, B., Liesenfeld, O., & Feldmeier, H. (2012). Impaired quality of life in adults and children with scabies from an impoverished community in Brazil. International Journal of Dermatology, 51(3), 275-282.

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

PART 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.

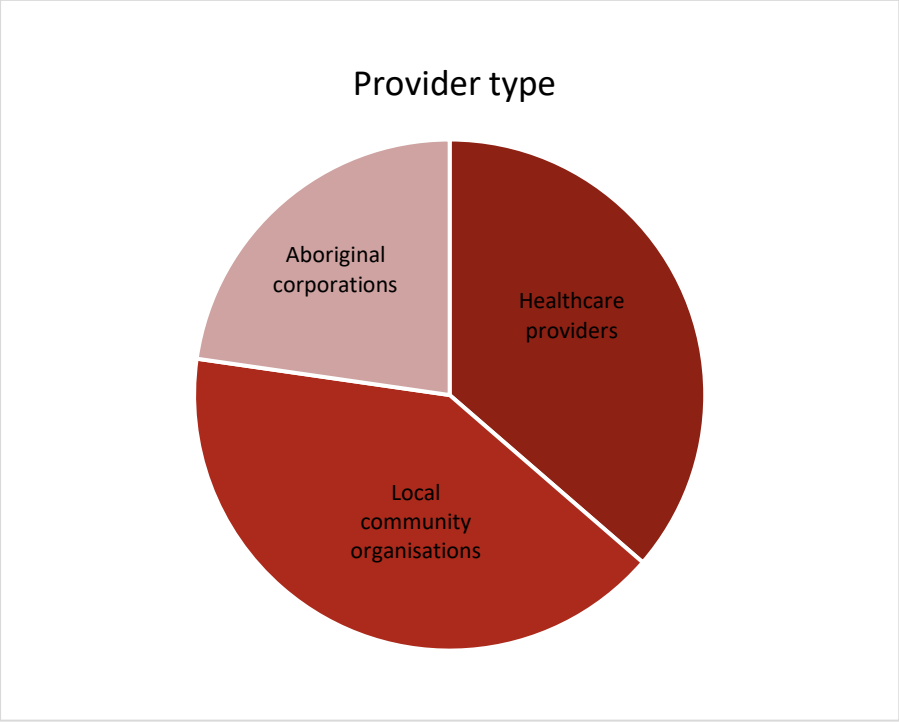

Figure 3.1. Provider type for completed projects

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.

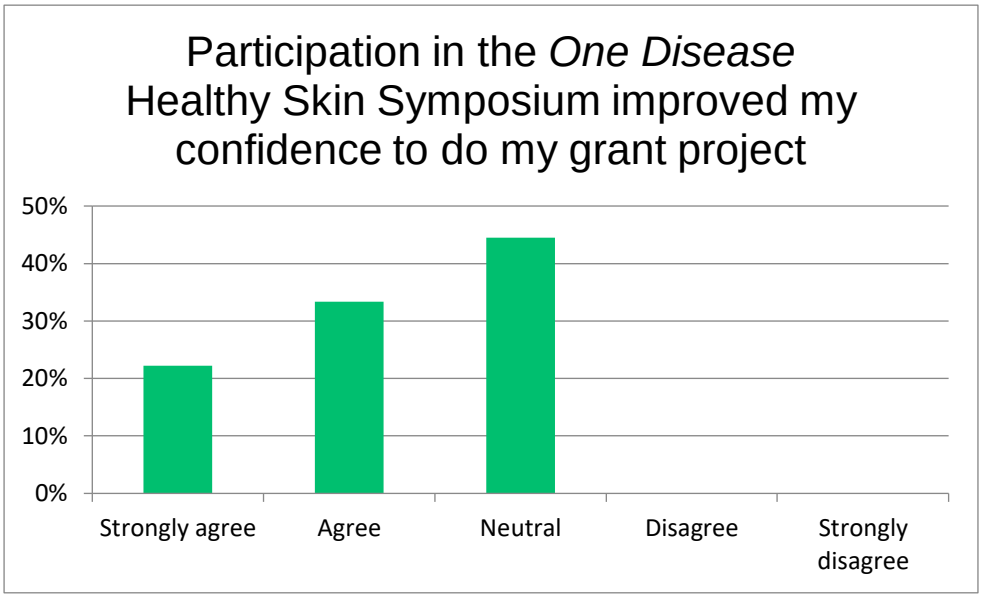

Figure 3.2 Grant project implementation confidence

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

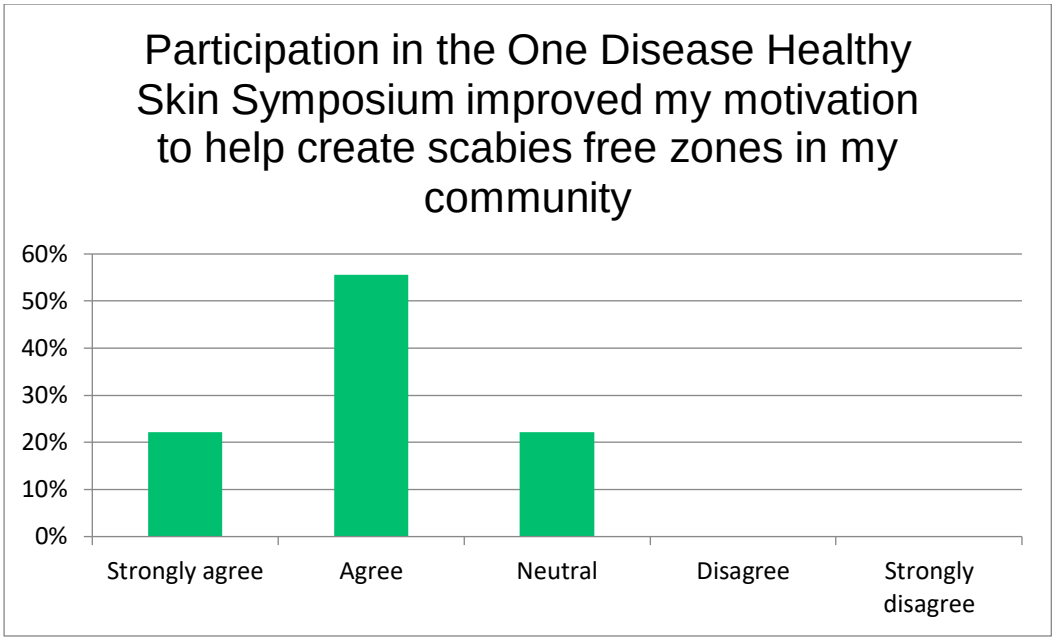

Figure 3.3 Scabies free zone motivation

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.

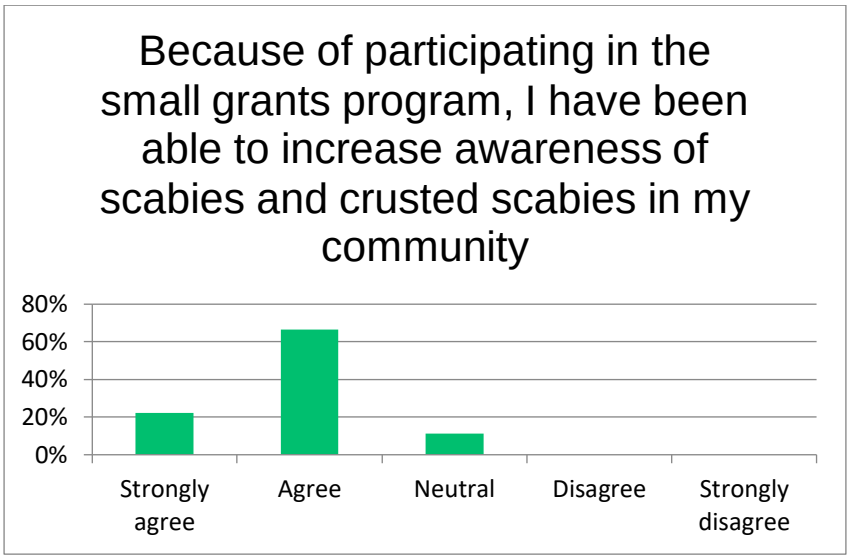

Figure 3.4. Increased community awareness of scabies and crusted scabies

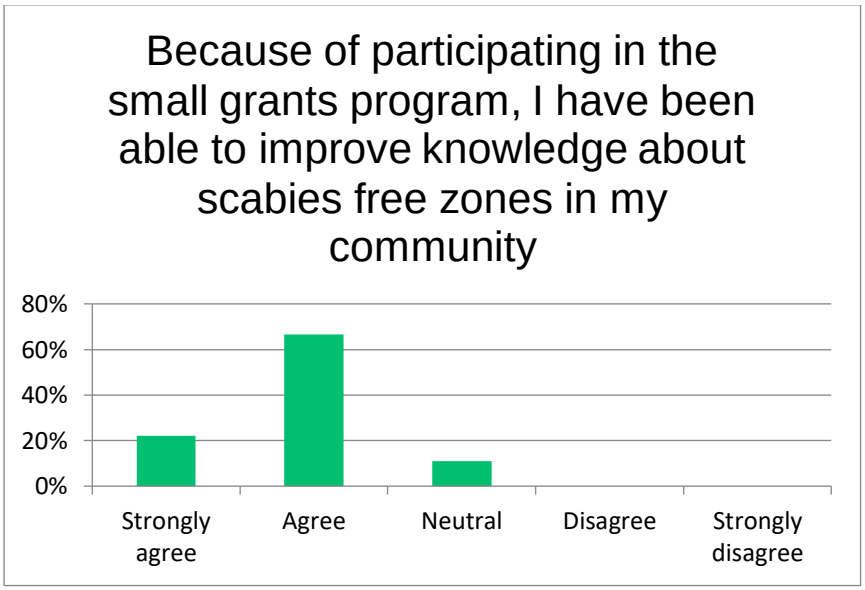

Figure 3.5. Increased community awareness of scabies and crusted scabies

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.