

ONE DISEASE AT A TIME

IMAGINE. PARTNER. ELIMINATE.

END OF YEAR REPORT 2012

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FOREWORD FROM THE CHAIR AND FOUNDER

We would like to thank you for your continued support of One Disease at a Time; your generosity in our first year has been crucial to our early success. We're looking forward to sharing with you, and the broader public, the stories of people and families we have partnered with. With these positive stories, our vision is to instill a sense of hope about Indigenous health in Australia.

As you know, our first initiative is to eliminate crusted scabies and scabies as public health issues in Australia. Crusted scabies is arguably one of the most devastating medical conditions in Australia. It is also one of the most misunderstood and neglected: patients and their families often suffer the condition in silence. 7 out of 10 children in remote Indigenous communities get scabies before their first birthday. One Disease is leading the way to change that, with the East Arnhem Scabies Control Program. This report is a summary of the first 12 months of the program.



Dr. Sam Prince.



A UNIQUE CONCEPT IN INDIGENOUS HEALTH

ONE DISEASE AT A TIME HAS A SIMPLE BUT GROUNDBREAKING VISION:

TO REDEFINE THE WAY AUSTRALIANS PARTNER WITH INDIGENOUS COMMUNITIES AND SOLVE COMMON PROBLEMS
TO SHARE STORIES OF HOPE THAT IGNITE CHANGE

The Strategic Review of Indigenous Expenditure report from the Australian government report on Indigenous expenditures over the last decade highlights that all too often programs are poorly implemented with limited community engagement and local adaptation resulting in poor outcomes despite the billions invested.

ONE DISEASE IS CHANGING THIS

By combining the wisdom of Indigenous Australia with excellence in the fields of medicine, management and operational research, we are developing a unique approach to deliver sustained, scalable and culturally acceptable outcomes.

THE VALUES THAT DRIVE AND FOCUS US

- People first: community comes first, do no harm and be humble
- Empowerment: enable people to help themselves via collaboration and ownership
- Pioneering: always pursue and embrace change and innovation
- Honesty: above all else, act with transparency and integrity
- Independence: remain free from any political, religious or financial agendas

OUR APPROACH

- Work with existing health models to minimise overlap, leverage resources and maximise sustainability of outcomes.
- Take an iterative approach to strategy and program development (analysis needs, hypothesise, test, evaluate, adapt and evolve).
- Develop strategies that are future proof (both scalable and able to be tailored).



Chronic Diseases Network Conference, Darwin, September, 2012.

WHY ARE WE DOING IT?

CRUSTED SCABIES

A NEGLECTED AND MISUNDERSTOOD DISEASE

Crusted scabies is a far more severe form of simple scabies. It is a highly infectious and devastating condition that occurs when an individual's immune system is not able to control scabies mite replication. Hyper-infection develops, often with up to a million or more scabies mites (compared with 5-10 in simple scabies). It is not uncommon in remote indigenous communities where many individuals are at risk of lifelong recurrences.

Patients with crusted scabies are "core transmitters" of simple scabies in communities. They have a lower life expectancy, often develop complications from secondary bacterial infections and family members often suffer recurrent scabies, skinsores and complications, including the inability to sleep.

Patients and families are often stigmatised, children may be given sedatives to sleep, are excluded from school, and employment and personal relationships are significantly affected by the disease. The disease is disfiguring and it has a significant impact on the psychosocial health and quality of life of family members.

Patients suffer their illness and shame in silence with little ongoing care. As it is highly infectious, managing it is the first step towards eliminating scabies as a public health issue in Australia.

The East Arnhem Scabies Control Program is the first in the world to trial a chronic disease case management approach to prevent recurrences. Preliminary results are promising.



Magnified section of crusted skin; The crusts are thickened (keratin layers) of skin containing thousands of scabies mites (4500 per gram of skin), eggs, mite faeces and bacteria.

SIMPLE SCABIES AND SKINSORES

A DISEASE BORN OUT OF DISADVANTAGE

In remote Indigenous communities, scabies affects 7 out of 10 children before their first birthday. Scabies infections and resulting skinsores can lead to chronic diseases, including kidney failure (post streptococcal glomerulonephritis) and rheumatic heart disease, and ultimately, premature death.

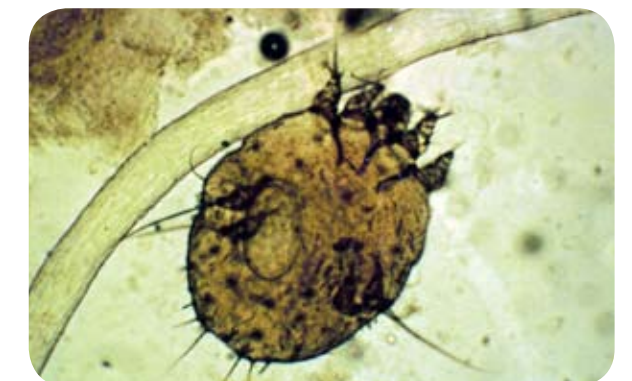
Therefore, scabies is one of the culprits behind significant chronic health issues for Indigenous people. The Australian Indigenous population houses the highest rates of rheumatic heart disease and post streptococcal glomerulonephritis in the world.

Eliminating scabies significantly reduces the flow on effects for down-stream conditions such as rheumatic heart disease and kidney failure. Moreover, the ongoing costs of initiatives to treat chronic diseases are enormous.

To illustrate, the cost of maintaining an adult from a remote community on dialysis is in excess of \$75,000 per patient per year, not including medication, relocation, housing, transport and hospitalisation. Added to this obvious financial expense is the immeasurable cost of family dislocation exacerbated by separation from a patient's homeland and social ties.



Magnified scabies mites.



THIS IS WHY ONE DISEASE BELIEVES PREVENTION IS BETTER THAN A CURE

THE EVOLUTION OF OUR PROGRAM

**INITIAL PROPOSAL FOR
IVERMECTIN MDA**

DEC 2010 – JULY 2011

We were invited to participate in an Ivermectin MDA with local health authorities. Before progressing we needed a greater understanding of the disease, past programs and needs of the community.

**INITIAL COMMUNITY AND
DISEASE ANALYSIS**

MARCH – JULY 2011

We conducted in-depth consultations with senior community leaders and community health workers as well as a detailed analysis of local and international skin programs. This included the Wadeye Healthy Skin program as it was reported to be one of the most successful scabies and skinsore control programs in Australia. From this research and the insights we gained, our program plan was developed.

**EAST ARNHEM SCABIES
CONTROL PROGRAM (EASCP)**

AUG 2011 – PRESENT

Our program is a multifaceted and effective partnership with Indigenous Australia to eliminate crusted scabies and scabies. It consists of **four key goals** with multiple strategies under each.

EAST ARNHEM SCABIES CONTROL PROGRAM

TREAT CORE TRANSMITTERS	1	Crusted scabies case management
	2	Supporting families with recurrent scabies
SUSTAINED REDUCTION OF REPRODUCTIVE RATE	3	Community surveillance for early treatment
	4	Social marketing for early treatment and compliance
	5	Development of next generation scabies cream
POINT IN TIME PREVALENCE REDUCTION	6	Healthy Skin, Healthy Homes events
	7	Ivermectin mass drug administration
OPERATIONAL ENHANCERS AND ENABLERS	8	Building community workforces
	9	Education tools for clinical staff and patients
	10	Sustainable washing machines
	11	Monitoring and evaluation
	12	Advocacy and systems-wide change

See pages 19 and 20 for detailed explanations.

A YEAR IN REVIEW

EARLY SUCCESS OF THE PROGRAM



This message stick was exchanged between senior community members and One Disease.

WORLD FIRST FOCUS ON CORE TRANSMITTERS

Ours is the first program internationally to focus on core transmitters (crusted scabies patients) as a means to most efficiently and effectively reduce the impact of simple scabies.

ELIMINATION OF CRUSTED SCABIES IN THE GOVE PENINSULA

- After developing relationships in community, seven cases of crusted scabies were confirmed clinically and by laboratory. Time since the last treatment or review for most of these patients was several months to several years. Many reported ongoing symptoms of crusting for a decade or more.
- Over the last 12 months crusting has been controlled (or eliminated as a public health issue) in these patients since the chronic care management plan (combining self care and monitoring) was initiated. The regular reviews ensured that recurrences of scabies prior to development of crusting was detected early and treated. In self-caring patients, in 12 months,

three recurrences with early crusting were detected requiring hospitalisation. Again, early detection meant infectivity and transmission of scabies to contacts and the community was minimised.

- A particularly difficult context in which to manage crusted scabies is where disabilities are present, meaning the preventative self-care plan cannot be implemented without disability services or regular respite care. One Disease coordinated services in the region and was able to put in place a plan to prevent hospitalisations and recurrences of crusting in a patient with crusted scabies and a disability that had led to monthly hospitalisations. Since June 2012, the care plan ensured only one recurrence in this patient.

DEVELOPING PARTNERSHIPS WITH LOCAL AUTHORITIES

- Miwatj Health and the Department of Health of the Northern Territory signed an MOU with One Disease to solidify their partnership in eliminating scabies as a health issue. Senior community clan leaders also extended their support through initiation of a formal alliance between One Disease and Miwatj with the exchange of a traditional message stick.
- We were involved in various Healthy Homes and Healthy Skin weeks across the region (Numbulwar, Gunyangara & Birritjimi, Yirrkala, Gapuwiyak, Ramininging, Milingimbi). These are part of a longer-term strategy to up-skill local clinicians and provide the community with broader education about the disease enabling them to seek early treatment.

PROGRAM ACTIVITIES IN TEN COMMUNITIES SINCE MID 2011

MANINGRIDA

- Sep '12 Supported NT Health Trachoma Program

MILINGIMBI

- Sep '11 HHHS Week
- Jul '12 Clinic in-service, Dermatologist visit

RAMINGINING

- Jul '12 Clinic in-service, Dermatologist visit
- Sep '12 HHHS week

GAPUWIYAK

- Aug '11 HHHS Week
- Sep '11 Skin screening

ANGURUGU

- Apr '12 Clinic in-service

NUMBULWAR

- Jul '12 Clinic in-service
- Oct '12 HHHS week

GUNYANGARA & BIRRITJIMI

- Nov '11 HHHS Week
- Jan '12 Skin screening
- Managing 1 crusted scabies patient
- Ongoing support for families with recurrent scabies
- 2 community workers

YIRRKALA

- Apr '12 School screening
- Jul '12 Skin screening, Dermatologist visit
- Oct '12 Mini-skin day
- Nov '12 Clinic in-service
- Managing 6 crusted scabies patients
- 2 community workers

UMBAKUMBA

- Apr '12 School screening

• HHHS: Healthy Homes, Healthy Skin.

BUILDING A WORLD CLASS TEAM

ON THE GROUND EAST ARNHEM LAND



Buddhima Lokuge
Program Consultant
Buddhi is a Program Consultant from EveryVoiceCounts. He

has been contracted to guide program strategy and implementation. He is a doctor who has worked internationally with Médecins Sans Frontières (MSF) as well as with the Australian Government.



Alex Kopczynski
Operations Manager
Alex has been working in the East Arnhem Region since

January 2005, primarily as an Environmental Health Officer with the NT Department of Health. He has extensive experience coordinating public health initiatives, including the “no germs on me” hand washing campaign and numerous Healthy Homes, Healthy Skin events.



Faye Alvoen
Crusted Scabies Nurse
Faye is a nurse with decades of experience working in Northern

Australia. She is currently providing chronic care support to individuals with crusted scabies in Yirrkala and Gunyangara. This includes regular skin checks, application of creams, provision of education and ongoing monitoring.



Wayalwanga Marika
Community Coordinator
Wayalwanga is a highly respected community

member of Wallaby Beach and Yirrkala with years of experience in the implementation of health programs. Wayalwanga was a healthy skin worker on the regional Healthy Skin Program of 2004 -2007.



Bamuniya Marika
Community Coordinator
Bamuniya has worked as a Strong Women, Strong Baby,

Strong Culture worker and for the Raypirri Rom program at Miwatj Health. Bamuniya is a senior member of the Yirrkala Community.



Bandiyal Maymura
Community Coordinator
Bandiyal is a retired health care worker who lives in

Nhulunbuy. Bandiyal's years of experience as a health care worker assists with monitoring scabies in the Gove Hospital and provides insights into families in the region.

HEAD OFFICE SYDNEY



Samantha Cran
Chief Executive Officer
Samanatha joined in June 2010, and has been named 100

Women of Influence by Australian Financial Review and Young Human Rights Medal Finalist of the Human Rights Commission of Australia 2012. She has experience in the marketing and communications sector.



Tim Foster
National Coordinator
Tim is a public health engineer who has several years' experience

managing WASH programs in sub-Saharan Africa. Prior to that he was a management consultant with the Boston Consulting Group in Australia, where he worked on a range of business strategy and public policy projects.



Chris Saroukos
Field Administrator and HR Coordinator
Chris recently graduated

with a degree in Anthropology from the University of Sydney. Chris hopes to study a Masters of Public Health in 2013.



Michele Bray
Communications Manager
Michele has experience in marketing and communications,

specialising in creating word-of-mouth and advocacy to create behavioural change.

VOLUNTEERS PAST AND PRESENT

A Huge Thankyou must go to our volunteers, who have given their time and enthusiasm to us and are a major driving force in our success:

Anthony Lieu – *IT*, Talia Waelsch – *Fundraising*, Georgina Taylor – *Fundraising*, Eva Deutscher – *Fundraising*, Paulavi Gangadia – *Graphic Design*, Michelle Holland – *Graphic Design*, Phil Jaksa – *Advocacy*, Yogi Lal-Parks – *Government Liaison*, Richard Barley – *Human Resources*.

OUR PEOPLE ARE THE BEST AT WHAT WE DO, HAVE COMMON VALUES, AND MAKE A LONG TERM COMMITMENT TO OUR ORGANISATION

FUNDRAISING AND BUDGET

INAUGURAL YEAR'S FINANCIAL OVERVIEW

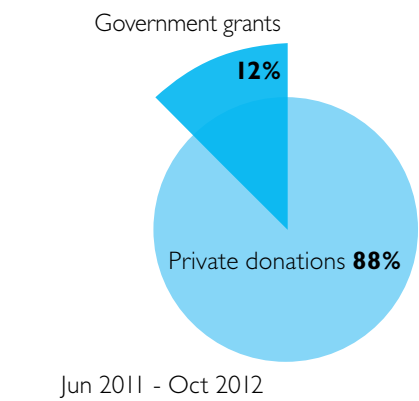
In our first year of operation, fundraising income was more than double operating expenditure (FY11-12).

One Disease at a Time needs to raise approximately \$3.5 million to cover program costs to year-end 2014.

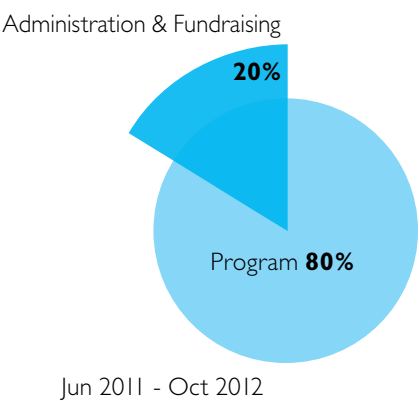
To date, we have raised approximately 60% of our necessary funds for year-end 2014 and need to raise an additional \$1.4 million to reach our budget.

Financial report for year end 30 June 2012 available upon request.

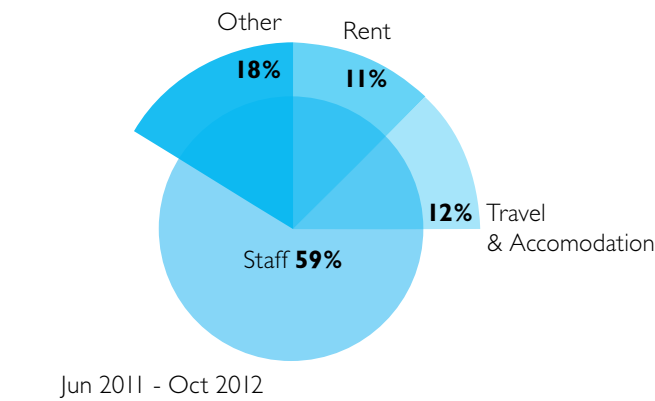
Sources of Income



Breakdown of Expenditure



Breakdown of Program Expenditure



CHANGING THE SYSTEM

GREATER ACCESSIBILITY TO TREATMENT

- Registration dossier submitted to the Therapeutic Goods Administration by Merck. Registration will allow Ivermectin (oral treatment for scabies) to be more easily prescribed and therefore more accessible in community.

INCREASING AWARENESS AND RECOGNITION OF A PREVIOUSLY NEGLECTED DISEASE

- For the first time in Australia, a preventative chronic care approach to crusted scabies has become part of treatment guidelines (CARPA) and Ivermectin has been included for treatment of simple scabies.
- Crusted scabies now has a formal classification (International Classification of Primary Care) code that is used by electronic clinical record systems in the region (e.g. Communicare). This new classification will enable more efficient management, tracking and monitoring of crusted scabies.
- To share our successes and instill a sense of hope amongst the Northern Territory health professionals, Yirrkala community assistant teacher, Yadadi Wanambi, a patient advocate for families with this condition, presented at the Chronic Disease Network conference with our program coordinator and local health centre management.

EVERYONE IS GETTING ON THE BANDWAGON

INCREASING SUPPORT FROM THE BEST MINDS
BUILDING ON OUR ROBUST TEAM OF MEDICAL VETERANS, BUSINESS LEADERS
AND PHILANTHROPISTS, WE WELCOME FOUR NEW MEMBERS TO OUR BOARD



Professor Hugh Taylor AC has a long and distinguished career in research into the causes and prevention of blindness in both developed and developing countries and has published extensively. He worked with Fred Hollows in the 1970s and spent 13 years at the John Hopkins University before returning to Australia in 1990. His current work focuses on Aboriginal eye health and the elimination of trachoma.



Professor Brian Schmidt formed the HighZ SN Search team, using distant exploding stars to trace the expansion of the Universe. His team's discovery of an accelerating Universe was Science Magazine's Breakthrough of the Year in 1998. In 2011 he became the 12th Australian to win a Nobel Prize for his groundbreaking research on supernovae and the expansion of the Universe.



Mr Geoff Rasmussen is a co-founder and Managing Director of Azure Capital - a boutique corporate advisory firm based in Perth. In 2011, Geoff was voted one of Australia's 20 Best Investment Bankers in the East Coles corporate survey. Geoff served on the Board of Youth Focus, an NGO providing services to young people at risk of suicide or self-harm. He is also the chairman of the Azure Capital Foundation.



Professor Ian Anderson has worked in Aboriginal Health for twenty-four years and has been the most successful aboriginal doctor in Australian history and instrumental in Aboriginal health policy development. He is currently the Director of the Murrup Barak Institute for Indigenous Development at the University of Melbourne.



CURRENT BOARD MEMBERS

Dr Sam Prince (Chairman), **Professor Jonathan Carapetis**, **Professor Frank Bowden**, **Ms Diane Kargas**, **Mr Peter Gordon**, **Ms Kate Sutton**, **Ms Anna Spraggett**

FAREWELLING BOARD MEMBERS

Ms Jennie Cameron Date resigned: July 2012
Mr Glenn Keys Date resigned: August 2012

ENDORSEMENT FROM STATE AND FEDERAL GOVERNMENT



Hon Warren Snowden
Minister for Indigenous Health.
"The work of Sam Prince and the team at One Disease is inspiring. Their dedication and cooperation with Miwatj and Northern Territory Health is important for changing health outcomes for Aboriginal people across East Arnhem Land."



Hon Peter Garrett
Minister for School education, Early Childhood and Youth.
"One Disease at a Time's wide-ranging ambition is driven by an understanding that to provide a lasting remedy, medical science must complement cultural awareness and ways of knowing. This approach reinforces the results across different generations and communities."



Her Excellency Ms Quentin Bryce AC
Governor General of the Commonwealth of Australia
"I commend this groundbreaking, bottom-up approach to disease eradication. I am so proud of the leadership and determination of Dr Sam Prince, his supporters and team of professionals who are effecting profound change." Her Excellency also facilitated an introduction to Prince Charles on his latest tour of Australia.

RAISING THE PROFILE OF ONE DISEASE AND THE EAST ARNHAM SCABIES CONTROL PROGRAM AMONGST THE AUSTRALIAN PUBLIC

\$84,921 value in media coverage across national and local channels and publications.

FOSTER HEALTH EDUCATION



TRAINING, EDUCATION, PARTNERSHIP

- One Disease provided training and education for clinical staff throughout East Arnhem, to enable them to better diagnose and treat scabies and crusted scabies. In-services have been carried out at health centres in numerous communities including Yirrkala, Numbulwar, Milingimbi and Ramingining. In addition to advice regarding case management, we have been invited to speak at meetings of clinic managers.
- We identified, and have established a partnership with the leading local Indigenous health education provider Aboriginal Resource and Development Services (ARDS). With them, we have developed a strategy for education sessions in remote communities, in the local language of Yolngu Matha. ARDS has considerable corporate knowledge and experience in conducting Microscopy and Germ Theory education in NE Arnhem Land. Implementation will take place in the next 12 months.

ACKNOWLEDGING OUR SUPPORTERS

ONE DISEASE AT A TIME WOULD LIKE TO ACKNOWLEDGE
OUR GENEROUS SUPPORTERS FOR THEIR INVESTMENT INTO
THE EAST ARNHAM SCABIES CONTROL PROGRAM

FINANCIAL SUPPORTERS



- Gourlay Charitable Trust
- Innovation ACT
- The Ghosh Family Foundation
- Nicholas Curtis
- The Jibber Trust
- Bray Kargas Family Fund
- Rotary Club Great Lakes
- The Myer Foundation
- Commonwealth Youth Forum

SERVICE SUPPORTERS



MOVING FORWARD GOALS, MEASURES, IMPACT

WE ARE COMMITTED TO HIGH IMPACT OPERATIONAL SOLUTIONS THAT DELIVER RESULTS TO THE COMMUNITIES WE SERVE

DEFINING MEASURABLE GOALS

- **Eliminate** crusted scabies as a public health issue in all participating East Arnhem communities by the end of the third year (Aug 2014).
- **Document** a 50% reduction in scabies and skinsore rates from baseline by the end of the third year (Aug 2014) in at least three participating communities, while aiming for all.
- **Support** related environmental health and regulatory initiatives.

PRINCIPLES AND PROCESS MEASURES

The East Arnhem Scabies Control Program utilises a partnership approach to implementation and will monitor progress against these indicators:

- Community leaders guide program implementation and ensure community engagement (community ownership and partnership).
- Community coordinators, workers and volunteers implement the program (capacity building and sustainability).
- Close collaboration with health centres and related regional health services (integration and exit strategy).

EVALUATING IMPACT OF PROGRAM

Ours is a holistic approach to evaluation, combining hard measures with qualitative review of how we have been able to shift the emotional burden of the disease:

- **Quantitative outcomes:** prevention of crusting and hospitalisation.
- **Qualitative outcomes:** improvement in wellbeing and employment.
- **Disease control:** prevention of spread of disease.

Data will be collected from three systems:

- **Epi-info:** a measurement and evaluation tool to track crusted scabies patients.
- **PCIS and Communicare:** Clinic health record systems.
- **Point in time screenings.**



Team members on the ground.


KEY STRATEGIES THE NEXT 12-18 MONTHS

TREAT CORE TRANSMITTERS

SUSTAINED REDUCTION OF REPRODUCTIVE RATE

POINT IN TIME PREVALENCE REDUCTION

OPERATIONAL ENHANCERS AND ENABLERS

- 
- 1 Crusted scabies case management:** a chronic care management model enables crusted scabies patients to remain scabies-free thanks to regular household check-ups, skin screening, application of creams, and assistance with showering.
 - 2 Supporting families with recurrent scabies:** targeted support is provided to families having difficulties with recurrent scabies by way of a preventative case management approach and localised Healthy Homes, Healthy Skin events.
 - 3 Community surveillance for early treatment:** senior and influential community members act as ambassadors and actively encourage community and family members to seek early treatment when suffering bouts of scabies.
 - 4 Social marketing for early treatment and compliance:** social marketing and community engagement tools and campaigns developed to encourage community members to seek early treatment and compliance when they contract scabies.
 - 5 Development of next generation scabies cream:** research and development into new scabicide creams that kill mites more rapidly than creams currently available over the counter.
 - 6 Healthy Skin, Healthy Homes events:** at the request of community health centres and senior community members, One Disease supports and coordinates Health Homes, Healthy Skin weeks, which involve whole community treatment with scabies creams, health promotion visits to households and schools, and community-wide clean-ups.
 - 7 Ivermectin mass drug administration:** if regulatory and logistic barriers can be overcome, and when requested by communities, we are building in-house capacity to implement a mass drug administration of Ivermectin, an oral scabies medication.
 - 8 Building community workforces:** local workers are crucial to daily program operations and critical liaisons, ensuring our activities and objectives align with the needs and priorities of the communities we serve.
 - 9 Education tools for clinical staff and patients:** training and education for clinical staff and patients to enable more accurate diagnoses and prompt, effective treatment of scabies and crusted scabies.
 - 10 Sustainable washing machines:** boosting functionality levels of household washing machines, our washing machine strategy links extended warranties with cyclical maintenance plans, low interest loans and a social marketing initiative.
 - 11 Monitoring and evaluation:** program impacts are monitored by drawing on routinely collected data through health centre clinical reporting, and intermittent community-wide skin screening. Monitoring is geared towards continuous quality improvement of operations, and captures both quantitative and qualitative performance indicators across five strategic domains.
 - 12 Advocacy and systems-wide change:** to maximise the impact of our work, we catalyse broader systems and structural changes to improve effectiveness of existing health services.



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