

Skin Cancer Prevention Programme

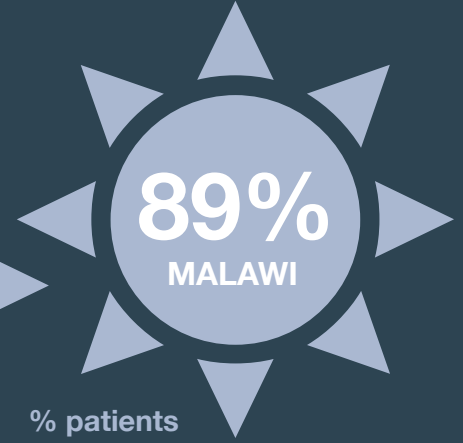
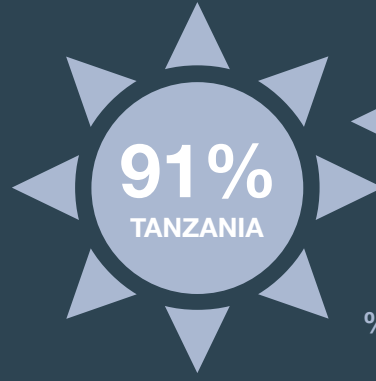
Annual Report

2018-2019



6435

people with albinism supported in dermatological health across Tanzania and Malawi



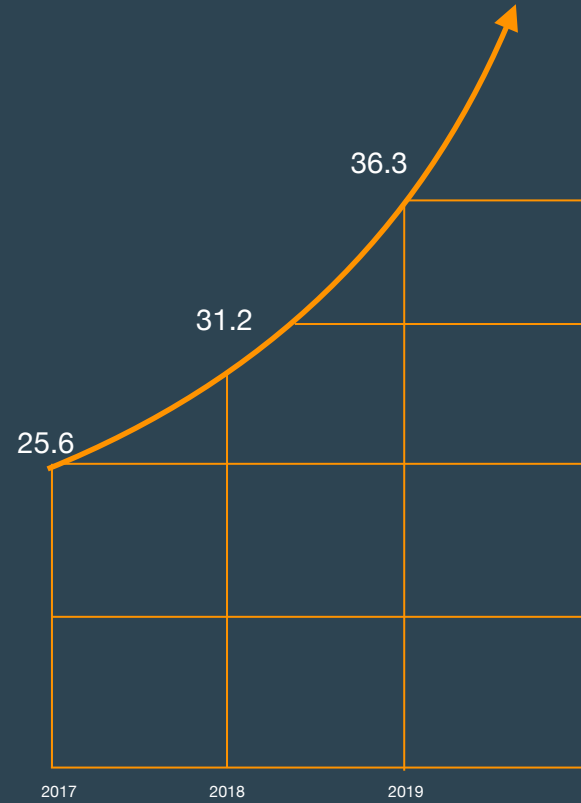
% patients using sunscreen

increase in registered patients in Tanzania

21.4%

43%

reduction in rates of actinic (solar) erythema in Malawi since 2017



% of national population of people with albinism reached in Tanzania

96%

patient attendance rate in Tanzania



Contents

1. Introduction	4
1.1 Theory of Change	6
2. Tanzania	7
2.1 Reduce the prevalence of skin cancer among people with albinism in Tanzania	8
2.2 Progress against targets	9
2.3 Delivery of clinical care and training	12
2.4 Distribution of sun protective items	14
2.5 Delivery of health education and training to people with albinism and wider community	14
2.6 Partner network development and mobilisation	15
2.7 Public awareness and national advocacy	17
2.8 Evaluation of outcomes	18
2.8.1 Reduction in presentations of skin cancer and conditions associated with its development	18
2.8.2 Behavioural changes in people with albinism demonstrating increased capacity to adopt self-care prevention measures	24
2.8.3 Greater understanding of albinism and skin cancer	29
2.8.4 Increased confidence and well being of people with albinism	30
2.8.5 More enabling institutional environment for the SCPP	31
2.8.6 Increased support network for people with albinism	31
3. Malawi	32
3.1 Reduce the prevalence of skin cancer among people with albinism in Malawi	33
3.2 Progress against targets	34
3.3 Delivery of clinical care and training	35
3.4 Distribution of sun protective items	37
3.5 Delivery of health education and training to people with albinism and wider community	37
3.6 Partner network development and mobilisation	39
3.7 Public awareness and national advocacy	40
3.8 Evaluation of outcomes	42
3.8.1 Reduction in presentations of skin cancer and conditions associated with its development	42
3.8.2 Behavioural changes in people with albinism demonstrating increased capacity to adopt self-care prevention measures	45
3.8.3 Greater understanding of albinism and skin cancer / 3.8.4 Increased confidence and well being of people with albinism	49
3.8.5 More enabling institutional environment for the SCPP	50
3.8.6 Increased support network for people with albinism	50
4. International Replication	51
4.1 Burkina Faso	52
4.2 Development of supporting resources and tools for replication	52
5. International Advocacy	54
6. Looking Ahead	56
7. Partners and Supporters	57



Introduction

Six years ago, in partnership with the Government of Tanzania and the Regional Dermatology Training Centre, Standing Voice launched its Skin Cancer Prevention Programme (SCPP), opening three small clinics in the city of Mwanza. Today, with the invaluable support of our partners, we are delivering comprehensive dermatological healthcare to more than a third of the national population of people with albinism in Tanzania, and have expanded into Malawi with great success. Across both countries, we are operating a network of 65 clinical sites, serving 6,435 people with albinism and their innumerable families and loved ones.

The SCPP was conceived in response to the crisis of deteriorating dermatological health facing people with albinism in Africa. Its programmatic philosophy—engaging in-country stakeholders to generate collective capacity and mutual accountability—has given families, communities and institutions in Tanzania and Malawi the chance to forge a different future for people with albinism. The programme empowers these actors to take ownership of the fight to protect people with albinism, and embed their dermatological health as a non-negotiable priority in global human rights discourse and the budgets and policy decisions of governments across the African continent.

This year has seen extraordinary gains for the SCPP, with reductions in rates of skin cancer across all of our operating zones. In Tanzania, rates of erythema have dropped by 14% year-on-year; in Malawi, the prevalence of the same condition has almost halved, from an alarming 95% in 2017 to just 52% now. Rates of actinic keratosis have fallen in both countries, with an accompanying drop in the frequency of cryotherapy administrations by SCPP dermatologists. In both countries, we have seen astounding gains in patient compliance, where people with albinism are increasingly absorbing and undertaking the preventative behaviours recommended in SCPP education sessions. In Tanzania, 95% of patients on average exhibit full or partial protection against UV exposure through correct use of sun-protective clothing. In Malawi, meanwhile, the percentage of examinations revealing satisfactory use of sunscreen has gone from

62% in 2017 to 74% in 2018 to 89% in 2019. In both countries, we are treating a population that is better educated, better connected, and better protected.

This is to say nothing of our clinical training, which has broken new ground in the most recent year. As a body of internationally recognised dermatology experts, our Skin Cancer Advisory Committee continues to act as a vital instrument of training, a vehicle for world-leading research, and a valuable mechanism of quality control in the delivery of SCPP clinics. With their leadership, we have surpassed an array of training targets in Tanzania and Malawi, expanding our bank of programme dermatologists to build local expertise and further pave the way for state handover. Finally, we have published a manual of best practice to assist clinicians across Africa in the treatment of patients with albinism: a ground-breaking resource that will strengthen our provision of training and accelerate replication of the SCPP in other African countries.

Of course, there is so much still to be done. There are families and communities across Tanzania and Malawi yet to be reached by the SCPP, and thousands of lives continue to be lost to untreated skin cancer beyond those countries' borders. It is incumbent on us to harness the findings of the SCPP and replicate its impact on a continental scale: an ambition we seek to realise fully, in collaboration with our partners, in the months and years ahead.

This report has been written at an alarming time for people with albinism in Tanzania and Malawi. In both countries, our beneficiaries are excluded from public services, shunned from community life, and plagued by the spectre of witchcraft-fuelled murder. Although Tanzania was the historical epicentre of these attacks, the centre of gravity has recently switched to Malawi, where 150 reports of human rights violations have emerged since 2014. Among the most recent of these involved a 54-year-old man with albinism in northern Malawi, who was dragged from his home and murdered in front of his 9-year-old son. Both hands were amputated and his heart was removed.

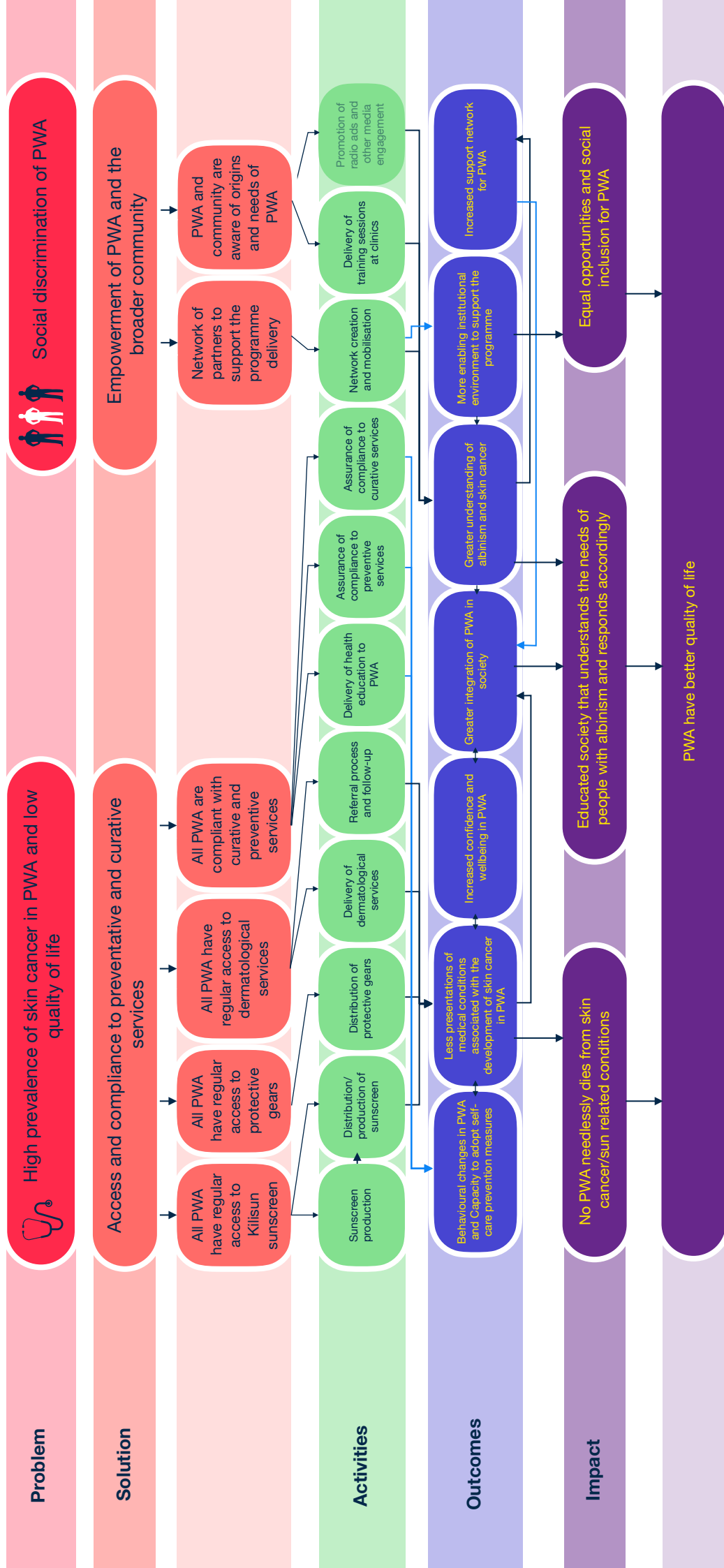
The SCPP was established not only to stop skin cancer, but to redefine people with albinism as human beings and resituate them at the centre of their society: as champions and role models; as ordinary people who are happy and healthy and safe. We will continue to fight for this cause in a spectrum of contexts, from our most remote clinics through to the halls of the United Nations. We are humbled and invigorated to have found partners so committed to sharing that goal.

To all of our partners and supporters, thank you from Standing Voice.



Harry Freeland
Executive Director

Skin Cancer Prevention Programme Theory of Change



TANZANIA





Tanzania

2.1 Reduce the prevalence of skin cancer among people with albinism in Tanzania

Over the last twelve months the SCPP has taken considerable strides to reduce the prevalence of skin cancer among people with albinism in Tanzania, with ever-increasing patient numbers, clinic locations, geographical reach and sun-protective items distributed. Significant efforts have been made to increase the capacity of all stakeholders engaged within the programme through numerous training sessions across multiple disciplines. All of these activities have taken place within the context of sustained advocacy, at national and international levels, for the dermatological needs of people with albinism in the country.

This year, we have sought to enrich our collection and analysis of qualitative data by closely studying the experiences of 50 new patients. For clarity, where 'new patients' or 'newly enrolled patients' are referred to in the following sections, we are referring to entirely new patients who had not received any SCPP services before their interview

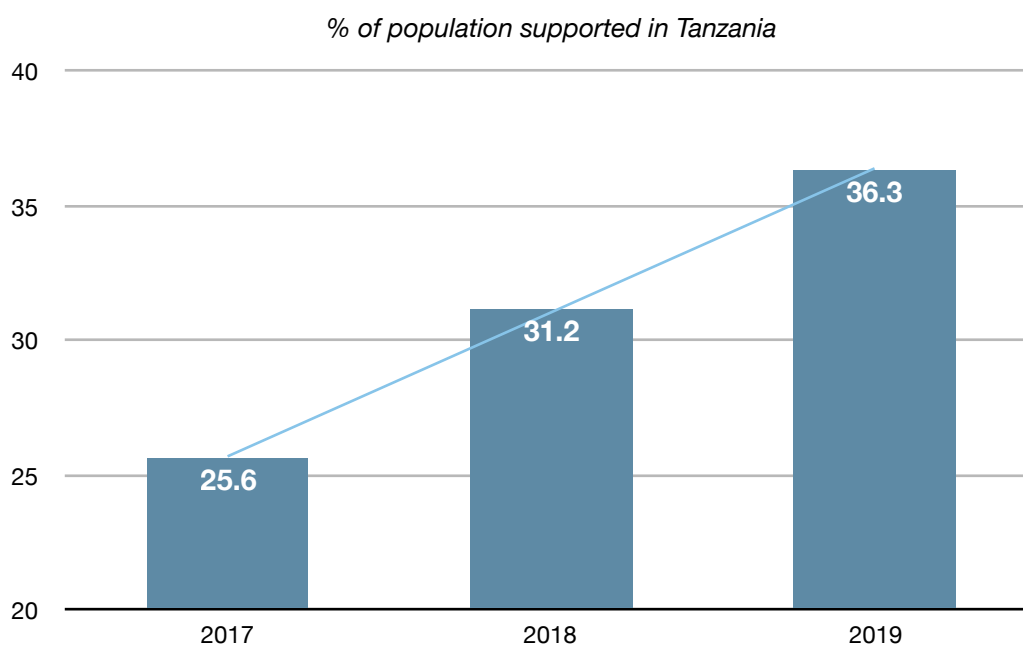
and who are now enrolled. Interviewees included patients of varying ages and life situations, with a balanced gender ratio. Our academic analysis of this data, led by Ed Stagg at the University of Manchester, had multiple layers of in-depth enquiry and has been based on the programme's refined Theory of Change. Our methodology for this analysis included a complex coding system to identify and categorise interview responses.

These interviews were conducted to widen and deepen our baseline qualitative data on people with albinism receiving the SCPP for the first time. This exercise has also yielded the most comprehensive baseline data we have to date on new patients' self-care behaviours and wider engagement with health services. We believe this is the most in-depth study of its kind yet attempted in Africa, and we are preparing it for publication. We will interview our sample of 50 patients each year for a further two years to track the impact of the SCPP over time, from a patient perspective.

2.2 Progress against targets

SUMMARY OF OUTPUTS			
	Current (as of May 2019)	Target (end of May 2019)	Progress towards targets
Number of clinics (including remotely supported)	58	36	+22
Number of registered clinic patients (including remotely supported)	4,225	4,500	-275
Total number of people with albinism receiving Kilisun only	1,753	n/a	n/a
Total number of people with albinism supported (clinic + Kilisun only)	5,978	4,500	+1,478
Number of clinic regions (including remotely supported)	13	15	-2
Total number of regions (including locations reached by Kilisun only)	22	15	+7

	2017	2018	2019 (up until May)*
Estimated % of all people with albinism in TZ supported	25.6%	31.2%	36.3%
SCPP geographical coverage	64.5%	67.7%	71.0%

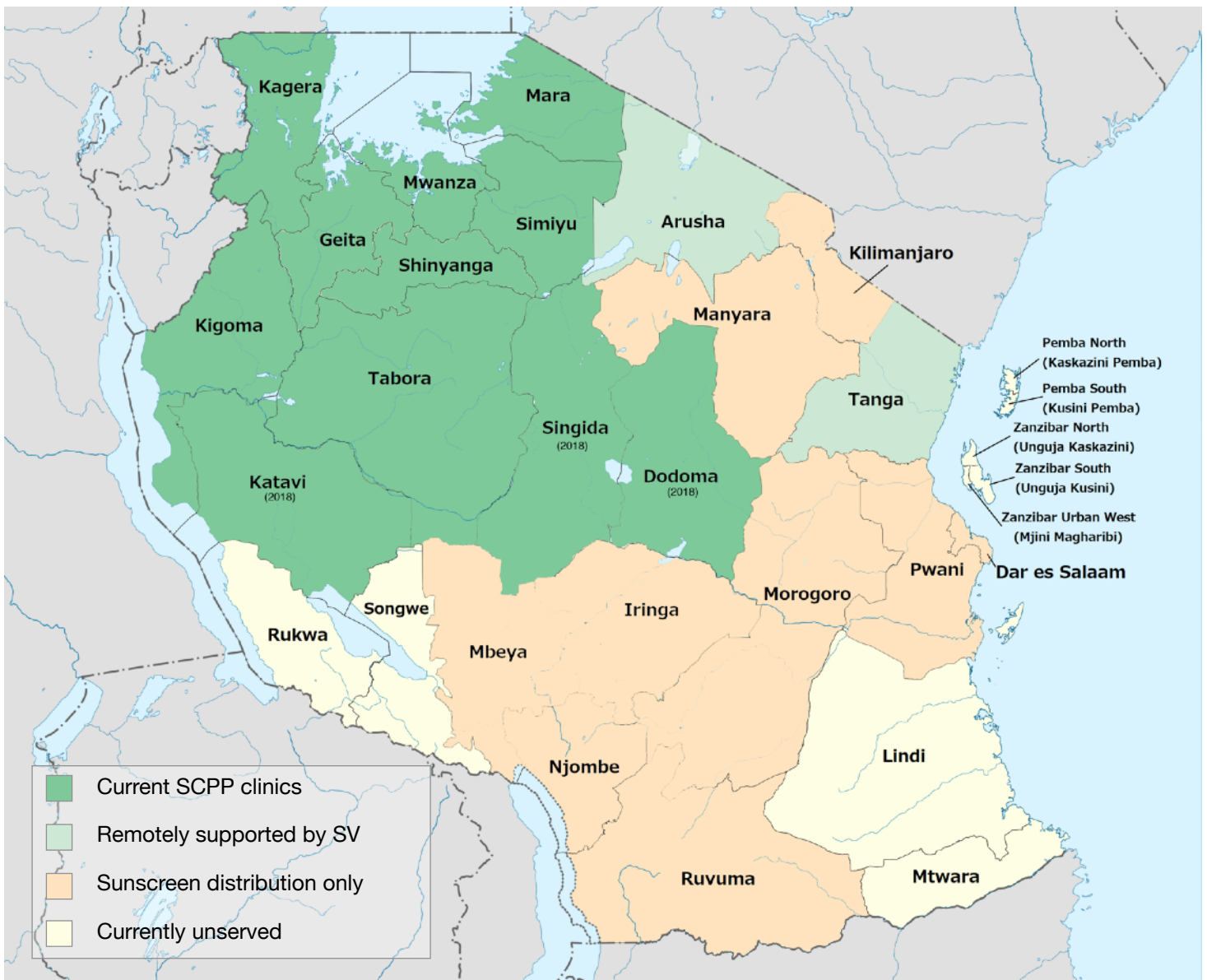


**Please note that the sample of clinical data collected and analysed for use in this report has been categorised by calendar year. Our data for 2019 is therefore only accurate to the end of May 2019. This means that some of our 2019 outputs are numerically lower than would be expected for a full calendar year. To correct this imbalance, we have used percentages (%) for rates and trends so far in 2019 wherever possible. Actual figures are still included for clarity.*

The Skin Cancer Prevention Programme now operates 58 clinic sites, far exceeding our 2019 target of 36 clinics. Furthermore, the last twelve months have seen continued acceleration of new clinic roll-out: we opened 13 new clinic sites, in comparison to 11 in 2018 and 5 in 2017.

Our total number of programme beneficiaries in Tanzania is now 5,978, exceeding our 2019 target of 4,500 by 32.8%. This growth reflects strong public awareness of the SCPP and serves as a promising sign that our service is continuing to access people with albinism in hard-to-reach

settings. Of our 5,978 beneficiaries, 1,753 are served through sunscreen distribution only, while 884 have accessed clinical services remotely supported by Standing Voice. The remaining 3,341 patients are formally registered in the SCPP and regularly receive our full clinical service (these 3,341 patients provide the sample that will be used for the rest of our analysis of Tanzanian data in this report); of these, 590 were newly enrolled in the most recent year, representing a healthy increase of 21.4%. When remote services are included this rises to 4,225 clinical patients, of whom 845 are new, indicating 26.5% growth.



DELIVERY OF TRAINING

	Achieved (June 2018-May 2019)	Target (end of May 2019)	Progress towards targets
Community Dermatologist training sessions	4	3	+1
Dermatosurgery training sessions	4	3	1
CSO training sessions	70	36	34
Community Ambassador training sessions	70	36	+34
Number of Community Dermatologists	12	15	-3

In an effort to guarantee the sustainability of the SCPP, Standing Voice has prioritised the training of community dermatologists and ambassadors in the most recent year. Although fewer have been recruited than intended (12 instead of 15), we have been delighted with the progress of our community dermatologists and have chosen to prioritise the depth and intensity of training provided. Because of this we have surpassed all other training-related

targets, delivering four training sessions each for community dermatologists and dermato-surgeons (instead of three). We have also delivered 70 training sessions each for community ambassadors and CSO representatives, almost doubling our target of 36. Next year we will look to sustain this intensity of training and increase its breadth, bringing our recruitment of community dermatologists back up to (or above) target level.



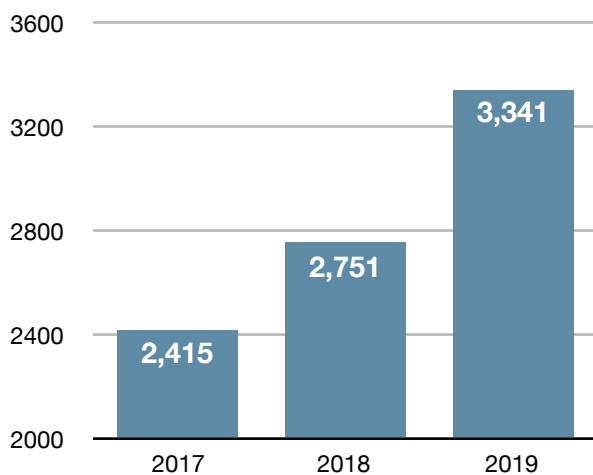
2.3 Delivery of clinical care and training

This year has seen extraordinary signs of growth and sustainability for the SCPP. All analysis of our Tanzanian data uses a sample, collected by the Standing Voice team, of 3,341 patients from 51 clinical sites across 11 regions of Tanzania. This sample uses our most comprehensive data, and excludes locations accessed through sunscreen distribution only or remote facilitation of services.

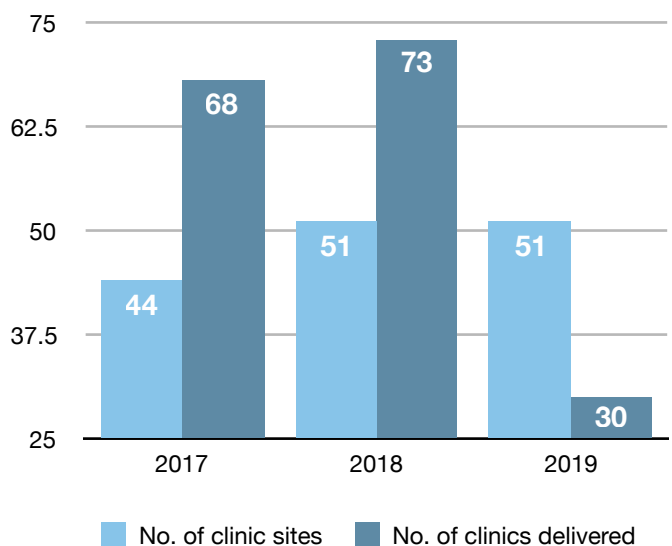
This sample shows that our patients, clinical sites and geographical coverage all continue to increase, while patient attendance hits an all-time high of 96%, indicating exceptionally high levels of retention and a

positive experience of our service by beneficiaries. Particularly promising has been the increasing capacity of our dermatologists to deliver minor surgeries on-site, rather than referring to larger central hospitals; only 20% of cases were handled in-house in 2017, as opposed 64% in 2018 and 51% so far in 2019. In-depth qualitative interviews have also revealed the level of confidence patients invest in our dermatologists, in comparison with clinical experiences outside the SCPP (see Section 2.8.5).

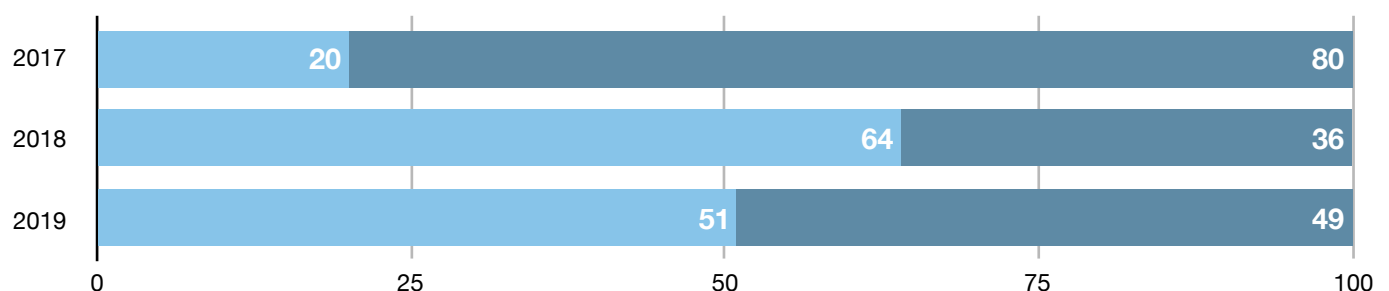
Number of Fully Registered Clinic Patients (Tanzania)



Number of Clinic Sites (Tanzania)



% Minor surgeries delivered within SCPP % Complex surgeries referred to larger hospitals





OVERVIEW OF PATIENT SAMPLE: TANZANIA

	2017	2018	2019 (up until May)
Number of registered clinic patients	2,415	2,751	3,341
Number of new clinic patients	-	336	590
Total number of patients examined in full	1,638	2,643	1,123
Clinic attendance rate (%)	68%	96%	n/a
Total number of examinations	2,293	3,650	1,157
Total number of clinic sites/locations	44	51	51
Number of clinics delivered	68	73	30
Number of TZ regions where full SCPP clinic service is available	8	11	11
Number of Community Dermatologists engaged	8	12	12
Number of Community Dermatologist trainings delivered	1	4	2
Number of Dermatosurgery trainings delivered	1	4	2
Number (and percentage) of complex cases referred to a large central hospital	35 (80%)	34 (36%)	17 (49%)
Number (and percentages) of minor cases operated by SV trained Community Dermatologists	9 (20%)	60 (64%)	18 (51%)

**During the last year a major audit was conducted on data from 2017 onwards. This involved cleaning and updating erroneous entries and as a result there are some minor discrepancies in 2017 data previously presented and 2017 data in this report. For continuity, this report hereafter presents only data captured from 2017 onwards.*

2.4 Distribution of sun protective items

Vast numbers of sun-protective items have been distributed through the SCPP to support the dermatological health of our beneficiaries. Since 2017 the programme has distributed 4,791 sun-protective hats, 207 umbrellas, 1,101 pairs of sunglasses and 21,300 pots of sunscreen. In total constitutes 27,399 sun-protective items distributed in total.

DISTRIBUTION OF HATS, SUN SHADE UMBRELLAS, SUNGLASSES AND SUNSCREEN				
	2017	2018	2019 (up until May)	Total (2017 up until May 2019)
Hats	645	3,186	960	4,791
Sun Shade Umbrellas	73	90	44	207
Sunglasses	877	216	8	1,101
Pots of Kilisun sunscreen	6,879	10,950	3,471	21,300
Total all sun protective items (2017 up until May 2019)				27,399

2.5 Delivery of health education and training to people with albinism and wider community

Health education and training for a range of stakeholders has continued to be a cornerstone of the SCPP in the most recent year. The programme promotes sustained capacity development for people with albinism and their families, as well as a range of support stakeholders including dermatology healthcare professionals, civil society representatives and community ambassadors. Since 2017 the SCPP has delivered a total of 301 health education

sessions, 171 civil society training sessions and 171 community ambassador training sessions. This training builds greater understanding of albinism and skin cancer among a range of significant actors, strengthening individual and institutional accountability for the welfare of our patients.

HEALTH EDUCATION AND TRAINING				
	2017	2018	2019 (up until May)	Total (2017 up until May 2019)
Health education sessions delivered	118	136	47	301
CSO trainings delivered	68	73	30	171
Community Ambassador trainings delivered	68	73	30	171

2.6 Partner network development and mobilisation

	2017	2018	2019 (up until May)
Ministry of Health (central administration)	1	1	1
Schools	10	12	12
District Albinism Association branches	15	24	24
District departments for social welfare	16	23	23
Local departments for education	1	1	1
Local council authorities	1	1	1
NGOs and CSOs	4	4	4
Hospital administrations	5	5	5
Community Radios	2	2	2
Department of Disability- national level	1	1	1
Clinicians	8	12	12
Albinism Association national office	1	1	1
KCMC/ RDTTC Moshi	1	1	1
Bugando Hospital	1	1	1
Ocean Road/ Muhimbili National Hospital	1	1	1
Total No. Partners	68	90	90

The SCPP is delivered in collaboration with an extensive network of partners. Currently the programme mobilises 90 partners across 11 regions of Tanzania. This is up from 68 in 2017—an increase of 32.4%—and chiefly consists of schools, Albinism Associations and Social Welfare Departments. We also engage council authorities, NGOs and CSOs, educational departments and hospitals and other health facilities. There has been a particularly significant increase in the number of albinism associations (up 60%) and social welfare departments (up 43.8%) engaged by the SCPP, with new partners concentrated in Singida, Katavi and Dodoma. Local branches of the Tanzania Albinism Society were critical partners in patient mobilisation, publicising dates and locations of clinics ahead of time. Members of these societies also took letters to the district authorities, to enable us to be granted permission to run our SCPP clinics. The fact we have been able to partner with central government

administration, for example the Ministry of Health, means we have been able to expand the programme quickly and efficiently over the past three years with the support of senior government stakeholders. Schools also played a key role in patient mobilisation and venue preparation. Two local radio stations (Sengerema FM and HUHESO FM) also helped maximise clinical attendance by broadcasting details of our clinic locations in the Mwanza and Shinyanga regions. Social Welfare Officers were actively involved in organising patient transport, so even those living in remote regions could access the clinics if needed. Finally, KCMC/RDTTC Moshi, Bugando Hospital and Muhimbili National Hospital continue to play a central role in our programme delivery, as any patients with more complex skin conditions are referred to these institutions for major surgical procedures. Across multiple levels and sectors, the Government of Tanzania is a central partner in the implementation of SCPP.



2.7 Public awareness and national advocacy

Standing Voice participates in national advocacy and awareness events to showcase and celebrate the Skin Cancer Prevention Programme in Tanzania and advocate for the dermatological health needs of our patients. In June 2018, the SCPP was in Simiyu for a special clinical service delivered to coincide with International Albinism Awareness Day. The clinic took place amid a carnival of colourful celebrations, with patients from 21 regions of Tanzania receiving care. The Deputy Minister Tamisemi, Josephat Kakunda, was in attendance and awarded Standing Voice a certificate of commendation for services to people with albinism. Interviews with new patients demonstrate that if they did access skin health information prior to their SCPP enrolment, there is a

high chance they did so through IAAD awareness, demonstrating the national importance of IAAD.

The media continues to be a significant vehicle through which we platform the SCPP and raise awareness of the skin cancer threat facing people with albinism, and also publicise clinic dates to patients. Over the last year we have engaged with a variety of local radio stations and national news outlets that have visited and reported on the SCPP interviewing clinicians, patients and SV staff. Below is a table listing media engagements in Tanzania.

Type of Media	Name of Media	Media Aired	National or Local
Radio	Sengerema FM	Multiple radio adverts	Local listenership (Mwanza Region)
TV	TBC	Two news story broadcasts	National viewership
Radio	HUHESO FM	Multiple radio adverts	Local listenership (Shinyanga Region)
TV	ITV	One news story broadcast	National viewership
TV	AZAM TV	One news story broadcast	National viewership

Having been deeply involved in the development of the UN's Regional Action Plan on Albinism in Africa, Standing Voice was appointed the Chair of the Coordinating Committee overseeing the development of Tanzania's National Action Plan (NAP) on Albinism (2019-2023). This process aims to domesticate the Regional Action Plan in order to secure the national implementation of best practices by all key stakeholders in Tanzania.

The current NAP draft has been compiled using input from all key stakeholders and guided by the NAP Coordinating Committee members. The committee consists of civil society and government representatives, including the Prime Minister's Office and Ministry for Labour, Youth, Education and

Disability. The committee is currently embarking on the final stage of refining and ratifying the National Action Plan with the involvement of independent development consultants. The skin health components of National Action Plan draw heavily on the activities implemented through the SCPP. Our increased participation and leadership in international advocacy within Africa has accelerated our leadership in the development of the NAP. The plan will act as a set of guiding principles for all stakeholders in their work to improve the lives of persons with albinism in Tanzania.

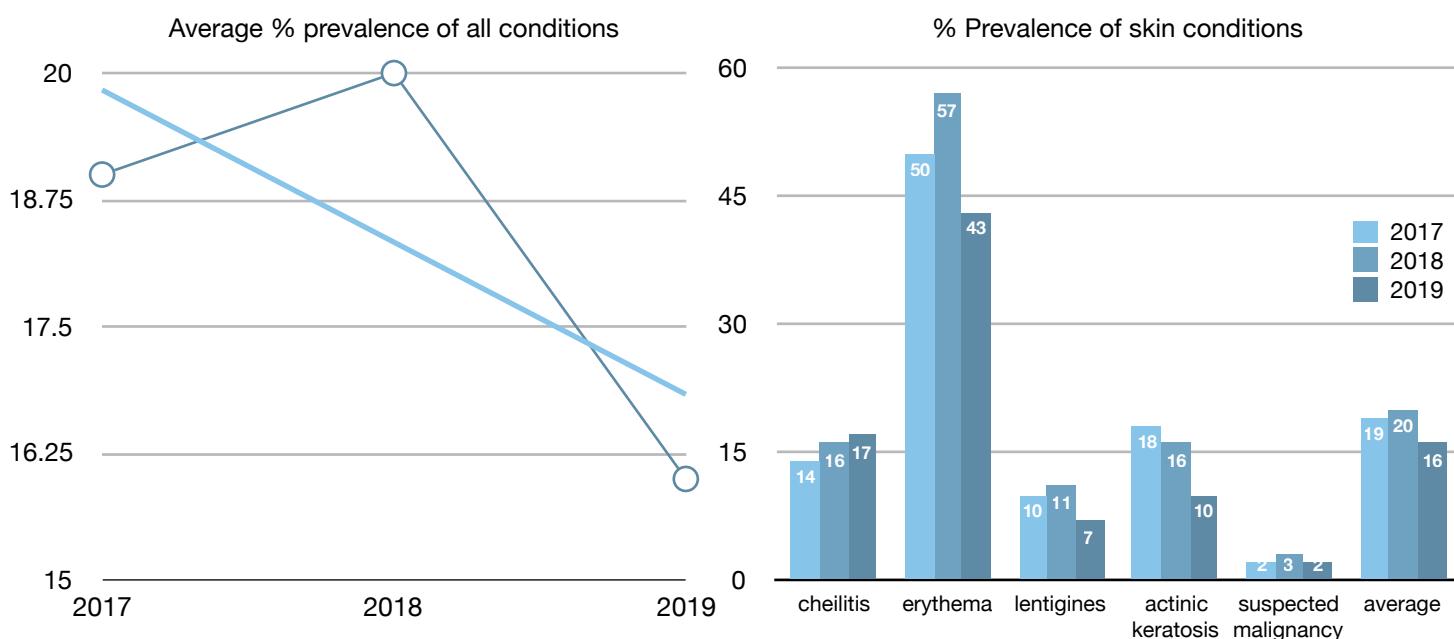
2.8 Evaluation of outcomes

The impact of the SCPP is calibrated by measuring our achievement of the outcomes identified in our programme Theory of Change, which has been refined and expanded in the last year. The SCPP is grounded in the assumption that achievement of these outcomes will deliver an overall impact of reduced skin cancer, increased social inclusion and a higher quality of life for people with albinism. Further analysis of our Tanzanian data is accordingly structured around these outcomes, which will be replicated for Malawi in Section 3 of this report. The outcomes are as follows:

- (1) reduction in presentations of skin cancer and conditions associated with its development;
- (2) increased patient compliance with preventative behaviours;
- (3) improved understanding of albinism and skin cancer among patients;
- (4) increased confidence and wellbeing of patients;
- (5) more enabling institutional environment for the SCPP; and
- (6) a stronger support network for patients.

2.8.1 Reduction in presentations of skin cancer and conditions associated with its development

CLINICAL PRESENTATIONS			
Number (and percentage) of examinations presenting with:	2017	2018	2019 (up until May)
Cheilitis	314 (14%)	568 (16%)	194 (17%)
Erythema	1,143 (50%)	2,088 (57%)	492 (43%)
Lentigines	233 (10%)	399 (11%)	82 (7%)
Actinic Keratosis	421 (18%)	595 (16%)	118 (10%)
Suspected Malignancy	50 (2%)	106 (3%)	19 (2%)
Average	432 (19%)	751 (20%)	181 (16%)



Broadly, our patient data shows a decrease in suspected skin cancers and other skin conditions over time. The majority of these conditions saw a mild increase in prevalence between 2017 and 2018, followed by a much sharper drop in 2019. This ostensibly curious trend can be attributed to the specific growth trajectory of the SCPP, which visited many new regions of Tanzania in 2018 but has yet to visit new regions so far in 2019 (new regions are scheduled for later this year). When the SCPP visits new regions for the first time, the prevalence of skin cancer and other malignant skin conditions is typically higher, since many populations of people with albinism have never received adequate dermatological care prior to encountering Standing Voice (this fact has been reinforced by the in-depth

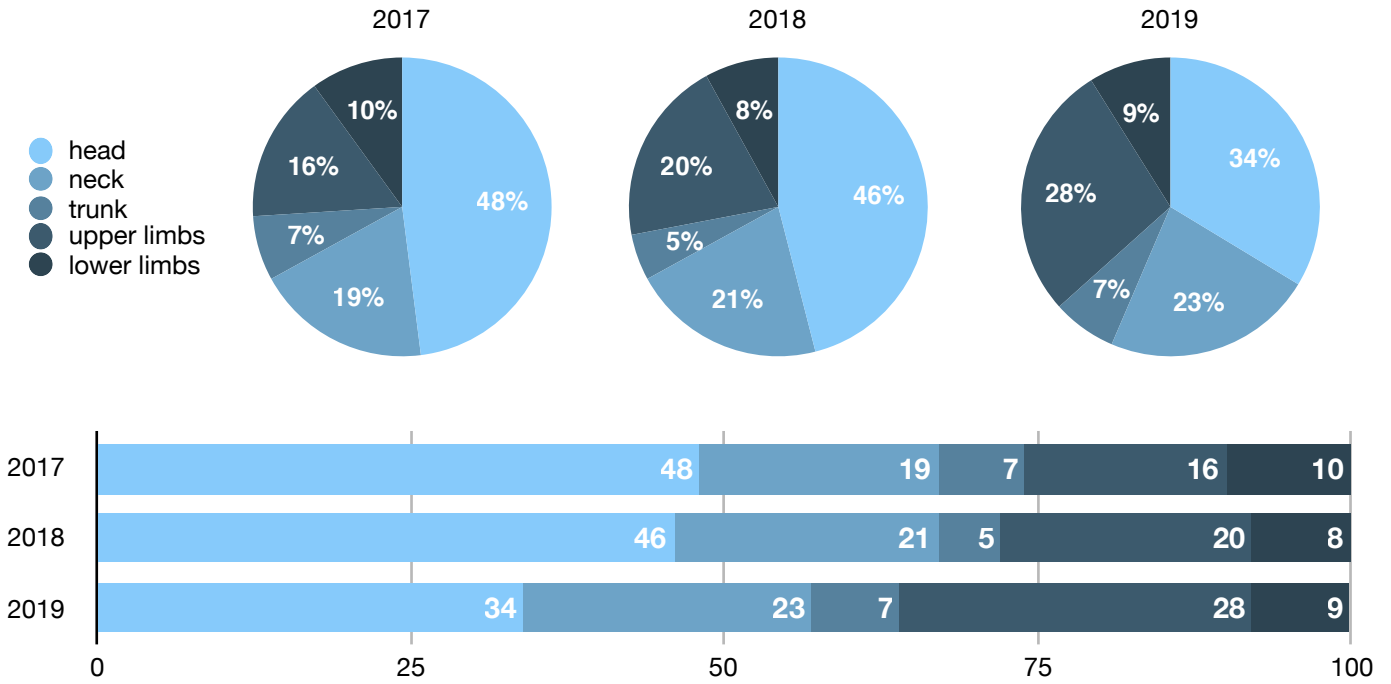
qualitative data collection we have conducted on a sample of 50 new patients this year). Visiting new regions in 2018 caused the prevalence of skin cancer and other conditions to increase, before dropping the following year, when many of the same patients were being seen and their dermatological health had been closely monitored.

It is extremely encouraging to see reductions across the board in the presentation of clinical conditions this year: rates of erythema have dropped by 14% year-on-year; actinic keratosis by 6%; and suspected malignancies by 1%. Only cheilitis has increased in prevalence so far in 2019, with a mild upturn of 1%. Across all conditions we have seen an average decrease of 4.2%.

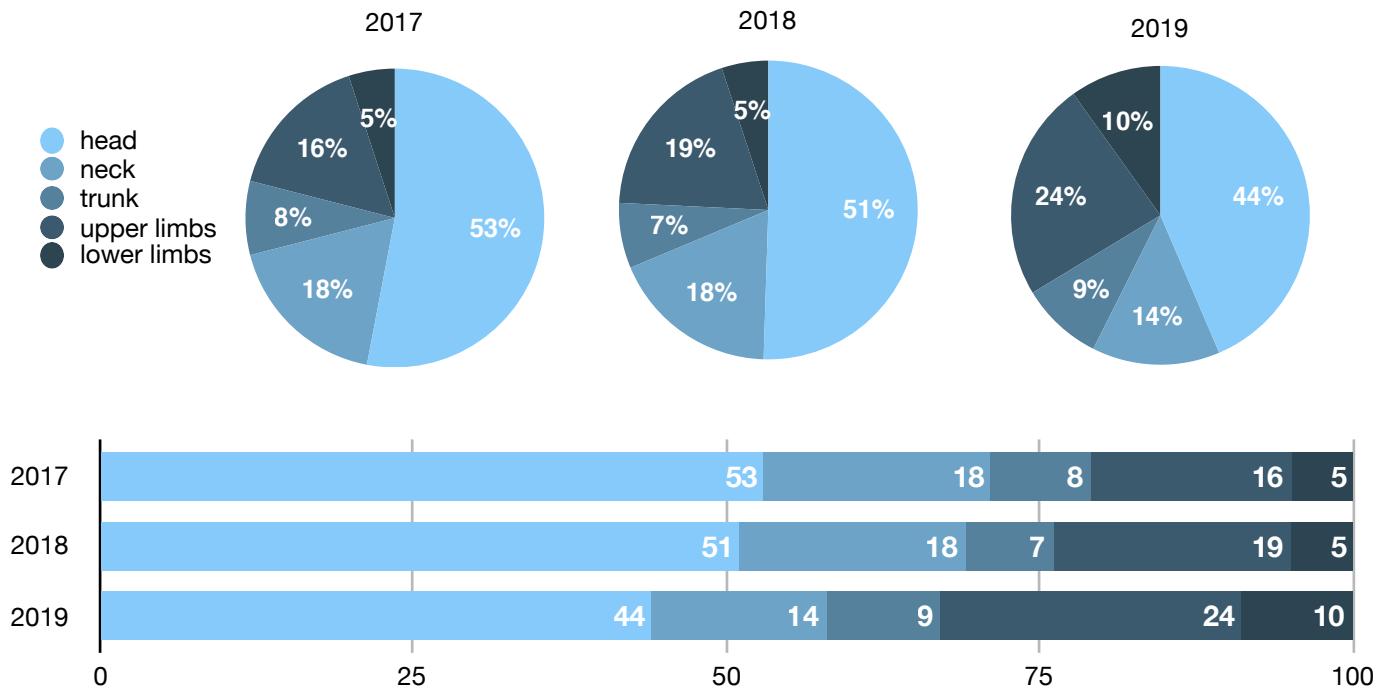
PRESENTATION OF CLINICAL CONDITIONS BY BODILY SITE

Erythema Detail			
Percentage of presentations on:	2017	2018	2019 (up until May)
Head, ears and eyelids	48%	46%	34%
Neck	19%	21%	23%
Trunk	7%	5%	7%
Upper limbs	16%	20%	28%
Lower limbs	10%	8%	9%
Lentiginos Detail			
Percentage of presentations on:	2017	2018	2019 (up until May)
Head, ears and eyelids	53%	50%	44%
Neck	18%	18%	14%
Trunk	8%	7%	9%
Upper limbs	16%	19%	24%
Lower limbs	5%	5%	10%
Actinic Keratosis Detail			
Percentage of presentations on:	2017	2018	2019 (up until May)
Head, ears and eyelids	28%	22%	19%
Neck	22%	22%	19%
Trunk	9%	8%	13%
Upper limbs	26%	31%	30%
Lower limbs	16%	17%	18%
Suspected Malignancies Detail			
Percentage of presentations on:	2017	2018	2019 (up until May)
Head, ears and eyelids	58%	41%	39%
Neck	14%	15%	12%
Trunk	14%	12%	15%
Upper limbs	6%	20%	21%
Lower limbs	7%	12%	12%

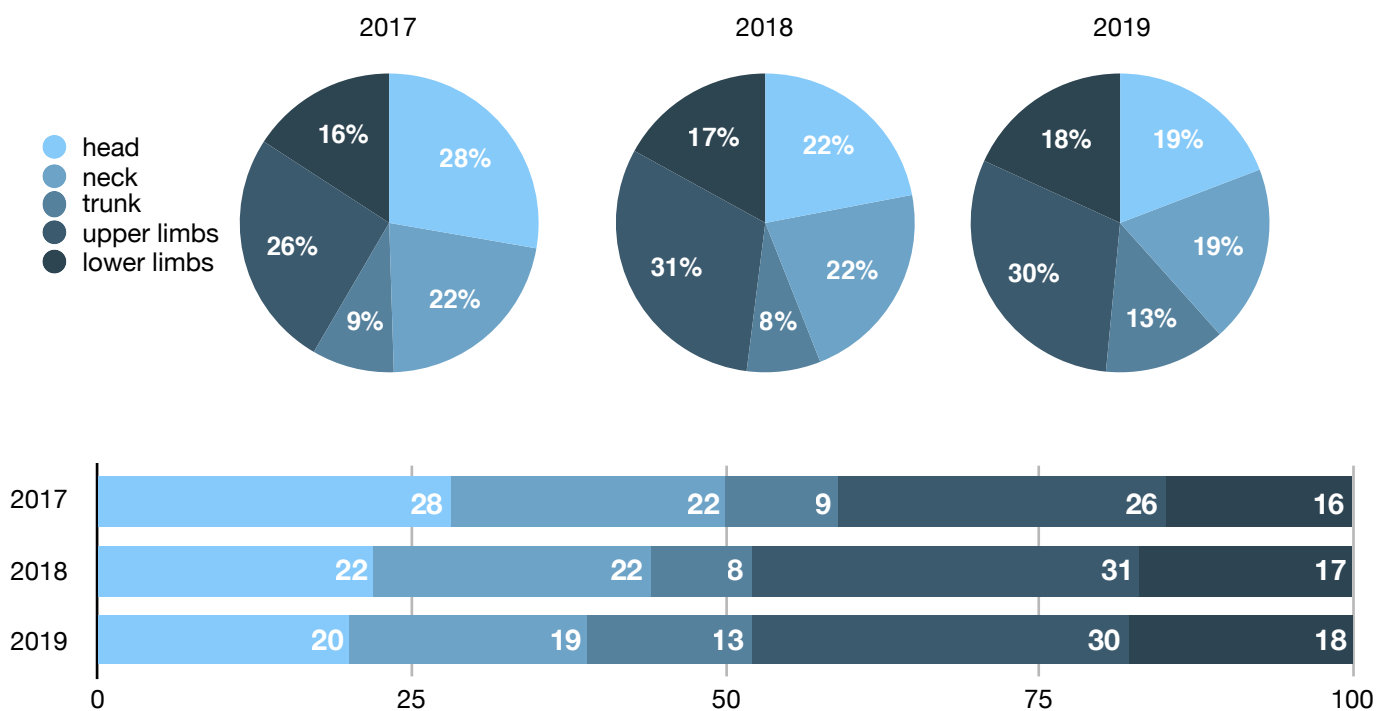
Erythema



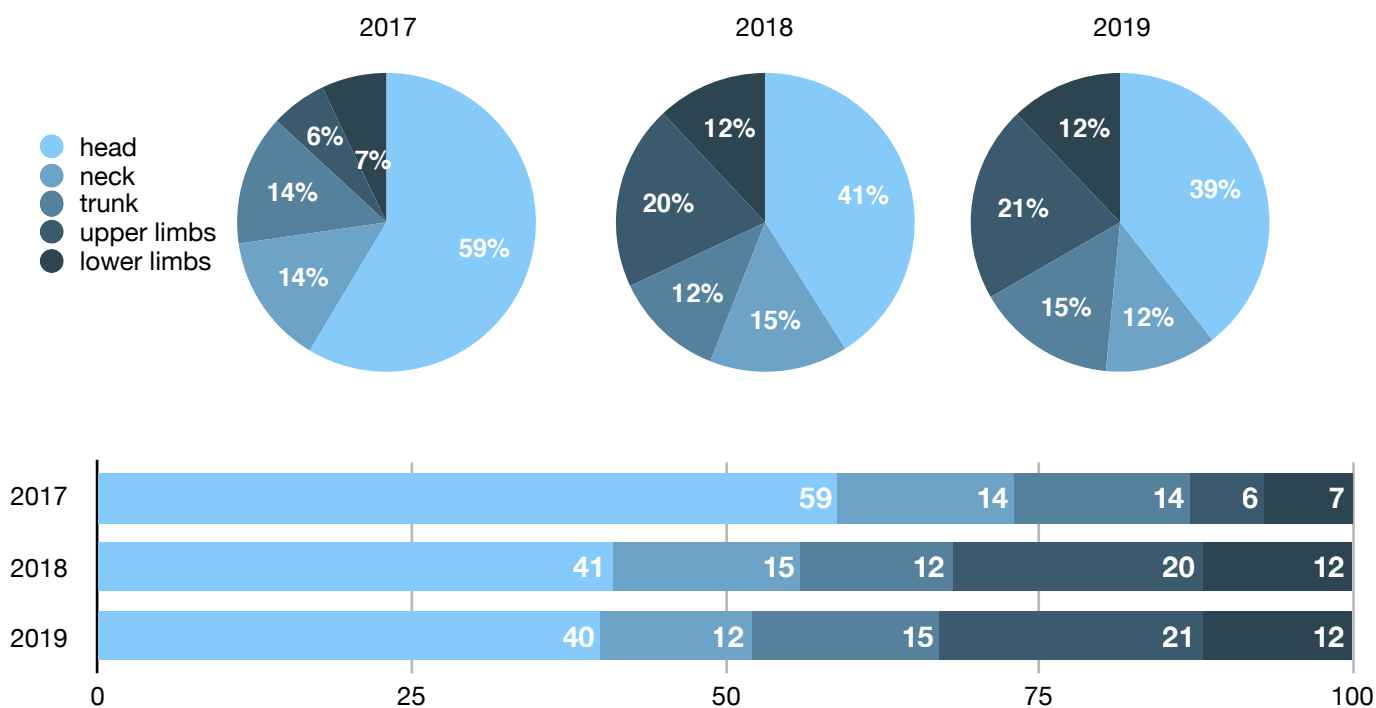
Lentigines



Actinic Keratosis



Suspected Malignancies



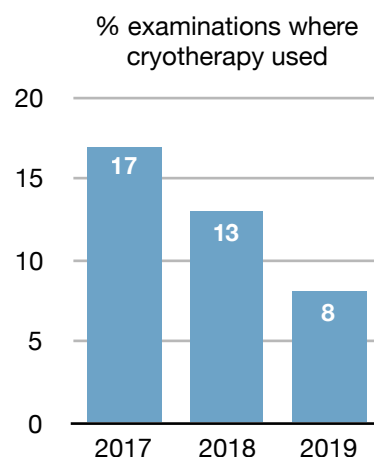
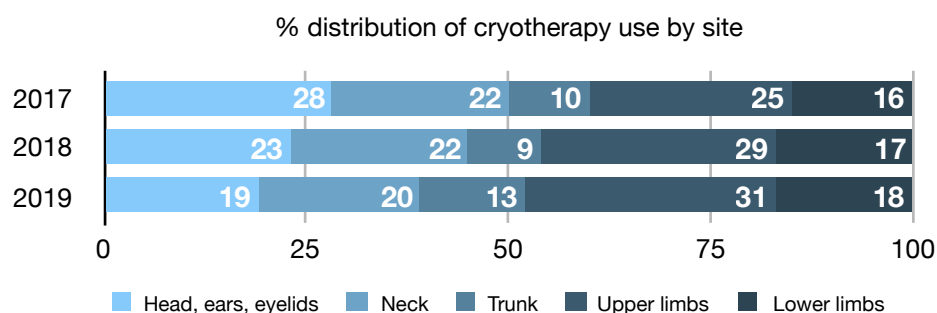


We are continuing to see fascinating trends in the distribution of clinical conditions by bodily site. Every single condition for which we have comprehensive data—erythema, actinic keratoses and suspected malignancies—shows a decreasing proportion of cases appearing on patients’ heads. From 2017 to 2019, the proportion of erythema presentations occurring on the head reduced from 48% to 46% to 34%; for actinic keratosis, a similar drop from 28% to 22% to 19%; and for suspected malignancies, a dramatic reduction from 59% to 41% to 39%. Across all conditions, we saw an average decrease in the proportion of presentations on the head from 47% in 2017 to 40% in 2018 to 34.5% in 2019.

Given the particular vulnerability of the head (ears, lips, eyelids) to sun exposure, this area of the body

has historically accounted for a disproportionately large number of presentations of clinical conditions associated with the development of skin cancer. Protecting this area from sun exposure has been a priority area for Standing Voice, and an important focus of our health education sessions, which aim to build patient knowledge and compliance in protective behaviours and self-care practices. We have invested significant energy in expanding our distribution of wide-brimmed hats, disseminating almost five times as many of these sun-protective items in 2018 (3,186) as 2017 (645). It is rewarding and reassuring to see a positive correlation between our increasing provision of sun-protective hats and decreasing proportion of skin conditions on patients’ heads. More analysis on preventative behaviours and compliance will follow in section 2.8.2.

TREATMENT			
Cryotherapy for Actinic Keratosis (AK)			
	2017	2018	2019 (up until May)
Total number (and percentage) of examinations in which patient received cryotherapy for AK	393 (17%)	493 (13%)	88 (8%)
Percentage of cryotherapy used on:			
Head, ears and eyelids	28%	23%	19%
Neck	22%	22%	20%
Trunk	10%	9%	13%
Upper limbs	25%	29%	31%
Lower limbs	16%	17%	18%
Referral for Further Treatment			
	2017	2018	2019 (up until May)
Total number (and percentage) of examinations referred for further treatment for suspected malignancy	44 (2%)	106 (3%)	19 (2%)

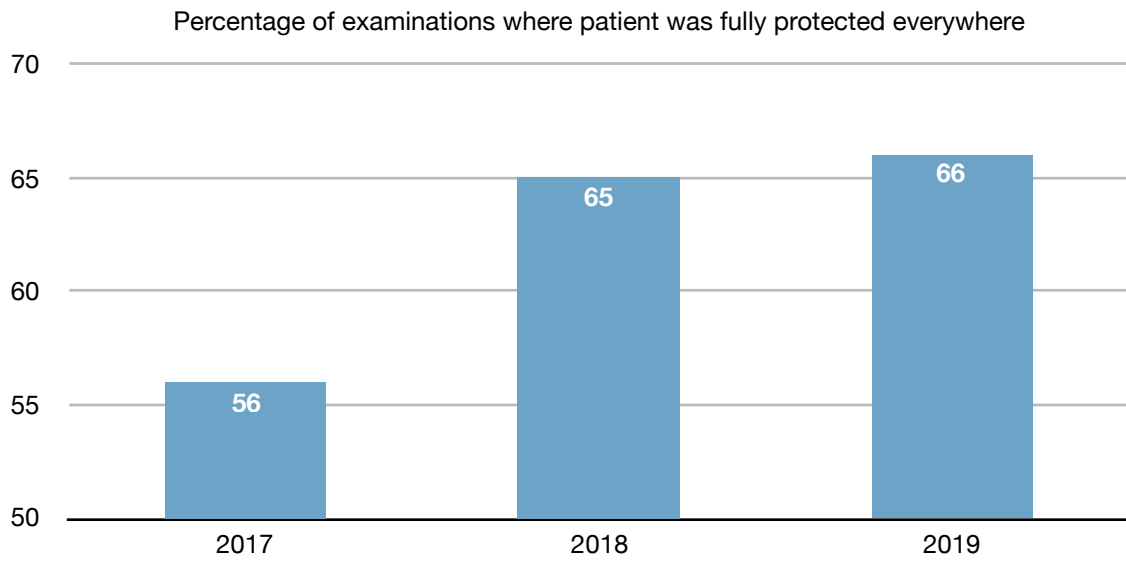


We continue to see promising reduction in the need for cryotherapy treatment among our patients. In 2017, cryotherapy was used in 17% of all patient examinations; in 2018, 13%; and so far this year, only 8%. This reduction correlates strongly with the reduction in rates of actinic keratosis (down from 18% in 2017 to 16% in 2018 and 10% in 2019), and provides an encouraging indication that patients are arriving at our clinics in a better state of dermatological health, to the effect that fewer

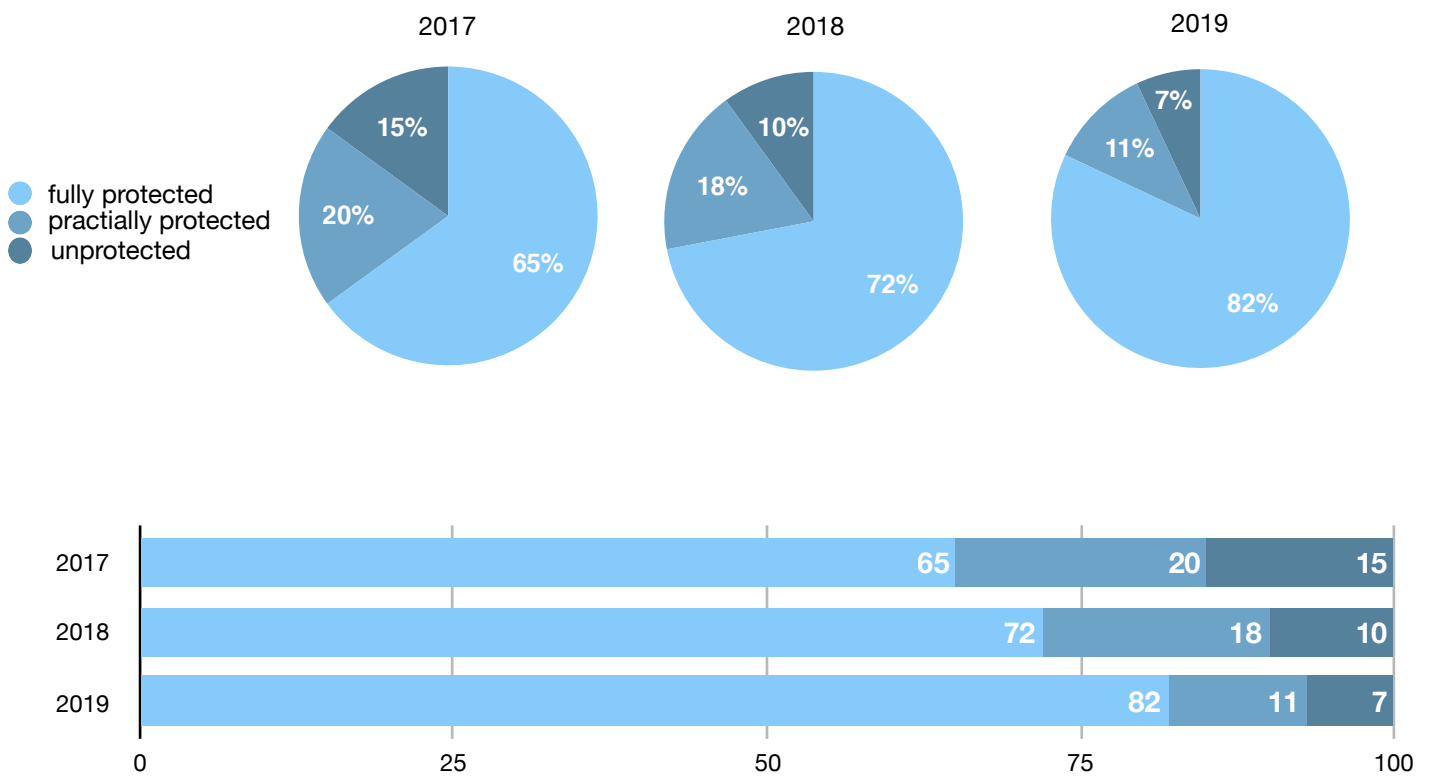
administrations of cryotherapy are necessary. We have also seen a promising reduction in the proportion of cryotherapy treatments applied specifically to patients' heads: a trend that corresponds clearly to the decreasing proportion of keratosis and other clinical conditions appearing on that area of the body, and a further sign of patient compliance following our distribution of sun-protective hats.

2.8.2 Behavioural changes in people with albinism demonstrating increased capacity to adopt self-care prevention measures

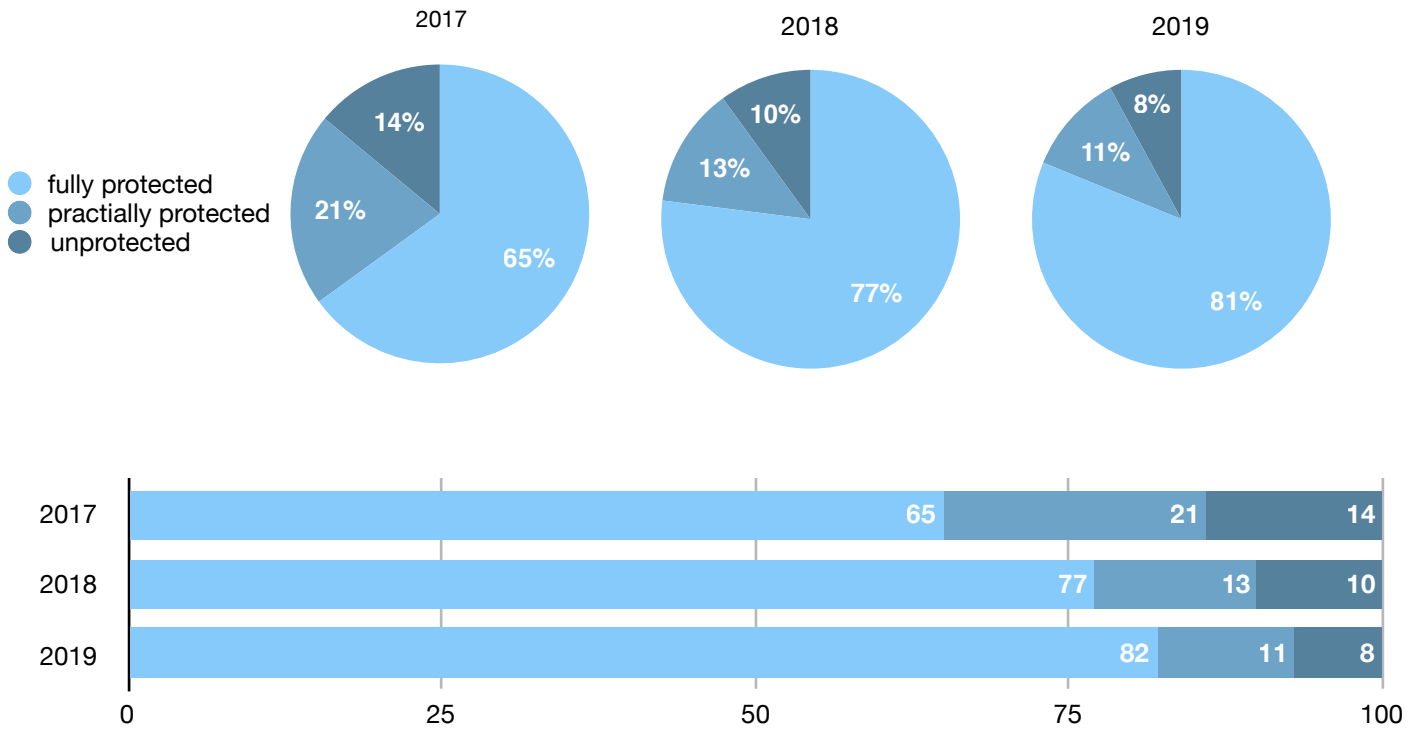
SUN PROTECTION USING CLOTHING			
Fully Protected			
Number (and percentage) of examinations where patient:	2017	2018	2019 (until May)
Fully protected everywhere	1,272 (56%)	2,407 (65%)	764 (66%)
Head, Ears and Eyelids			
Number (and percentage) of examinations where patient:	2017	2018	2019 (until May)
Fully protected	1,491 (65%)	2,273 (72%)	945 (82%)
Partially protected	459 (20%)	559 (18%)	132 (11%)
Unprotected	340 (15%)	335 (10%)	80 (7%)
Neck			
Number (and percentage) of examinations where patient:	2017	2018	2019 (until May)
Fully protected	1,477 (65%)	2,785 (77%)	948 (82%)
Partially protected	492 (21%)	468 (13%)	127 (11%)
Unprotected	321 (14%)	374 (10%)	76 (8%)
Upper Limbs			
Number (and percentage) of examinations where patient:	2017	2018	2019 (until May)
Fully protected	1,614 (71%)	2,971 (82%)	985 (85%)
Partially protected	442 (19%)	439 (12%)	129 (11%)
Unprotected	229 (10%)	223 (6%)	41 (4%)
Lower Limbs			
Number (and percentage) of examinations where patient:	2017	2018	2019 (until May)
Fully protected	1,745 (77%)	3,077 (85%)	980 (85%)
Partially protected	397 (17%)	429 (12%)	135 (12%)
Unprotected	131 (6%)	109 (3%)	41 (3%)



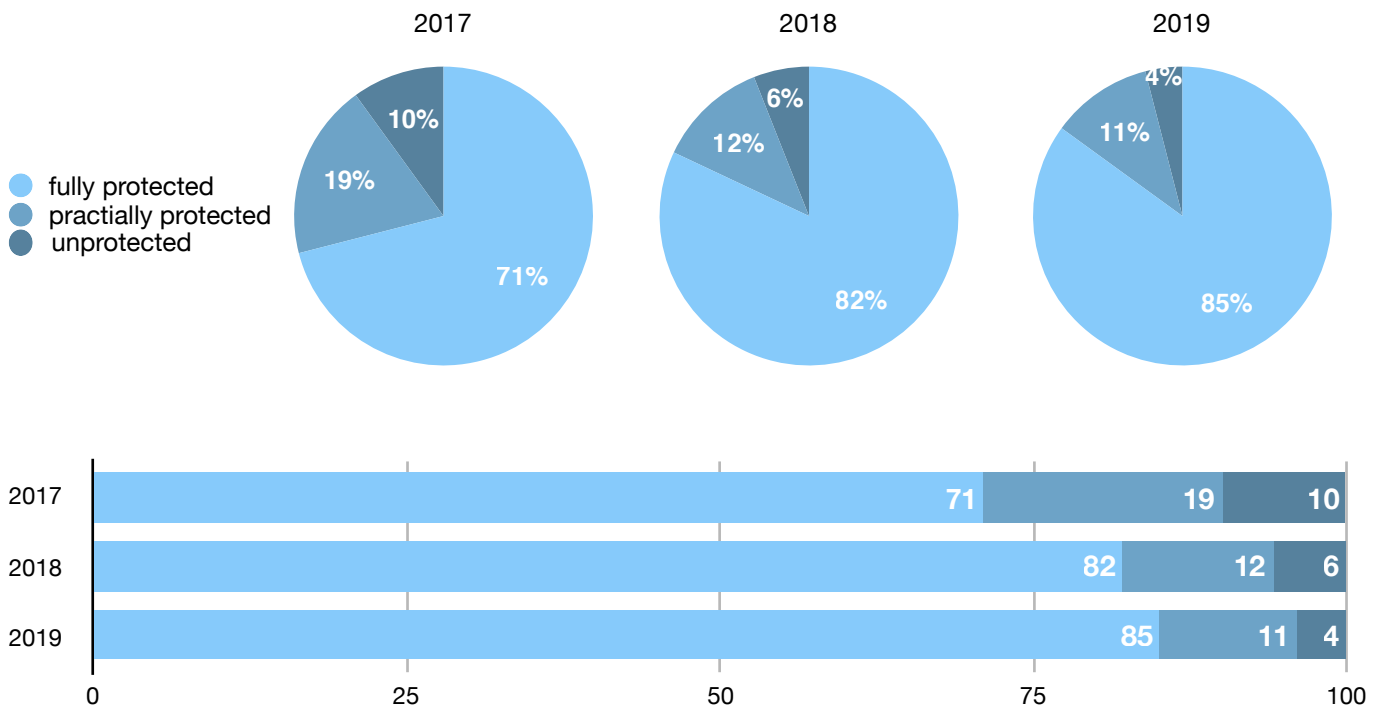
Head, Ears, Eyelids



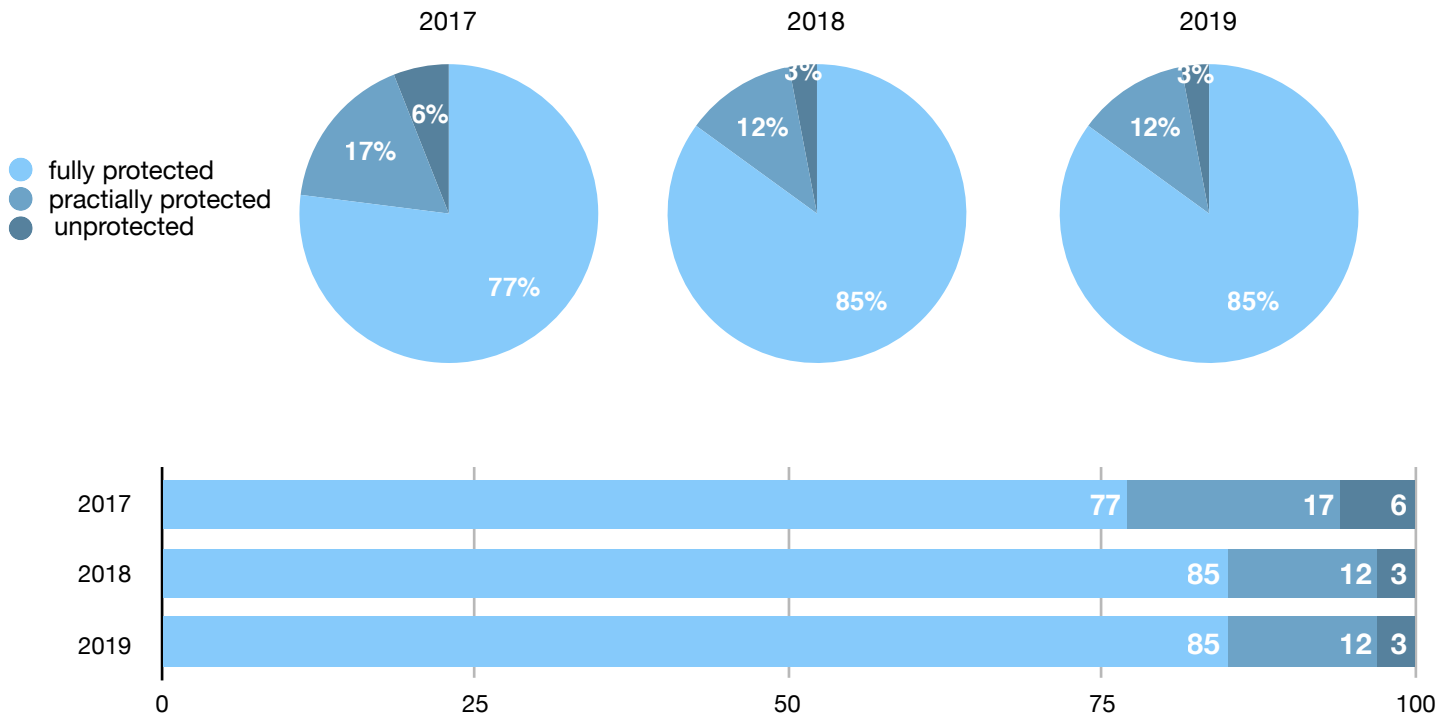
Neck



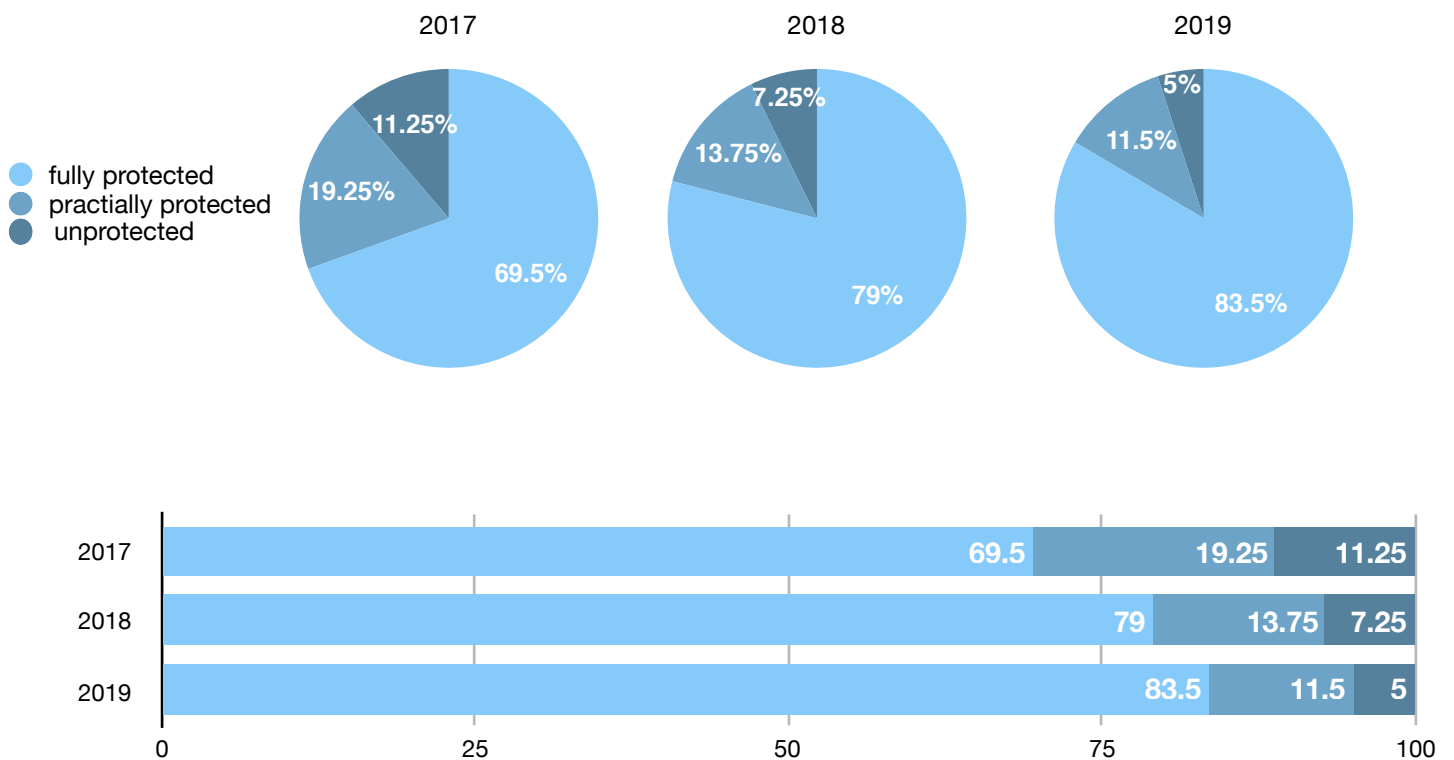
Upper Limbs



Lower Limbs



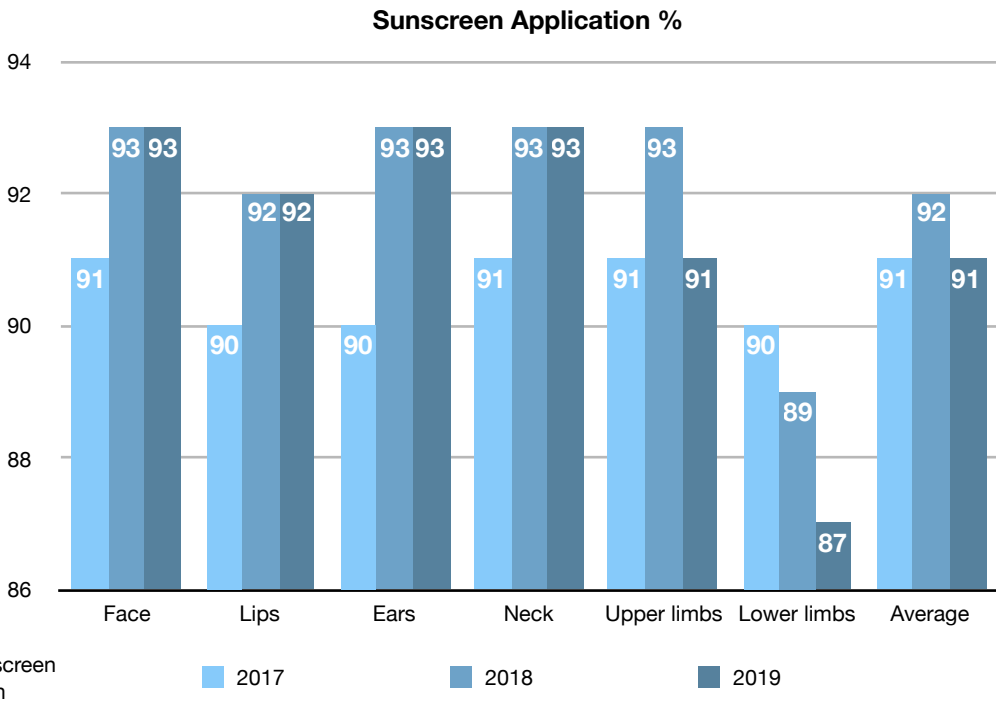
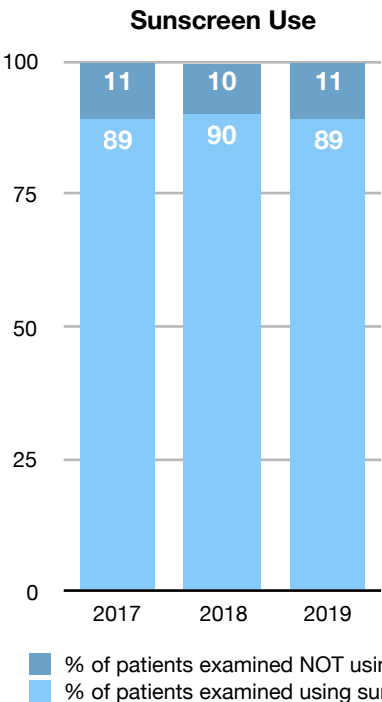
Average



Our recent data shows a breadth of positive behavioural change among people with albinism. Increasingly our patients are complying with recommended preventative practices and proactively engaging in self-care. The percentage of dermatological examinations where patients were successfully using sun-protective clothing to guard against UV exposure across all areas of the body increased from 56% in 2017 to 65% in 2018 and 66% in 2019. These increases become sharper when isolated to specific sun-exposed regions of the body: the proportion of patients fully protecting their heads increased from 65% in 2017 to 72% in 2018 and 82% in 2019; full protection of the neck correspondingly increased from 65% to 77% to 81%; the upper limbs, from 71% to 82% to 85%;

and the lower limbs from 77% to 85% to 85%. The proportion of patients practising partial prevention correspondingly decreased across all parts of the body; and those practising no protection whatsoever, already the smallest cohort, reduced further still. Across all areas of the body, the average proportion of examinations where patients were fully protected increased from 69.5% in 2017 to 79% in 2018 and 83.75% this year; partial protection dropped from 19.25% to 13.75% to 11.25%; and no protection fell from 11.25% to 7.25% to 5%. That 95% of all examinations are revealing full or partial protection on average is an extraordinary sign of patient compliance and an exciting indicator of positive behavioural change in the prevention of skin cancer through patient self-care.

SUN PROTECTION USING SUNSCREEN			
Summary			
Number (and percentage) of examinations where patient:	2017	2018	2019 (up until May)
Was using sunscreen	2,032 (89%)	3,306 (90%)	1,026 (89%)
Was not using sunscreen	247 (11%)	335 (10%)	131 (11%)
Detail			
Number (and percentage) of examinations where patient applies sunscreen to:	2017	2018	2019 (up until May)
Face	2,033 (91%)	3,336 (93%)	1,071 (93%)
Lips	2,012 (90%)	3,265 (92%)	1,063 (92%)
Ears	2,027 (90%)	3,308 (93%)	1,074 (93%)
Neck	2,030 (91%)	3,334 (93%)	1,073 (93%)
Upper Limbs	2,031 (91%)	3,302 (93%)	1,057 (91%)
Lower Limbs	2,020 (90%)	3,181 (89%)	1,012 (87%)
Average	2,026 (91%)	3,287 (92%)	1,058 (91%)



Our data shows that sunscreen use is consistently very high among our patient population. 89% of all patients were using sunscreen across all sun-exposed areas of the body in 2017, versus 90% in 2018 and 89% this year. This trend continues when sunscreen use is isolated to each area of the body, including the face, lips, ears, neck, and upper and lower limbs. The proportion of patients not using sunscreen—11% in 2017, 10% in 2018 and 11% in 2019—is broadly consistent with the number of new patients inducted into the SCPP each year. Our in-depth qualitative interviews with new patients have this year consolidated our perception that most people with albinism in Tanzania not reached by the SCPP are failing to access and use sunscreen. This explains why new patients receiving SCPP services for the first time do not report sunscreen use, and accounts for the proportion of patients not complying with this particular preventative behaviour. Intensive data collection on a sample of patients indicates that people with albinism tend to continue

using sunscreen once they are provided with it and given appropriate instruction in its application and storage. Data also shows that individuals who do not use sunscreen are more likely than others to not perform other preventative measures: a correlation that helps to explain the simultaneity of positive behavioural change we have seen in patients' application of sunscreen and use of sun-protective clothing.

Comparing this to the data presented in section 2.8.1, it is encouraging to see a broad correlation between the decreasing rate of clinical conditions associated with the development of skin cancer and the increasing rate of patient compliance in the use of preventative items like sun-protective clothing and sunscreen. This is a positive indication that the health education delivered through the SCPP is penetrating patient behaviour and delivering long-term improvements in patient capacity to administer self-care.

2.8.3 Greater understanding of albinism and skin cancer

In-depth interviews with new patients in 2019 have generated an insightful baseline to measure patient understanding of albinism and skin cancer. These interviews reveal that although many new patients understand the sun poses a theoretical risk, they sometimes fail to comprehend any specific link between the sun and skin cancer. Many new patients also frequently underestimate the measures that can be taken to prevent skin cancer. Indeed, our qualitative data shows a persistent confusion among new patients regarding the distinction between curative and preventative measures. Where prevention is partially understood, this understanding is often limited to simply staying in the shade. Our interviews also show that new patients who develop an understanding of albinism and skin cancer through personal experience or word of mouth are frequently less informed than those who receive formal training. There is also a demonstrated failure among many new patients to understand the genetic origins of albinism, and to appreciate the consequences of leaving skin cancer untreated. Many patients demonstrate a misperception that they do not need to seek dermatological care or practise prevention if their skin looks 'healthy enough'. There is also a particularly dangerous misconception that babies and children are too young to receive clinical services.

Our data has yielded equally rich insights into the current understanding of albinism and skin cancer among other stakeholders, including the relative and service providers of patients. Parents without albinism who care for children with albinism reveal a poorer understanding of preventative behaviours than the majority of people with albinism, while local leaders in communities previously unreached by the SCPP are commonly ill-informed about sun protection. Many new patients report difficulty accessing health services in minor health centres due to a lack of knowledge and understanding among health professionals regarding the dermatological needs of people with albinism.

These findings indicate that the current understanding of albinism and skin cancer among people with albinism and other stakeholders not currently served by the SCPP is limited. This data will form an indispensable baseline against which to track any developments moving forward.



2.8.4 Increased confidence and well being of people with albinism

Our qualitative data reveals that self-awareness and self-value are both required for confidence and wellbeing. Though self-awareness comes across strongly in interviews with new patients, it is clear that many participants lack self-awareness in the sense that their understanding of albinism is limited.

Additionally, the failure of society to care for people with albinism is frequently lamented by interviewees, and held responsible for negatively affecting their confidence and wellbeing. This appears to have a disproportionately high impact on women, ranging from highly personal experiences of rejection, such as the abandonment of mothers by fathers of children with albinism, to more generalised perceptions of isolation and ostracism. Both men and women reflect that their experience of being abandoned by their families and communities has negatively affected their wellbeing and made life more difficult for them and their children. This seems to be more acutely felt by women, although there are cases where men report mistreatment on account of their child's condition. Overall, women report higher

levels of abandonment, including physical abuse in the form of withholding food and being beaten up, and emotional abuse including accusations of adultery. This contributes to poor wellbeing among mothers who experience this. Mothers of children with albinism also articulate anxiety about the threat of violence toward their children.

Conversely, there is evidence in our qualitative data that community acceptance of children with albinism – whether by the mother's family, or father's, or both – promotes positive relationships between both parents and their families and produces a stronger support network for the child. This in turn is credited with increasing interviewees' wellbeing and confidence.

In the next year, we will continue collecting in-depth qualitative data to measure further progress toward this outcome.

2.8.5 More enabling institutional environment for the SCPP

Delivering structural transformations to the landscape of dermatological care for people with albinism in Africa is a long-standing priority of the SCPP. By delivering comprehensive training and building long-term relationships with a network of health institutions and agencies, the SCPP strives to create a more sustainable systemic climate for skin cancer prevention services to reach (and continue reaching) people with albinism and their families.

Our qualitative data collected on new patients demonstrates that the healthcare system in Tanzania requires additional support and capacity development in order for skin cancer to be adequately prevented and treated among people with albinism. Many of our new patients interviewed this year disclosed that they had never received skincare services prior to encountering the SCPP. Patients attribute this difficulty of access to a number of factors, including: the geographic sparseness of health institutions equipped to provide dermatological care, and long distances between these and patients' homes; the cost of travel to these centres; and the risk of intensive sun exposure during journeys to such centres. Many patients also do not own mobile phones, which they identify as a barrier to remote communication with service providers. When patients do access services, they report concerning levels of ignorance among doctors, who sometimes fail to identify or acknowledge a patient's albinism, or distribute

damaging and misguided information, such as that sunscreen is not required if one's skin 'looks healthy'.

However, interviewees do provide valuable evidence of the support network afforded by motivated members of key institutions. Where knowledge is lacking among stakeholders, the motivation to assist in other ways is still effective. This includes health professionals, local association leaders, religious leaders and teachers who signpost patients to new services, including the SCPP.

Interviewees in particular identify the government as a key institution responsible for protecting the rights of people with albinism to health, education, employment, housing and food security. The provision of sun protection education is viewed as a key responsibility shared by many stakeholders, including the government, NGOs and the media.

Standing Voice has continued a nationwide campaign of advocacy and awareness-raising to generate stronger institutional accountability for the dermatological welfare of people with albinism (see section 2.7). Combined with our intensive training of health professionals—and leadership in the wider movement to domesticate the UN Regional Action Plan on Albinism in Tanzania—this process will help to strengthen systemic support for the SCPP.

2.8.6 Increased support network for people with albinism

Developing a robust support network for our patients is a critical priority for the SCPP, and has been reflected in our sustained commitment to building functional partnerships with a variety of stakeholders (see section 2.6). The SCPP currently mobilises 90 partners across 11 regions of Tanzania (up from 68 partners in 2017, an increase of 32.4%). We have particularly expanded our partnerships with albinism associations (up 60%) and social welfare departments (43.8%), in large part due to the perception by our patients that these stakeholders are among the most critical for their welfare. Indeed the majority of new patients entering the SCPP are signposted to the service by a partner of Standing Voice, including healthcare institutions and

professionals, albinism association leaders, teachers and district government officials. In many cases the government commits considerable time to signposting patients, often writing letters to individuals to encourage their attendance. Patients report that these partners are successfully functioning as their wider support network, which is particularly critical for those experiencing exclusion or ostracism in their own families or communities. Continued momentum in partnership-building will be a cornerstone of our efforts moving forward, in the coordination, delivery and replication of the SCPP.



MALAWI



Malawi

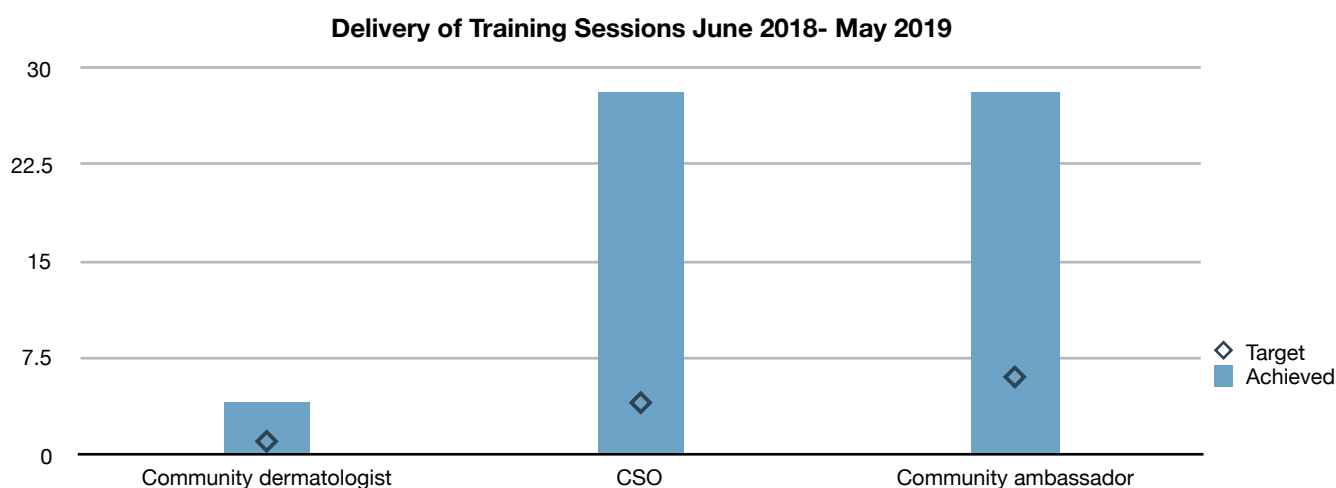
3.1 Reduce the prevalence of skin cancer among people with albinism in Malawi

The development of the SCPP in Malawi has intensified significantly over the last year. We now proudly operate in two districts of the country (Mangochi and Machinga) and continue to be well supported by their respective local health authorities. The commitment of the Mangochi and Machinga district health officers has been critical to our success as they provide local institutional support which is essential to service delivery: releasing clinicians from their hospital duties to conduct SCPP clinics, and providing vehicles and drivers to transport patients, venue space in health centres and surgical theatres, and a free supply of sunscreen.

The Malawian SCPP invests considerably in clinical capacity development, which is beginning to yield positive results. The numbers of clinicians whose diagnostic ability has improved is continually increasing and we look forward to our ongoing work with those individuals as we seek to empower them to manage skin cancer cases within their districts. Our efforts to raise the visibility of the SCPP have also intensified with greater media engagement and national advocacy across Malawi.

3.2 Progress towards targets

SUMMARY OF OUTPUTS			
	Current (as of May 2019)	Target (end of May 2019)	Progress towards targets
Number of clinic locations	7	6	+1
Number of registered patients	457	750	-293
Number of clinic districts	2	2	0
Number of Community Dermatologists	12	4	+8
DELIVERY OF TRAINING			
	Achieved (June 2018-May 2019)	Target (end of May 2019)	Progress towards targets
Community Dermatologist training sessions	4	1	+3
Dermatosurgery training sessions	4	1	+3
CSO training sessions	28	4	+24
Community Ambassador training sessions	28	6	+22



The Skin Cancer Prevention Programme now operates 7 clinic sites in Malawi, exceeding our 2019 target of 6. Our total number of registered patients is 457. Although promising, our rate of growth in Malawi has been slower than in Tanzania. This difference can be traced to the contextual limitations of operating in Malawi, where we have found the level of dermatological expertise to be lower than in Tanzania. Our targets for patient reach in Malawi were determined following our earlier experiences in Tanzania, where the SCPP was established in 2013: the reduced availability of skilled clinicians in Malawi—and absence of an in-country institution equivalent to the Regional Dermatology Training Centre in Tanzania—accounts for this comparatively modest trajectory of growth. Instead, the infant years of the SCPP in Malawi have been marked by an intensive focus on training to promote the rapid capacity

development of dermatologists and other clinicians, so that further clinical roll-out is made feasible and sustainable. This particular strategic decision is reflected in our surpassing of all training-related targets in Malawi, where we have engaged 12 community dermatologists (tripling our target of 4) and successfully delivered a prolific programme of stakeholder training: in the last year, community dermatologists and dermato-surgeons have each received 4 training sessions (our targets were 1 for both), while CSO representatives and community ambassadors have each received 28 training sessions (our targets were 4 and 6 respectively). Our decision to prioritise training and establish strict quality control means the SCPP is ripe for rapid expansion in Malawi, where we expect patient reach to accelerate considerably next year.

3.3 Delivery of clinical care and clinical training

This year has seen healthy signs of growth across all metrics for the SCPP in Malawi. Our patients, clinical sites and geographical coverage are all increasing, while the intensity and breadth of our stakeholder engagement has enabled all training targets to be surpassed. Our bank of registered patients has steadily increased since 2017, adding 188 new patients in 2018 and 90 new patients in the first five months of 2019 alone. Our number of clinic sites has more than doubled since 2017 (from 3 to 7), with the SCPP now active in both Mangochi and Machinga: two districts of Malawi where the rights of people with albinism have been identified as highly at risk. Interestingly, our Malawian data reveals an increasing number of surgeries referred to larger central hospitals (up from 3 in 2017 to 15 in 2018 and 7 in the first five months of 2019 alone). Observations by our highly experienced visiting international specialists indicate this trend derives less from any

capacity limitations of SCPP dermatologists and more from an increasing number of complex cases emerging in our clinics. This in itself is a fascinating development that albinism society leaders have encouragingly attributed to the increasing public awareness of the SCPP as it penetrates more deeply into rural communities and gains the trust and recognition of prospective beneficiaries. The precarious security situation of people with albinism in districts where the SCPP is currently active provide a further layer of explanation for the potential hesitations felt by new patients travelling to receive SCPP services for the first time. The stronger publicity drive accompanying our more recent clinics –coupled with the reassurance patients may take from our increasing collaboration with local police– may help to explain why patients with complex cases are finding the confidence and trust to enter the SCPP.



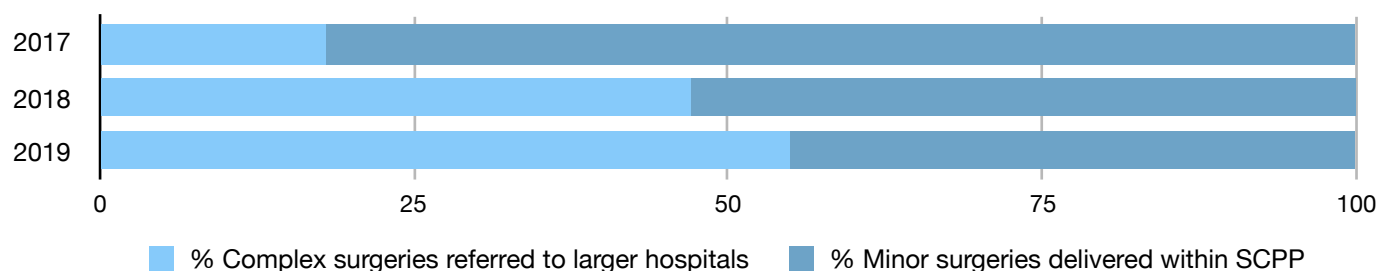
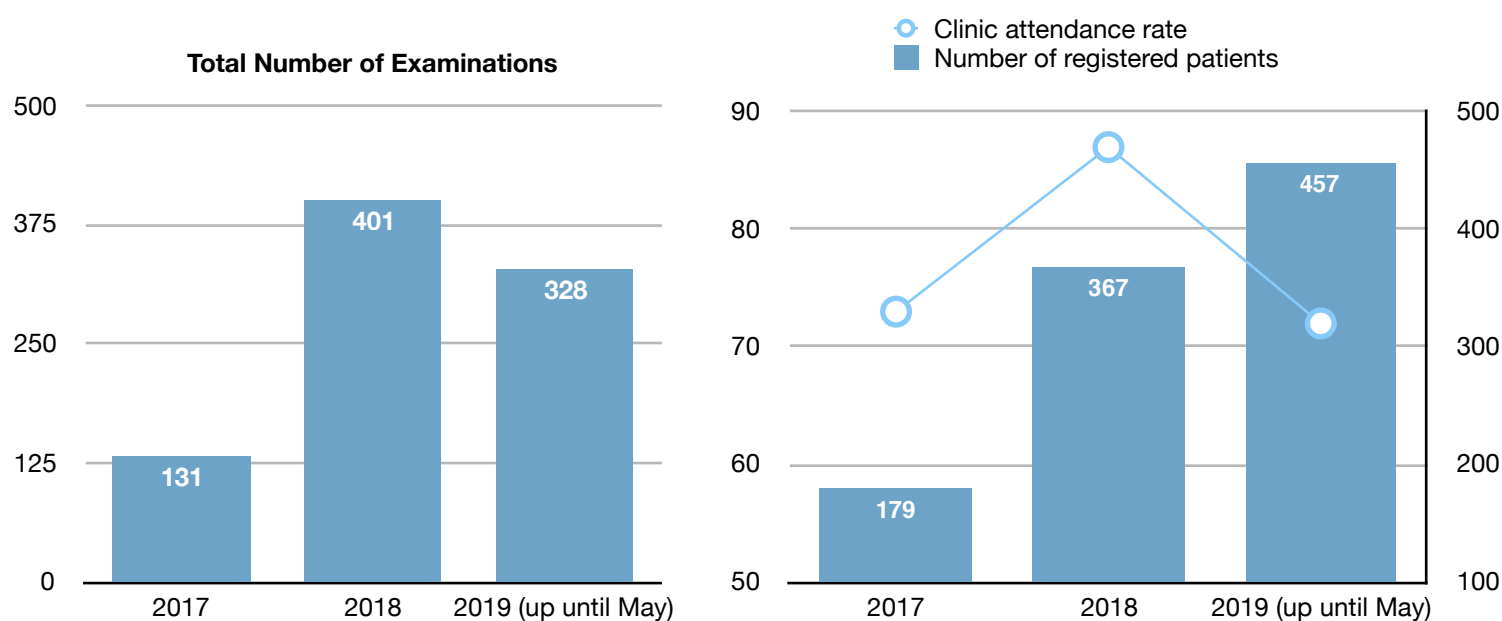
SCPP OVERVIEW: MALAWI

	2017	2018	2019 (up until May)
Number of registered clinic patients	179	367	457
Number of new clinic patients	-	188	90
Total number of patients examined in full SCPP clinical service	131	318	328
Clinic attendance rate (%)	73%	87%	72%
Total number of examinations	131	401	328
Total number of clinic sites/locations	3	7	7
Number of clinics delivered	3	11	7
Number of Malawian districts where full SCPP clinic service is available	1	2	2
Number of Community Dermatologists engaged	6	8	12
Number of Community Dermatologist trainings delivered	1	3	2
Number of Dermatosurgery trainings delivered	1	3	2

FURTHER TREATMENT

	2017	2018	2019 (up until May)
Number (and percentage) of complex cases referred to a large central hospital	3 (60%)	15 (43%)	7 (50%)
Number (and percentage) of minor cases operated by SV trained Community Dermatologists	2 (40%)	20 (57%)	7 (40%)

Total Number of Examinations



3.4 Distribution of sun protective items

Vast numbers of sun-protective items have been distributed through the SCPP to support the dermatological health of our beneficiaries in Malawi. Since 2017 the programme has distributed 400 sun-protective hats and 1,720 pots of sunscreen. In total this constitutes 2,120 sun-protective items distributed in total.

DISTRIBUTION OF HATS, SUN SHADE UMBRELLAS, SUNGLASSES, AND SUNSCREEN				
	2017	2018	2019 (up until May)	Total (2017 up until May 2019)
Hats	72	0	328	400
Pots of Sunscreen	262	802	656	1,720
Total all sun protective items (2017 up until May 2019)				2,120

3.5 Delivery of health education and training to people with albinism and wider community

Health education and training continues to be a priority in the replication of the SCPP in Malawi. The programme promotes sustained capacity development for people with albinism and their families, as well as a range of support stakeholders including dermatology healthcare professionals, civil society representatives and community ambassadors. Since 2017 the SCPP has delivered a total of 45 health education sessions, 21 civil society training sessions and 21 community ambassador training sessions. This training strengthens knowledge and understanding of albinism and skin cancer among an array of partners, strengthening individual and collective capacity to protect the welfare of our patients.

HEALTH EDUCATION AND TRAINING				
	2017	2018	2019 (up until May)	Total (2017 up until May 2019)
Health education sessions delivered	7	24	14	45
CSO trainings delivered	3	11	7	21
Community Ambassador trainings delivered	3	11	7	21
Total of all health education and training (2017 up until May 2019)				87



3.6 Partner network development and mobilisation

	2017	2018	2019 (up until May)
Ministry of Health (Central Administration)	1	1	1
District Departments for Social Welfare	-	1	1
Department of Disability - National Level	1	1	1
Malawi Police service - District police station	-	1	1
District hospital officers	1	2	2
Queens Central Hospital- Skin Department	1	1	1
Kamuzu Central Hospital- Skin Department	-	-	1
Clinicians	6	8	12
NGO and CSOs	-	2	2
Local council authorities	1	2	2
Traditional leaders	7	14	14
Health centre managers	4	7	7
Albinism Association national office	1	1	1
UNC project	-	-	1
District Albinism Association branches	1	2	2
Community Radios	1	3	3
Total No. Partners	25	46	52

Standing Voice began working in Malawi in 2016. Since then, the SCPP has significantly expanded and our numbers of partners has more than doubled in Malawi. Our greatest acceleration in partnership-building occurred between 2017 and 2018 (up 84%), but even in the last year we have mobilised 6 new stakeholders in delivery of the SCPP. Specifically, the numbers of clinicians and traditional leaders engaged by the programme has doubled since 2017.

The breadth and efficacy of our partnerships has been particularly transformative for the SCPP in Malawi. We are now working with two civil society organisations who mobilise their own beneficiaries with albinism to attend our clinics. We also partner with three community radio stations to broadcast multiple radio adverts to publicise the dates and locations of SCPP clinics. Since 2018, we have begun collaborating with the Malawian police service to guarantee the security of patients travelling to our clinics: strategically a particularly pertinent

partnership, given the sharp escalation of violence toward people with albinism in Malawi since 2017. Police also take part in our education sessions during clinics, sharing safety and security recommendations with our patients. In order to deliver clinics, we work with local council authorities and the central administration of the Ministry of Health, as well as the national and district offices of the Association of Persons with Albinism in Malawi. Finally, we engage two major hospitals (Queens Central and Kamuzu Central) who operate on the patients we refer with more complex skin conditions. The UNC Project, for example, is a collaboration between the Malawian Ministry of Health and the University of North Carolina, and supports the SCPP with biopsies and histology reports.

Across all levels and several sectors, the Government of Malawi is a critical partner in the delivery of the SCPP.



3.7 Public awareness and national advocacy

As in Tanzania, the media in Malawi is a critical outlet for publicising clinics to patients and sensitising the general public to the dermatological needs of people with albinism. Over the last twelve months various media outlets have reported on the SCPP, with *The Nation* newspaper, for example, writing an article on

clinics in Mangochi in April 2019. Below is a table listing media engagements in Malawi that presents considerable national coverage across radio, television and print media as well as local coverage in the districts where the SCPP is operating.

Type of Media	Name of Media	Media Aired	National or Local
Radio	Zodiak	Three news story broadcasts	National listenership
Newspaper	The Nation	One news article	National readership
Radio	Dzimwe	Multiple radio adverts	Local listenership (Eastern Region)
Radio	Radio Maria	Multiple radio adverts	National listenership
Radio	Radio Islam	Multiple radio adverts	National listenership
Radio	Umoyo	Multiple radio adverts and participated in local albinism programme (airs every Saturday morning)	Local listenership (Mangochi District)
Radio	Umoyo	Multiple radio adverts and participated in local albinism programme (airs every Tuesday morning)	Local listenership (Mangochi District)
TV	Zodiak	One news story broadcast	National viewership
TV	MBC	One news story broadcast	National viewership

Standing Voice has been involved in the interpretation of the UN Regional Action Plan on Albinism in Africa into a National Action Plan for Malawi. Standing Voice attended the launch of the plan on the 23rd of June with various stakeholders such as the UN and APAM alongside the Government of Malawi. The Malawian Minister of Gender, Children, Disability and Social Welfare, Dr Jean Kalirani, explained that the plan will be implemented from 2018 to 2022 and will guide comprehensive efforts to address challenges people with albinism face in various areas, such as health. We look forward to collaboration with all stakeholders to ensure effective implementation of the National Action Plan.

In March 2019 Standing Voice was invited by the US Embassy in Malawi to participate in a screening of the ground-breaking BBC Two documentary *Born Too White*, a film that Standing Voice was instrumental in producing. *Born Too White* follows Oscar Duke, a British doctor with albinism, as he travels to Tanzania and Malawi to see what life is like for people who share his condition, visiting Standing

Voice's life-saving programmes and meeting the incredible people we work alongside. We were delighted to see that a very diverse audience, comprising both state and civil society actors, were encouraged by the film's key messages. The audience acknowledged the gravity of the crisis still facing people with albinism in Malawi and were supportive of Standing Voice's work.

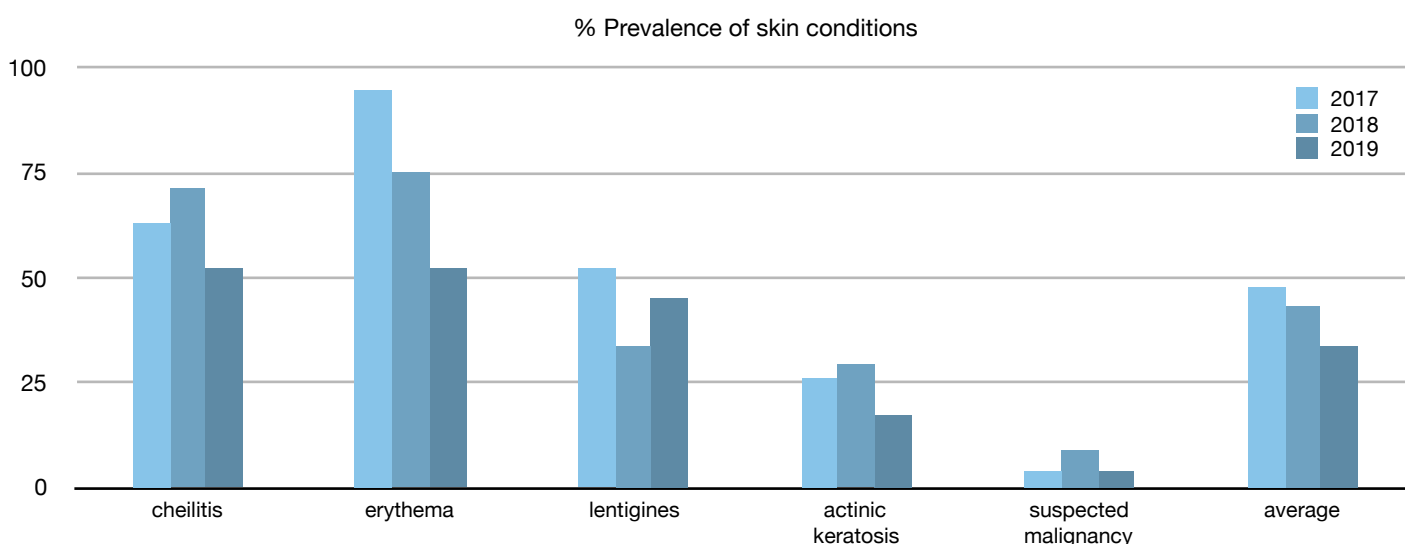
In April 2019, the Irish Embassy in Malawi hosted a dinner on behalf of Standing Voice for a policy and programme dialogue on a number of issues relating to health, education and the social protection needs of people with albinism in Malawi. In addition to the Irish Ambassador, guests at the dinner included the Japanese and German Ambassadors, representatives from the American Embassy and UN Women, as well as Malawian government representatives from the Ministries of Gender and Health. This event offered us a great opportunity to share our work and continue our high-level engagement and collaboration to raise awareness of the health challenges faced by people with albinism in Malawi.



3.8 Evaluation of outcomes

3.8.1 Reduction in presentations of skin cancer and conditions associated with its development

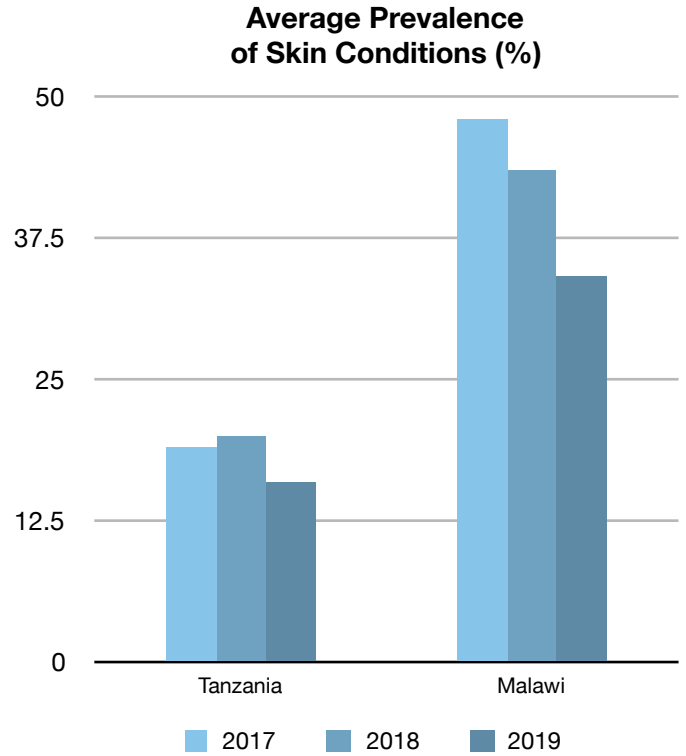
CLINICAL CONDITIONS			
Number (and percentage) of examinations presenting with:	2017	2018	2019 (up until May)
Cheilitis	83 (63%)	283 (71%)	169 (52%)
Erythema	125 (95%)	299 (75%)	171 (52%)
Lentigines	68 (52%)	135 (34%)	148 (45%)
Actinic keratosis	34 (26%)	118 (29%)	55 (17%)
Suspected malignancy	5 (4%)	35 (9%)	14 (4%)
Average	63 (48%)	174 (43.6%)	111 (34%)



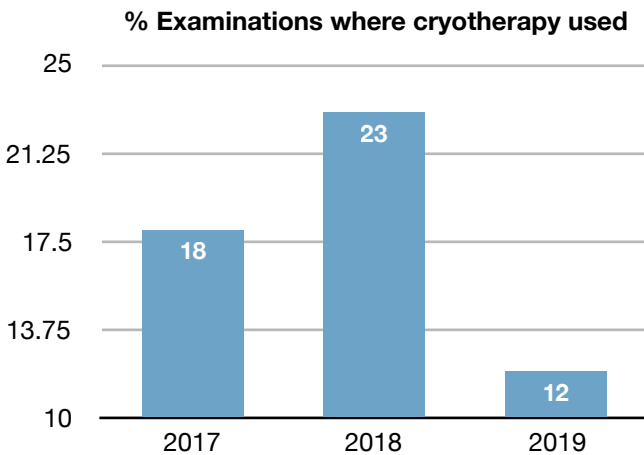
Data collected on our Malawian patients between 2017 and 2019 reveals a deeply encouraging trend of reduction in suspected skin cancers and other skin conditions. Despite a couple of conditions mildly increasing from 2017 to 2018—a fact that can confidently be attributed to the radical growth of the SCPP in Malawi, which drew 188 new patients in 2018 and more than doubled in size—every single condition for which we collect data decreased in prevalence between 2017 and 2019. Rates of cheilitis rose from 63% in 2017 to 71% in 2018, but dropped more sharply to reach 52% in 2019; actinic keratosis fell from 29% in 2018 to 17% in 2019; and the rate of suspected malignancies more than halved year-on-year, from 9% in 2018 to 4% this year. Especially encouraging has been the particular trajectory of erythema, whose prevalence in our patient population fell from an alarming 95% in 2017 to 75% in 2018 and just 52% in 2019. Erythema—the clinical name for sunburn—is a short-term

indicator of skin damage and often an early sign that patients are not successfully protecting against dangerous exposure to UV radiation. That its prevalence has almost halved in as little as two years—from almost all patients presenting symptoms in 2017 to only half now—is highly reassuring evidence of patient compliance, and shows that people with albinism and their families are absorbing and undertaking the preventative recommendations issued in the health education sessions of the SCPP. Reducing the incidence of erythema is often a first line of defence against the development of more serious skin conditions and cancers, so our success in this area should be taken as a great source of promise. Across the board and despite our increasing numbers of new patients, the average prevalence of all clinical conditions has fallen from 48% in 2017 to 43% in 2018 to 34% in 2019 in Malawi.

This is broadly consistent with what we would expect to see in Malawi, where the SPPP is newer and most patients have no prior history of receiving quality dermatological healthcare. In Tanzania, where the SPPP has been active since 2013, the average prevalence of clinical conditions is lower than in Malawi, but the rate of reduction is slower, falling from 19% in 2017 to 16% in 2019. This pattern can be attributed to the contextual specificity of Tanzania, where thousands of patients have been receiving SPPP services for years, and where previously rapid reductions in the prevalence of clinical conditions have since stabilised and levelled (comparison between the two countries is visualised in the graph opposite). In Malawi as well as Tanzania, falling rates of clinical conditions provide positive evidence that the model of intervention developed by Standing Voice and its partners is successfully improving dermatological health outcomes for people with albinism.



TREATMENT			
Cryotherapy for Actinic Keratosis			
	2017	2018	2019 (up until May)
Total number (and percentage) of examinations in which patient received cryotherapy for AK	24 (18%)	92 (23%)	40 (12%)
Referral for Further Treatment			
	2017	2018	2019 (up until May)
Total number (and percentage) of examinations referred for further treatment for suspected malignancy	5 (4%)	35 (9%)	14 (4)



As in Tanzania, we have seen an encouraging reduction in the rate of cryotherapy use across our patient examinations in Malawi, which has fallen by 6% since 2017. This decrease correlates strongly with the reduction in rates of actinic keratosis (down by 12% since last year), and provides a reassuring sign that our patients' skin is healthier at the point of service delivery, meaning fewer administrations of cryotherapy are needed.



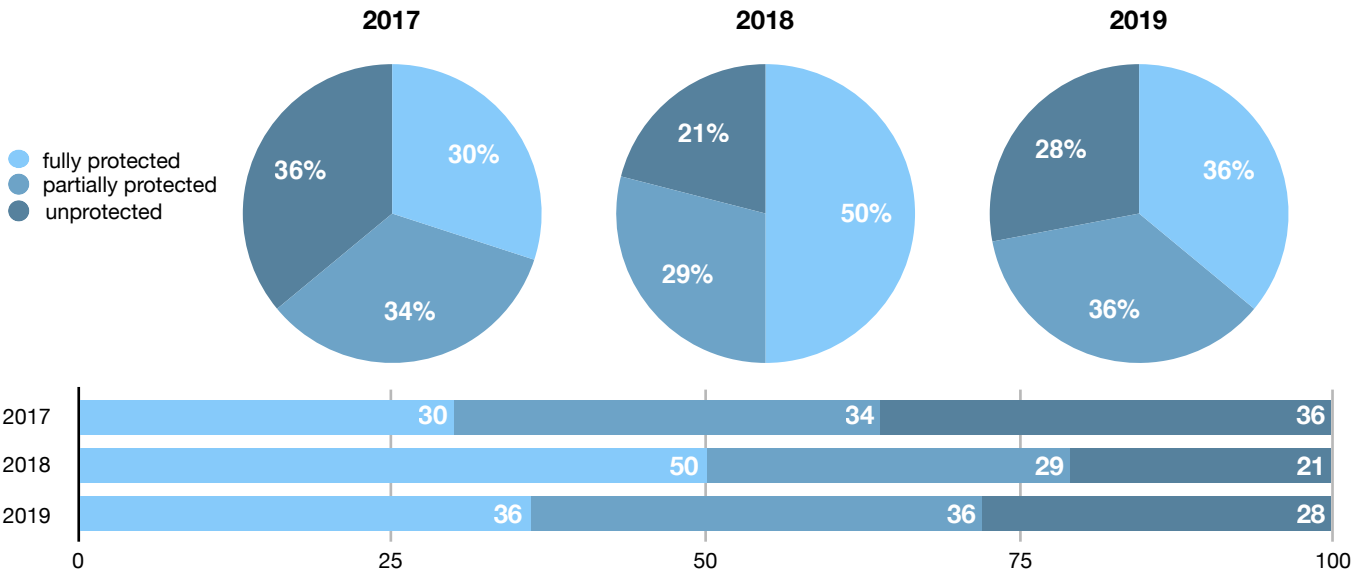
3.8.2 Behavioural changes in people with albinism demonstrating increased capacity to adopt self care prevention measures

SUN PROTECTION USING CLOTHING			
Head, Ears and Eyelids			
Number (and percentage) of examinations where patient is:	2017	2018	2019 (up until May)
Fully protected	39 (30%)	199 (50%)	144 (36%)
Partially protected	44 (34%)	118 (29%)	144 (36%)
Unprotected	47 (36%)	84 (21%)	113 (28%)
Neck			
Number (and percentage) of examinations where patient is:	2017	2018	2019 (up until May)
Fully protected	39 (30%)	168 (42%)	105 (32%)
Partially protected	26 (20%)	117 (29%)	85 (26%)
Unprotected	65 (50%)	118 (29%)	137 (42%)
Upper Limbs			
Number (and percentage) of examinations where patient is:	2017	2018	2019 (up until May)
Fully protected	64 (49%)	287 (73%)	210 (65%)
Partially protected	26 (20%)	83 (20%)	66 (20%)
Unprotected	40 (31%)	30 (7%)	50 (15%)
Lower Limbs			
Number (and percentage) of examinations where patient is:	2017	2018	2019 (up until May)
Fully protected	69 (54%)	278 (69%)	259 (80%)
Partially protected	39 (31%)	100 (25%)	52 (16%)
Unprotected	20 (15%)	24 (6%)	14 (4%)

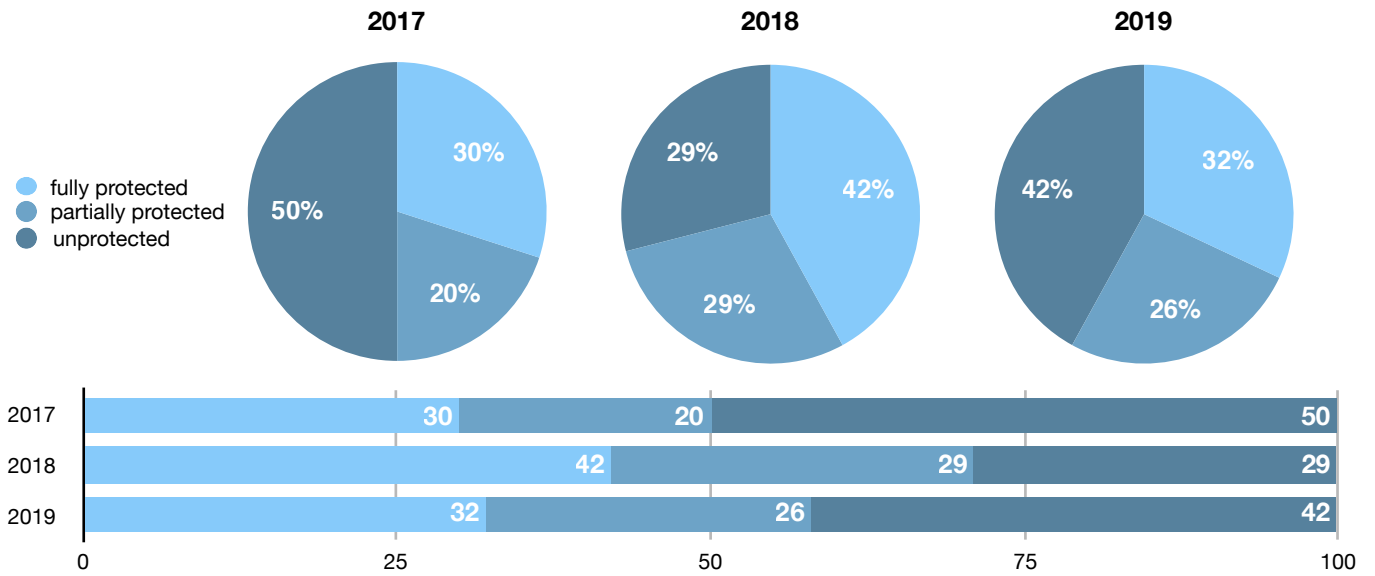
Our recent data indicates a general trend of positive behavioural change among our patient population. Increasingly our patients are complying with recommended preventative practices outlined in SCPP health education clinics. Broadly, we can see that the percentage of dermatological examinations where patients are using sun-protective clothing to guard against UV exposure has increased since 2017. The proportion of examinations where patients were fully protecting their heads increased mildly from 30% in 2017 to 36% in 2019; full protection of the neck saw a similarly moderate increase from 30% to 32% in the time period; full protection of upper and lower limbs rose much more sharply, from 49% to 65% and 54% to 80% respectively between 2017 and 2019. The proportion of examinations

where patients practised no protection correspondingly decreased across all bodily sites from 2017 to 2019. Across all areas of the body, the average proportion of examinations revealing full protection through clothing increased from 41% in 2017 to 53% this year. These improvements are not quite as dramatic as in Tanzania (owing to the comparative infancy of the SCPP in Malawi), but reveal positive indications of growing patient compliance. (Comparisons of data on sun-protective behaviours for Tanzania and Malawi are visualised below, at the end of this section.) That 78% of all examinations on average in 2019 are revealing full or partial protection through clothing is a solid foundation of compliance that can be consolidated and deepened in the months and years to come.

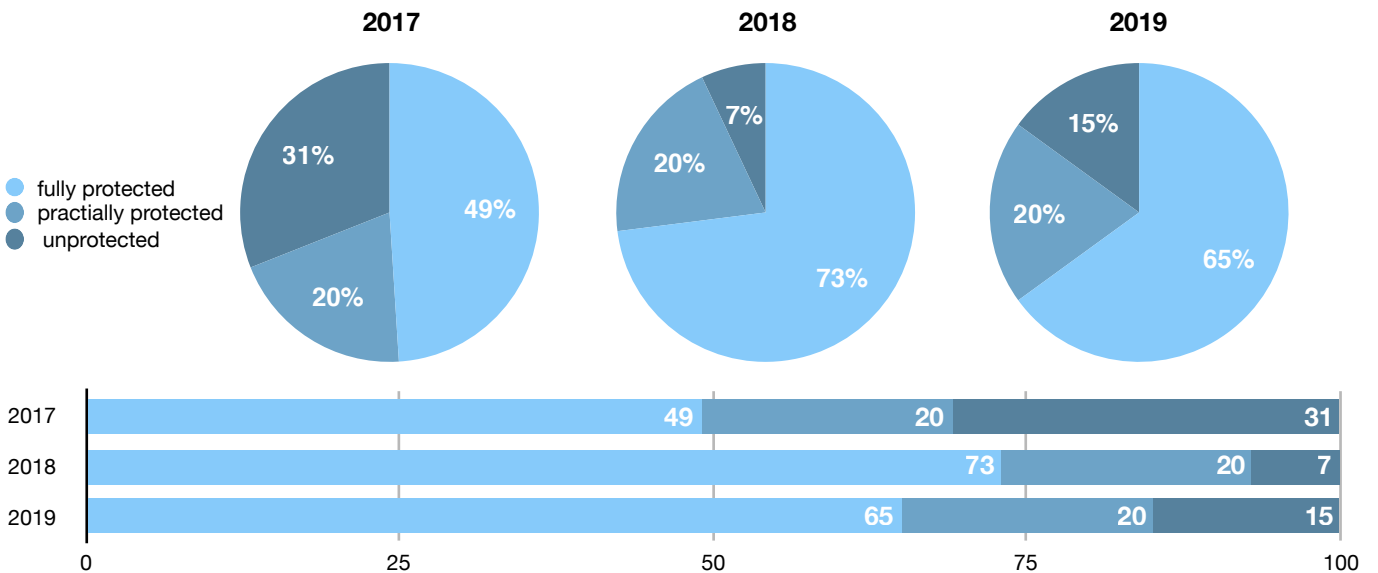
Head, Ears, Eyelids



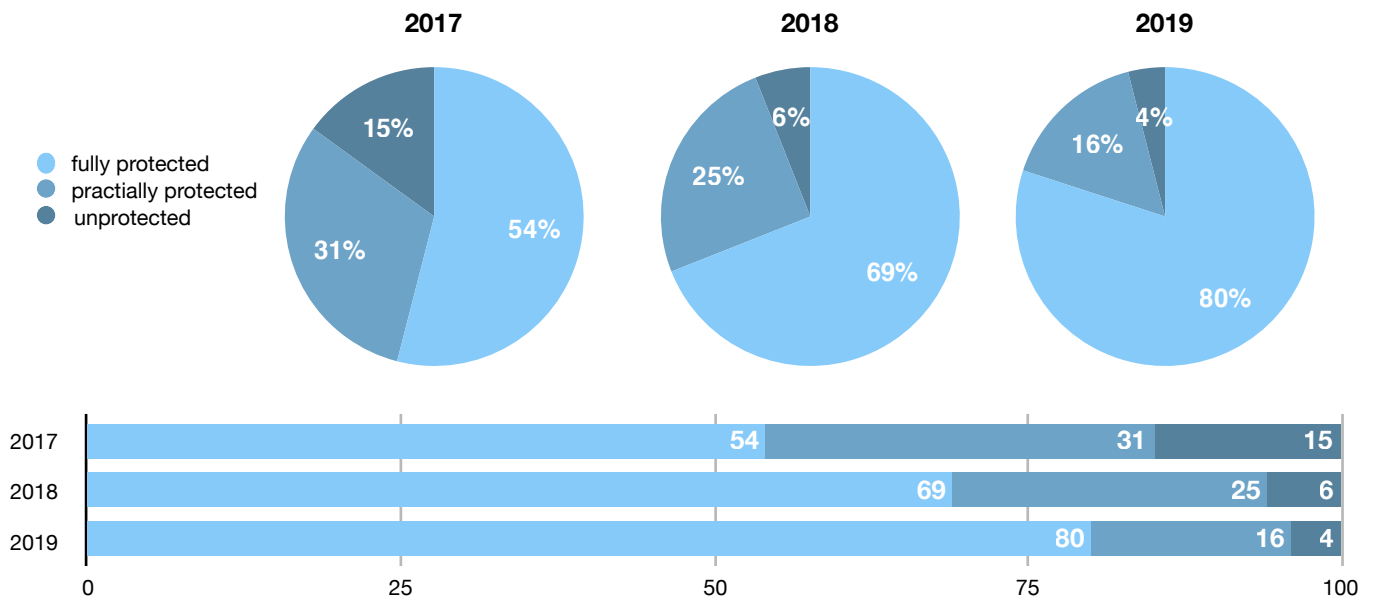
Neck



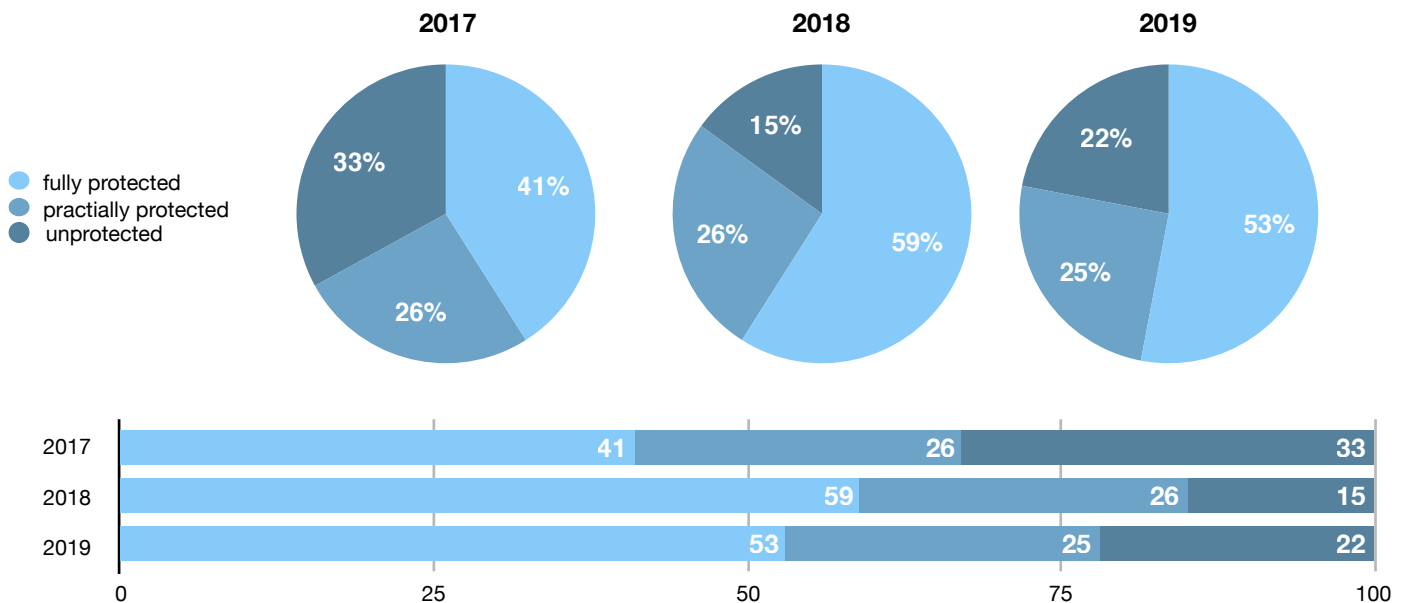
Upper Limbs



Lower Limbs



Average



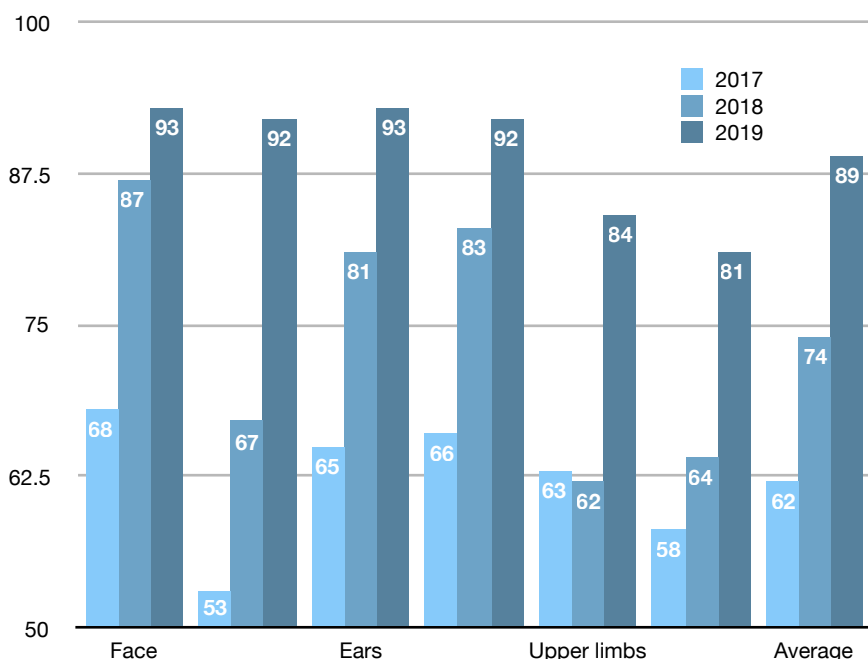
Our data for patient sunscreen use is among the most impressive we have collected in Malawi. We can see that sunscreen use has improved significantly in the last two years across all areas of the body. The percentage of examinations where patients applied sunscreen to the face increased from 68% in 2017 to 87% in 2018 to 93% in 2019; for the lips, from 53% to 67% to 92%; for the ears, from 65% to 81% to 93%; from 66% to 83% to 92% on the neck; and for the upper and lower limbs, from 63% to 84% and 58% to 81% respectively between 2017 and 2019. Across these sites, the average rate of sunscreen use grew from 62% in 2017 to 74% in

2018 to 89% in 2019: an incredible acceleration in patient compliance, with 15% growth in the last year alone. Comparing this to the data presented in section 3.8.1, we can observe an encouraging correlation between the decreasing rate of clinical conditions associated with the development of skin cancer and the increasing rate of patient compliance in the use of sun-protective clothing and sunscreen. This is a promising sign that the preventative practices explored in SPP education sessions are impacting patient behaviour and delivering tangible clinical results in the improvement of dermatological health for people with albinism in Malawi.

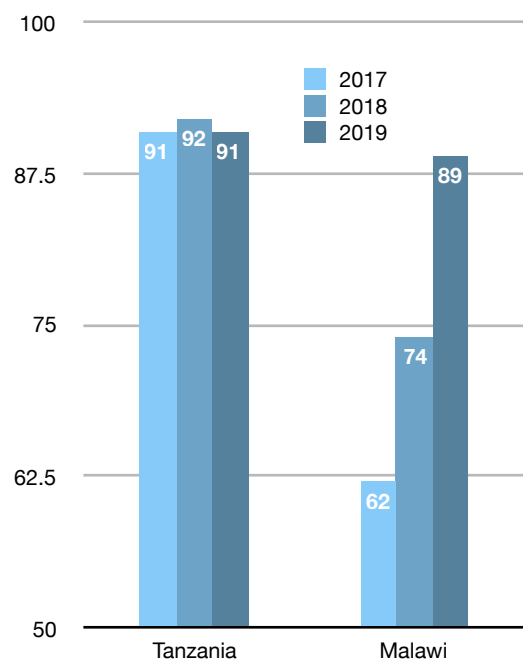
SUN PROTECTION USING SUNSCREEN

Number and percentage of examinations where patient applies sunscreen to:	2017	2018	2019 (up until May)
Face	89 (68%)	349 (87%)	306 (93%)
Lips	70 (53%)	268 (67%)	302 (92%)
Ears	85 (65%)	323 (81%)	306 (93%)
Neck	87 (66%)	331 (83%)	303 (92%)
Upper Limbs	83 (63%)	248 (62%)	275 (84%)
Lower Limbs	76 (58%)	255 (64%)	267 (81%)
Average	82 (62%)	296 (74%)	293 (89%)

Sunscreen Application %

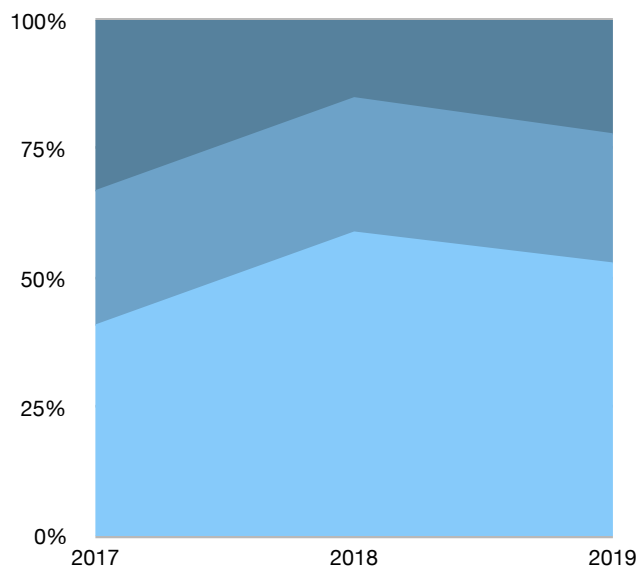


Averages Rates of Sunscreen Application (%)

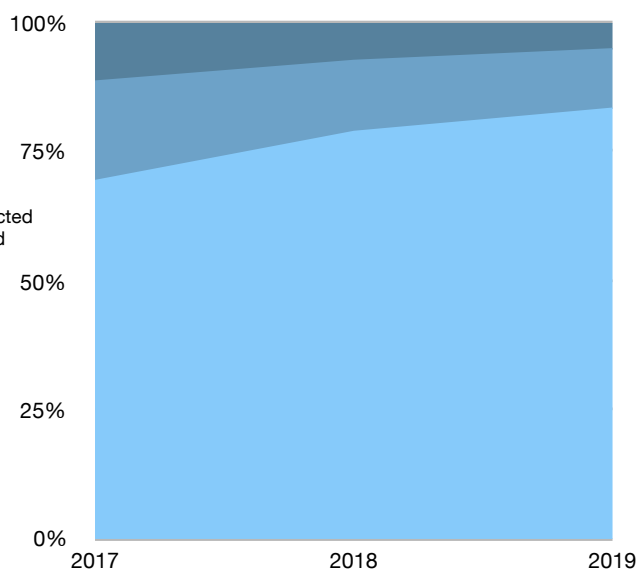


Average Rate of Use of Sun-Protective Clothing (%)

Malawi



Tanzania





3.8.3 Greater understanding of albinism and skin cancer / 3.8.4 Increased confidence and wellbeing of people with albinism

Deepening patients' understanding of albinism and skin cancer and increasing their confidence and wellbeing are critical outcomes for the SCPP. In Tanzania we have collected comprehensive qualitative baseline data on these outcomes through conducting semi-structured interviews with new patients. The SCPP in Malawi is nascent in comparison to Tanzania and we are yet to develop the monitoring and evaluation capacity there to conduct a similar in-depth baseline study. This is a critical aim for the SCPP in Malawi in the coming months.

Although comprehensive baseline data is unavailable, we do have a wealth of anecdotal evidence that patients feel more confident and cared for as a result of their engagement with the SCPP. This is particularly the case with patients who are referred with a suspected malignancy that is

subsequently surgically treated. A recently referred patient commented: *"Since the operation I can now sleep, since I am pain-free and my sore was bleeding a lot. I could not do any work at home or even travel to the market but now I can"*. That patient's mother relayed that her *"daughter now is better; she is doing really well and can work. The doctors were also very nice and really helped her"*.

In terms of improving patients' understanding of skin cancer it is encouraging that, as a proxy measure, clinical conditions are reducing in our patient population. Although this does not explicitly evidence greater understanding of albinism and skin cancer, it is clear that prevention measures are being observed, indicating that patient understanding of the link between sun exposure and skin cancer has improved.



3.8.5 More enabling institutional environment for the SCPP

Capacity strengthening of the Malawian health system and its stakeholders is a critical priority of the SCPP. Only by investing in the skills and knowledge of our partners—at district and national levels, across state and civil society spheres—can we create an institutional climate for the SCPP to be reliably embedded over the long term.

This year we have taken considerable strides to maximise engagement with (and participation by) Malawian institutions in delivery of the SCPP. Standing Voice’s ongoing contribution to Malawi’s National Action Plan on Albinism—a domestication of the Regional Action Plan for Africa, originally launched by the UN—has generated a platform for us to articulate the dermatological health needs of people with albinism before a range of national actors. Standing Voice attended the launch of the plan in June alongside various stakeholders such as

the UN, the Association of Persons with Albinism in Malawi and the country’s central government. The Malawian Minister of Gender, Children, Disability and Social Welfare outlined implementation guidelines for the plan and reflected specifically on continuing needs of people with albinism in the area of dermatological health. Moving forward, we are excited to embed the SCPP in public policy through implementation of the national plan. Standing Voice enjoyed further opportunities for state interaction in April, when the Irish Embassy in Malawi hosted a policy dialogue forum on our behalf to discuss the multi-sectoral challenges faced by people with albinism in Malawi. Guests included representatives of Standing Voice, the Embassies of Japan, Germany and the U.S., UN Women, and the Government of Malawi itself, specifically from the Ministries of Gender and Health.

3.8.6 Increased support network for people with albinism

Beyond ensuring the sustainability of the SCPP, partnership-building can have extraordinary benefits for patient welfare and compliance. For this reason, it has been a sustained priority of the SCPP to engage and sensitise a diversity of stakeholders in Malawi, who can together provide a stronger support network for patients and their families. As in Tanzania, we have invested considerable energy in expanding our partnerships, which have more than doubled in number in Malawi since 2017. Accompanying this quantitative growth has been an equally remarkable acceleration in the functional

quality across all of our partnerships, which are helping to make the SCPP a more efficient and impactful service in each of the locations where it operates. From the media to albinism societies to NGOs, and from clinicians to traditional leaders to a spectrum of government actors spanning national administrations, district departments and local authorities, the SCPP has engaged a remarkable breadth of partners in Malawi: all of whom show increasing commitment to protecting the welfare and dermatological health of people with albinism in the country.



International Replication

This year we have made encouraging steps to realise the international replication of the SCPP in a third African country. In Burkina Faso, we have seen promising signs of preliminary progress, where full clinical replication is planned for the coming year. We have also launched a manual of best practice for clinicians treating patients with albinism: a groundbreaking publication that will facilitate replication in Burkina Faso and elsewhere across the African continent. The continued development of our Skin Cancer Advisory Committee, a body of internationally recognised dermatology experts, will

facilitate further knowledge transfer and network building as our plans for further replication advance.

In the coming months and years, we intend to expand the SCPP across Africa to reach populations whose needs remain direly underserved. We invite collaborations to help us achieve this goal, and encourage direct approaches from individuals or organisations working to prevent skin cancer among people with albinism in Africa. Please send expressions of interest to info@standingvoice.org.

4.1 Burkina Faso

Since 2018 we have been in discussion with the Fondation Pierre Fabre about supporting La Société Burkinabè de Dermatologie, d'Esthétique et de Cosmétologie (SOBUDEC) and L'Association Burkinabè pour l'Inclusion des Personnes Albinos (ABIPA) to replicate the SCPP in Burkina Faso. Last year we provided expert guidance on an application submitted by SOBUDEC and ABIPA. This resulted in further engagement during this year that began with an in-country visit to Burkina Faso in September 2018. The main component of this visit was a two-day workshop with SOBUDEC and ABIPA, designed and delivered by Standing Voice in partnership with the Fondation Pierre Fabre. The objectives of this workshop were to:

1. Develop relationships between Fondation Pierre Fabre, SV, SOBUDEC and ABIPA
2. Deepen Fondation Pierre Fabre and SV's understanding of local context
3. Review and refine the proposed project using SCPP's expertise
4. Develop tools and resources to support the management and delivery of the proposed project in line with the SCPP model

Standing Voice presented the SCPP as an example of an impactful outreach dermatology programme reaching high numbers of people with albinism. Key components for successful delivery were emphasised and our collaborative film with the Fondation Pierre Fabre, *Surviving the Sun*, was

shown to demonstrate how the programme works in practice. The workshop then supported SOBUDEC and ABIPA to understand key project management and delivery tools such as the SCPP Theory of Change and log frame, as well as data collection strategies and stakeholder mapping. We were delighted to partner directly with the Fondation Pierre Fabre in the implementation of this training, and would relish similar opportunities for joint collaboration in future.

Following the workshop, Standing Voice hosted Professor Pascal Niamba, Head of SOBUDEC, in Tanzania for a field trip to observe the SCPP in practice. Professor Niamba observed our routine clinical delivery, and was also present during one of our SCPP training workshops, which demonstrated how the SCPP implements clinical capacity development.

The workshop and field visit to Tanzania proved essential in restructuring the proposed SOBUDEC and ABIPA project, through sharing key elements of the SCPP model. We look forward to continued engagement in this project moving forward and providing the SCPP model as a framework for implementation in Burkina Faso.

4.2 Development of supporting resources and tools for replication

This year we have invested considerable energy in the development of relationships and resources to facilitate further replication of the SCPP. We have continued to strengthen the training and research function of our Skin Cancer Advisory Committee, while also compiling and publishing the *Manual of Best Practice: Skin Cancer Prevention and Management for Persons with Albinism in Africa*.

Produced in collaboration with the International Foundation for Dermatology and funded by the Novartis and the Fondation Pierre Fabre, this manual is the first ever internationally recognised resource enabling clinicians to deliver effective quality care to patients with albinism, specifically in African

contexts. It targets consultant dermatologists, surgeons, dermatology officers, clinical officers and nurses and largely draws on the experience of SCPP personnel. It aims to consolidate current learning and drive improvements in clinical practice for professionals working to promote the dermatological health of people with albinism in Africa. As a user-friendly tool for change, the manual will help us achieve faster and more reliable replication of the SCPP internationally. Its French translation, verified by SV Skin Cancer Advisory Committee members Professors Gérard Lorrette and Bayaki Saka, will be explicitly mobilised for replication in Burkina Faso next year.



The compilation of the manual was led by the Chairperson of our Skin Cancer Advisory Committee, Dr Andrew Sharp, and managed by our Programmes Manager Jamie Walling; contributions were received from our committee members, and other global health experts from Tanzania, Malawi, the United Kingdom, the USA and Spain.

Throughout 2018 the manual was field-tested during programmatic interventions in Tanzania and Malawi. In June 2019, it will be presented to leading international stakeholders at the World Congress of Dermatology in Milan and a major disability rights conference at the United Nations in New York.

Standing Voice's Skin Cancer Advisory Committee is in the process of developing a training framework based on the manual that will complement this resource. This framework will provide a clear guide and structure for how to train clinicians using our recommended and well-evidenced best practices for preventing and managing skin cancer in people with albinism. This standardised training material will be deployed to accelerate replication next year.



International Advocacy

The last year has seen a marked escalation in our efforts to build the international profile of the SCPP. We have used a number of platforms within and beyond Africa to call global attention to the crisis of dermatological health facing thousands of people with albinism across the continent. The sustained and intensive advocacy done by Standing Voice and its partners has led a number of African governments to formally recognise the needs of people with albinism, and take greater responsibility for the fulfilment of their right to health.

This year—in recognition of our unique expertise in the field of albinism in Africa—the United Nations Economic and Social Council awarded Special Consultative Status to Standing Voice. This status enables us to attend and hold events at the UN, and provides an avenue for us to participate directly in the compilation of UN reports and intelligence gathering: an opportunity we have exercised already this year through participation in the 40th Session of the Human Rights Council in Geneva, and one we

will look to capitalise on further in June at the Conference of States Parties to the Convention on the Rights of Persons with Disabilities, a major disability rights conference at the UN Headquarters in New York City.

Our increasing collaboration with the UN has opened up a vital pathway of dissemination for key findings captured through the SCPP, which is fast becoming the leading source of albinism-related skin cancer data for stakeholders interacting within the UN system. The SCPP has received particular attention and acknowledgement as a best practice by the UN Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, Ikponwosa Ero, who is leading the development of a Regional Action Plan on Albinism in Africa in conjunction with a multiplicity of partners. Throughout this process, the SCPP has provided a blueprint for collaborative action to address the dermatological health crisis facing people with albinism and their families in Tanzania and Malawi and elsewhere across Africa.

The health-based targets and recommendations outlined in the Regional Action Plan are largely modelled on SCPP findings and methodology. These include the following:

- Train all health-care workers of all kinds on all issues relevant to the human rights of persons with albinism*
- Train teachers and educators on albinism and how to provide reasonable accommodation for pupils/students*
- By 2021, conduct national assessment on locally produced sunscreen and, wherever feasible, start production*
- By 2021, sunscreen should be on all national lists of essential medicine*
- By 2021, import taxes should be waived on sunscreen and similar dermatological products for reasonable accommodation of persons with albinism*
- By 2021, ensure provision of health care and health care insurance to all persons with albinism, including training for health professionals, awareness raising for families and surgery*
- By 2021, develop at least one programme that touches on multiple and intersecting discrimination faced by persons with albinism*
- By 2021, amass through evidenced-based methods, data on persons with albinism per country, disaggregated at minimum by sex, gender, and age, and health status (vision and skin cancer), as well as types of school and families*

Beyond the United Nations, our team of experts has continued to fulfil a series of international engagements this year through conferences and workshops in South Africa, Uganda, Namibia, Geneva, the UK and the Gambia.

In July 2018, Standing Voice was invited by Amnesty International to join the South African Development Community (SADC) Human Rights Caucus in South Africa. The event regrouped African human rights experts and practitioners, providing a forum for the exchange of ideas and development of strategies to advance human rights advocacy and albinism campaigning at the SADC level. The delegation reconvened a month later in Namibia to refine the recommendations compiled in South Africa. Our Tanzania Operations Manager, Alex Magaga, worked

together with other regional stakeholders to devise a joint declaration for consideration by Heads of State at the SADC's 38th Summit in August 2018 in Windhoek. This declaration focused on the relationship between social discrimination and poor dermatological health for people with albinism in Sub-Saharan Africa.

In August 2018, Standing Voice was invited to a capacity building workshop on albinism and human rights in Pretoria, South Africa. Hosted by the Centre for Human Rights at the University of Pretoria, the workshop brought together albinism organisations from Ghana, Zimbabwe and Tanzania among others, as well as service providers, advocates, media professionals and government representatives. At this event, our representatives received valuable training aimed at further developing our lobbying and advocacy capacity.

In September 2018, we also presented at a high-level albinism strategy meeting held at the Office of the United Nations High Commissioner for Human Rights (UNHCR). The meeting, titled 'Albinism and Human Rights', was co-hosted by the UN and Trinity Western University. Our presentation explored interdisciplinary approaches to research and advocacy, and aimed to demonstrate how the SCPP is empowering patients to become informed self-advocates, able to understand their own health and communicate their health needs to others. Our programme film [Surviving the Sun](#) received its first UN screening before an audience of world-leading albinism experts. We delivered a follow-up paper at Lancaster University exploring similar themes in January 2019.

In October 2018 our Director of Development, Jon Beale, attended and presented at the 63rd Session of the African Commission on Human and People's Rights in Banjul, the Gambia. Standing Voice used this event to showcase the SCPP and share key statistics generated through its activities.

Next year, we look forward to continue speaking out on international platforms and raising the voices of people with albinism until they carry around the world. Together with our partners, we come one step closer to illuminating the needs of people with albinism—within and beyond the issue of skin cancer—before a truly global audience.



Looking ahead

This year has seen the SCPP take significant strides to reduce the prevalence of skin cancer among people with albinism in Tanzania and Malawi. This year our database of fully registered patients has increased by 21.4% in Tanzania and 24.5% in Malawi. In both countries, we have opened new clinical locations, expanding our geographical reach and intensifying collaborations with government and civil society partners. We are delighted to have seen a broad reduction in the prevalence of many clinical conditions, as well as a surge in patient compliance and promising uptake of recommended preventative behaviours. The vast majority of our targets have been met or surpassed.

These achievements should refresh our momentum moving forward. There is still much work to be done for the SCPP, and our plans for 2019/2020 are ambitious: we will continue to serve our existing patients, while also striving to access those families and communities who currently lie beyond reach. We will open clinics in new regions, visiting the remotest corners of Tanzania and Malawi to pursue parity of access for people with albinism everywhere. We will engage and train new dermatologists, and use our

recently published manual of best practice to launch a comprehensive training package for clinicians across Africa working to support people with albinism by replicating our vision. We will also invest considerable energy in deepening our data analysis, and using our UN Special Consultative Status to disseminate the findings of the SCPP on a scale not previously attempted.

Emboldened by our achievements but humbled by the work left to do, we are poised to embark on our most ambitious programme of activity in the coming year. Walking side-by-side with our partners and supporters, we are confident in our ability to build on the progress we have already made. Looking ahead to the next year but also beyond it, we are excited to explore opportunities for long-term collaboration between Standing Voice and others who share our goal of delivering better dermatological health for people with albinism across the continent of Africa.

Together, we can ensure no one is left behind.



Partners & Supporters

This year the SCPP has continued to flourish only because of the commitment and capability of our partners, both public and anonymous. There are too many to list in full, but we extend particular thanks to:

Principal Funder

Fondation Pierre Fabre

Other Funders

The Wellcome Trust
Bilton Charitable Foundation
The Edge
The Wheeler Family and all Standing Voice Malawi supporters in Ireland
International Foundation for Dermatology / International League of Dermatological Societies
Rotary
Leicester Royal Infirmary Dermatology Department

Partners in Tanzania

Government of Tanzania
Regional Dermatology Training Centre
Kilimanjaro Sunscreen Production Unit (KCMC/RDTC)
Private Hospital Advisory Board
Ministry of Health, Community Development, Gender, Elderly and Children
Ministry of Regional Administration and Local Government
Prime Minister's Office - Department of Labor, Youth, Employment and Disability
Dermatologists, Surgeons, Dermatology Officers, Clinical Officers, Nurses
Referral hospitals (Bugando, Kilimanjaro Christian Medical Centre, Muhimbili, Ocean Road Cancer Institute)
Regional and district hospitals and health centres

NGO and CSO partners
Tanzania Albinism Society
Under the Same Sun
New Light Children Centre Organisation
Mennonite Central Committee
Beyond SunCare

Media partners
Union of Tanzania Press Clubs
Sengerema FM
Huheso FM
TBC
ITV
AZAM TV

Partners in Malawi

Government of Malawi
Ministry of Health
Regional and District Administrative Authorities
Hospitals and health centres
Dermatologists, Surgeons, Dermatology Officers, Clinical Officers, Health Surveillance Assistants
Ministry of Gender, Children, Women, Disability and Elderly Affairs
UNC Project with Kamuzu Central Hospital
Malawi Police Service

NGO and CSO partners
Association of Persons with Albinism in Malawi
Malawi Network Against Trafficking
Red Cross
Federation of Disability Organisations in Malawi

Media partners
Zodiak
The Nation
Dzimwe
Radio Maria
Radio Islam
Umoyo
MBC

Other Partners

United Nations Independent Expert on the Enjoyment of Human Rights by Persons with Albinism
UN agencies (UN Women, UNICEF, UNDP)
Irish Embassy in Malawi
US Embassy in Malawi

And thanks to:

Standing Voice Skin Cancer Advisory Committee
Standing Voice Health Programmes Staff and Volunteers
SCPP patients, their guardians and families

