

Standing Voice

Annual Report and Accounts 2025

Registered with FUNDRAISING REGULATOR

Registered charity No.1151250

FOREWORD

2025 was another year of significant progress for Standing Voice as we continued to strengthen our programmes and deepen our impact across Tanzania and Malawi. Working alongside governments, organisations of persons with albinism, healthcare providers and community partners, we expanded access to healthcare, education, livelihoods and welfare services, helping more people with albinism to live healthier, safer and more independent lives.

During the year, our programmes directly benefited more than 14,000 people with albinism through specialist dermatology and eye care services, psychosocial support, education initiatives, economic empowerment programmes and community-based outreach. We also continued to strengthen national systems through healthcare worker training, research, advocacy and support for government-led service delivery, strengthening the long-term sustainability of our programmes and supporting greater national ownership.

These achievements were realised against a challenging backdrop. Political, economic and regulatory pressures in both Tanzania and Malawi created a more complex operating environment, placing additional strain on health systems and the communities we serve. Despite these challenges, the dedication of our staff, partners and volunteers ensured that services continued uninterrupted and that the charity met or exceeded its principal objectives for the year.

None of this would have been possible without the generosity and commitment of our supporters. We extend our sincere thanks to all our institutional donors, charitable trusts, foundations, corporate partners and individual supporters whose investment makes our work possible. We are equally grateful to our government partners, organisations of persons with albinism, healthcare professionals and civil society organisations, whose collaboration remains fundamental to the success and sustainability of our programmes.

As we look ahead to 2026, we will continue building on the strong foundations established over the past thirteen years. Alongside the continued expansion of healthcare services, we will further strengthen our work in safeguarding, economic empowerment, education, research and broader systems strengthening, ensuring that people with albinism can access the services, opportunities and protection they need to thrive.

On behalf of the Board of Trustees, we thank everyone who has contributed to Standing Voice's mission during the past year. Together, we remain committed to a future in which people with albinism can live with dignity, safety, equal opportunity and full inclusion.



Sabine Zettler
Chair of the Board of Trustees
27/10/2026

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1. LEGAL AND ADMINISTRATIVE INFORMATION

Charity Name	Standing Voice (UK)
Charity No.	No. 1151250 Charitable Incorporated Organisation (CIO)
Administrative offices	Standing Voice UK Unit 34b Regent Studios 8 Andrews Road London E8 4QN Standing Voice Tanzania P.O. BOX 1902 Isamilo, Mwanza Tanzania Standing Voice Malawi Area 14 Plot No.63 Lilongwe
Registered Addresses	49 Newick Road London E5 0RP P.O. BOX 180 Ukerewe Island, Mwanza Tanzania Area 14 Plot No.63 Lilongwe
UK Board of Trustees	Sabine Zetteler (Chair) Gurmeet Kaur (Treasurer) Eshita Uadkat Innocentia Magijima Harry Freeland Jonathan Beale
Malawi Board of Trustees	Grace Malera Tadala Chinkwezule Jonathan Beale
Tanzania Board of Trustees	Katwale Magaga Martha Mganga Harry Freeland
UK Administration	Harry Freeland, Alfred Thomas, Ruth Ayarza, Reiss Tigwell, James Parkin

2. REPORT OF THE TRUSTEES

2.1 Constitution

Standing Voice (UK) was constituted under a Foundation Constitution that came into effect on 14th March 2013, on which date Standing Voice became registered as a Charitable Incorporated Organisation (CIO). The trustees are the only members of the CIO. If the CIO is wound up the members have no liability to contribute to its assets and no personal responsibility for settling its debts or liabilities.

2.2 Board of Trustees

Standing Voice has three international boards: Standing Voice UK (6 members), Standing Voice Tanzania (3 members) and Standing Voice Malawi (3 members). Trustees are appointed by existing trustees through an electoral process. There may be no fewer than three trustees at any one time on the Board of Trustees. Standing Voice trustees hold quarterly board meetings. The board also addresses governance matters as and when necessary, through e-mail or other means as necessary.

In selecting trustees, consideration is given to the overall breadth of knowledge and experience required of the Board of Trustees. Candidates are typically interviewed by at least two existing trustees and nominations are then presented for approval to the board. Successful candidates, once appointed, receive appropriate documentation about the roles and responsibilities of being a Standing Voice trustee.

2.3 Advisory Board

Standing Voice teams are supported by an Advisory Board made up of ten experts from six countries (Malawi, Tanzania, USA, UK, Malawi, and Ireland). This includes a wide range of expertise in the fields of public health, dermatology, ophthalmology, education, trauma recovery, genetics, general medicine and surgery, and in-depth knowledge on albinism.

The Advisory Board provides expert guidance to the UK Board and staff management teams, by advising on the design and implementation of our programmes. The Advisory Board also works closely with Standing Voice's wider staff teams, with a primary focus on developing resources and training manuals, leading the delivery of clinical and surgical training, conducting research and publication, and identifying funding opportunities.

Our warmest thanks go to our Advisory Board; Our current Chair of the Board Dr Andrew Sharp, and members; Professor Daudi Mavura, Dr Kelvin Mponda, Bonface Massah, Professor Melissa Levin, Dr Elizabeth Roberts, Dr Mark Wheeler, Dr Patricia Lund, Professor Charlotte Baker and Dr Mark Fish.









2.4 Organisational Structure

The UK Board of Trustees governs Standing Voice on a voluntary basis, meeting quarterly or as needed. As Standing Voice Malawi and Tanzania report to the UK entity, the UK Board holds primary governance responsibility for the organisation's global operations. Trustees bring diverse expertise spanning international development, human rights, financial management, media, public relations, and the arts.

Standing Voice maintains locally registered offices in both Malawi and Tanzania, each overseen by a local Board of Trustees. These boards ensure compliance with local governance standards and bring together professionals in law, human rights, organisational management, and national human rights institutions. Day-to-day leadership of our country teams is provided by the Executive Director in Malawi and Operations Director in Tanzania.

Harry Freeland has served as Executive Director of Standing Voice UK since April 2014 and sits on both the UK and Tanzania Boards of Trustees. During the reporting period, the UK team included five paid staff, supported by a dedicated group of volunteers. Globally, as of December 2025, Standing Voice teams includes 25 staff in Tanzania and 12 in Malawi, and 5 in the United Kingdom, bringing the total international staff to 42.

People with albinism are central to Standing Voice's leadership and decision-making structures. They are represented as trustees and senior leaders across our offices in the UK, Malawi, and Tanzania, ensuring that our governance, programmes, and fundraising remain grounded in lived experience and accountable to the communities we serve.

2.5 Contributions of Medical Expert Volunteers

During the reporting period, the partnership benefited from the critical contributions of skilled volunteers from a wide range of professional and academic backgrounds, all committed to improving the health and wellbeing of persons with albinism.

Throughout 2025, our programmes were strengthened by local and international volunteers, including academics, dermatologists, plastic surgeons, ophthalmologists, psychotherapists, geneticists, nurses, and optometrists. These experts played a crucial role in advancing the partnership's work by delivering training, developing resources, providing medical advice and mentorship, presenting at conferences, and supporting our staff, teams, and partners.

This pool of specialised knowledge in albinism informs all aspects of our global operations. To formalise and sustain this expertise, we established an Advisory Board that works closely with staff, providing strategic guidance and specialist input. We are deeply grateful to all those who generously shared their time, skills, and insight throughout 2025, helping to strengthen the reach, quality, and impact of our work.

While there are too many volunteers to acknowledge individually, several contributions merit special recognition. In Malawi, volunteer specialists from Malawi and Ireland—including plastic surgeons, consultant dermatologists, nurses, and anaesthetists—delivered impactful surgical training in Zomba, strengthening local capacity in skin cancer management.

Counsellors across our programmes continued to benefit from professional supervision provided by a UK-based psychotherapist and trauma specialist. Their expertise has been instrumental in developing systems of support for the mental health and wellbeing of individuals affected by albinism-related trauma, including members of our own staff team.

In Tanzania, clinical and surgical training was delivered by British and Tanzanian Mohs surgeons and consultant dermatologists from Leicester Royal Infirmary, working alongside experts from the Regional Dermatology Training Centre and Bugando Medical Centre.

Ongoing oversight of our Vision and Education Programme was provided by Tanzania and US based Optometrists who specialise in albinism.



Consultant Dermatologist Dr Aine Kelly oversees classroom teaching in Zomba in August 2025

2.6 Our Purpose and Objectives

Standing Voice is an international NGO working in Tanzania and Malawi, with its headquarters in the United Kingdom. Standing Voice's primary objective is to improve the quality of life of people with albinism in Africa.

The objectives of the CIO are:

I. the advancement of education;
II. the advancement of mental and physical health and the saving of lives;
III. the relief of poverty and the improvement of the conditions of life in socially and economically disadvantaged communities;
IV. the promotion of human rights and the promotion of equality and diversity, in particular but without limitation so as to relieve the needs of people who are socially excluded by assisting them to integrate into society.

For the purposes of the above:

I. "human rights" means human rights as defined in the Universal Declaration of Human Rights and subsequent United Nations conventions and declarations and will be promoted in particular by education about human rights and promoting respect for human rights;

II. people who are "socially excluded" means people who are excluded from society, or parts of society, as a result of one or more of the following factors: financial hardship; youth or old age; ill health (physical or mental); disability or medical condition; discrimination on the grounds of sex, race, ethnic origin, religion, colour, creed or sexuality; poor education or skills attainment.

Standing Voice exists as a catalyst to amplify the voices of others. We aim to empower the people we work with to be the agents of change in their own lives, to build resilience and be healthy and self-sufficient. We currently focus on promoting the social inclusion of people with albinism in Tanzania and Malawi, whilst building the capacity of human rights defenders and partners in other countries in the region. Our team has over 19 years' experience working with this group and has pioneered innovative models of working that have a proven record of replication and scalability.

People with albinism are commonly the victims of social exclusion in Sub-Saharan Africa, which has led to witchcraft-fuelled murder and marginalisation from health and education services. Our work with this group centres around several programmatic areas: Skin Cancer Prevention, Low Vision and Education, Trauma Recovery, Economic Empowerment and Advocacy. Through our core programmes our support is holistic and comprehensive to reflect the complex needs of people with albinism in their local context. We achieve our objectives by collaborating with a network of local stakeholders (such as government bodies, local community groups and NGOs). All of our initiatives promote the social inclusion of people with albinism by:

I. Advancing understanding and knowledge about albinism in wider society
II. Advocating for progressive state action
III. Developing the skills and expertise of both people with albinism and wider community members
IV. Increasing the positive impact of local service providers
V. Promoting the positive impact of local non-governmental stakeholders (civil society)

The trustees of Standing Voice declare that they have had regard to both the Charity Commission guidance on public benefit and section 17(5) of the Charities Act 2011 on public benefit in carrying out their duties to achieve the charity's objectives.

3. PRINCIPAL ACTIVITIES

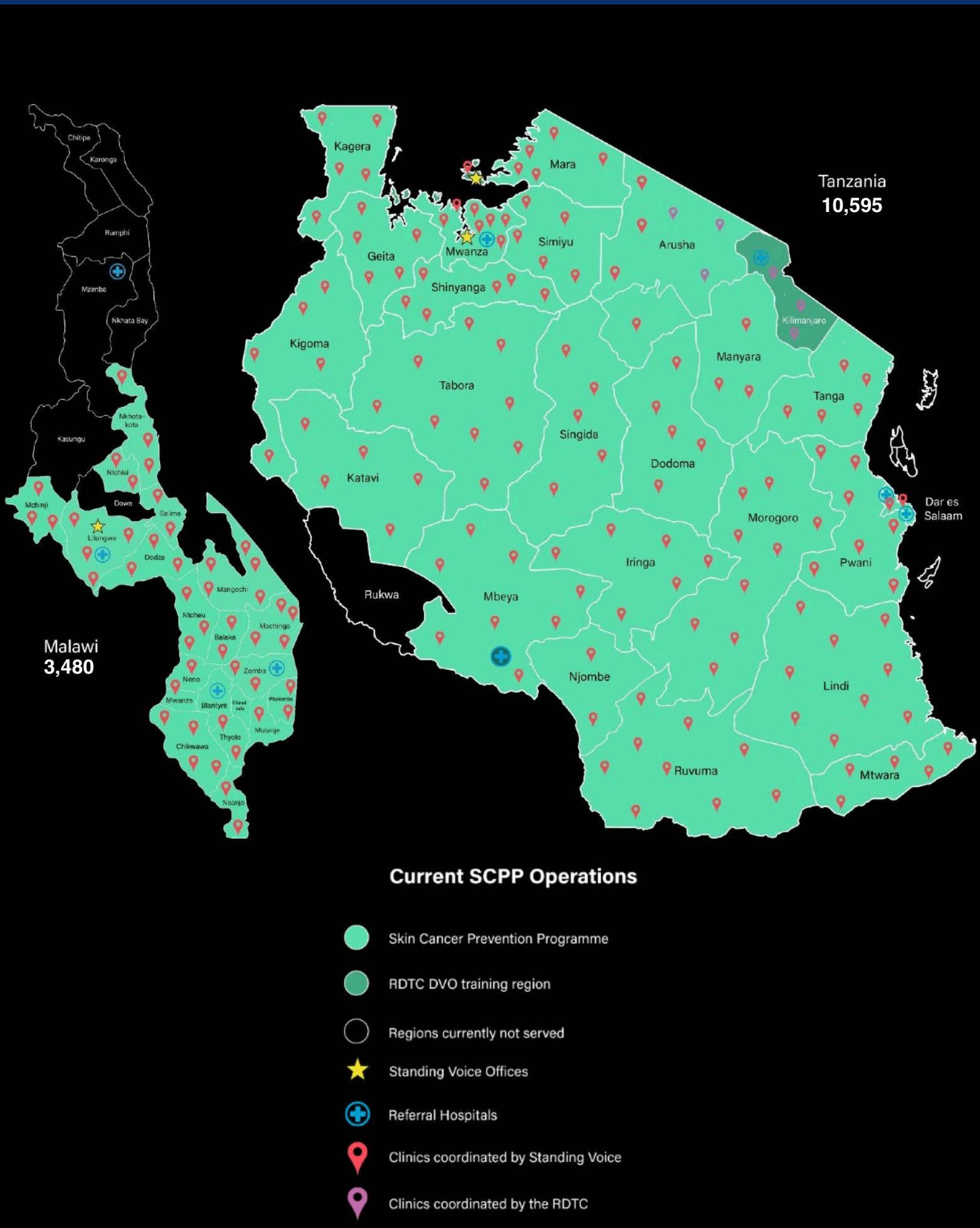
In 2025, Standing Voice focused on strengthening dermatology, eye care, welfare and livelihoods programmes for people with albinism across Tanzania and Malawi. Through targeted interventions, we expanded access to specialist healthcare, inclusive education, sustainable livelihoods, psychosocial support, and trauma-informed services, helping people with albinism live healthier, safer, and more independent lives.

Across all programmes, 14,075 people with albinism directly benefited from Standing Voice's activities, while many thousands more were reached through community outreach, professional training, research, and advocacy. Together, these efforts have strengthened systems of care, increased public awareness, challenged stigma and discrimination, and promoted greater inclusion of people with albinism within their communities and public services.



Geographical Reach (Dec 2025)

Total people with albinism served through all programmes: 14,075



3.1 Demographic Breakdown - all programmes

	Tanzania		Malawi	
	Number	%	Number	%
Total registered clients (across all programs)	10,595		3,480	
Female	5,376	50.7%	1,765	50.7%
Male	5,219	49.3%	1,715	49.3%
Average age	21		20	
0-4	1530	14.4%	531	15.3%
5-9	1754	16.6%	545	15.7%
10-14	1499	14.1%	514	14.8%
15-19	1419	13.4%	469	13.5%
20-24	1129	10.7%	381	10.9%
25-29	822	7.8%	336	9.7%
30-34	629	5.9%	217	6.2%
35-39	508	4.8%	153	4.4%
40-44	378	3.6%	126	3.6%
45-49	293	2.8%	85	2.4%
50-54	224	2.1%	47	1.4%
55-59	155	1.5%	26	0.7%
60-64	116	1.1%	16	0.5%
65-69	66	0.6%	18	0.5%
70-74	36	0.3%	9	0.3%
75-79	17	0.2%	6	0.2%
80 >	20	0.2%	1	0.02%

Patient Demographics: Gender and Age Distribution

Across all programmes we were encouraged to observe continued gender parity within our target population. In Tanzania, females and males represent 50.7% and 49.3% of all registered persons with albinism, respectively. In Malawi, the distribution is exactly the same, also with 50.7% female and 49.3% men.

Our participant base continues to be dominated by younger age groups, reflecting the broader age structure of the general population in both countries. The average age of registered patients in Tanzania is 21, and 20 years in Malawi. 58.5% of registered patients in Tanzania and 59.9% in Malawi are aged 19 or below.

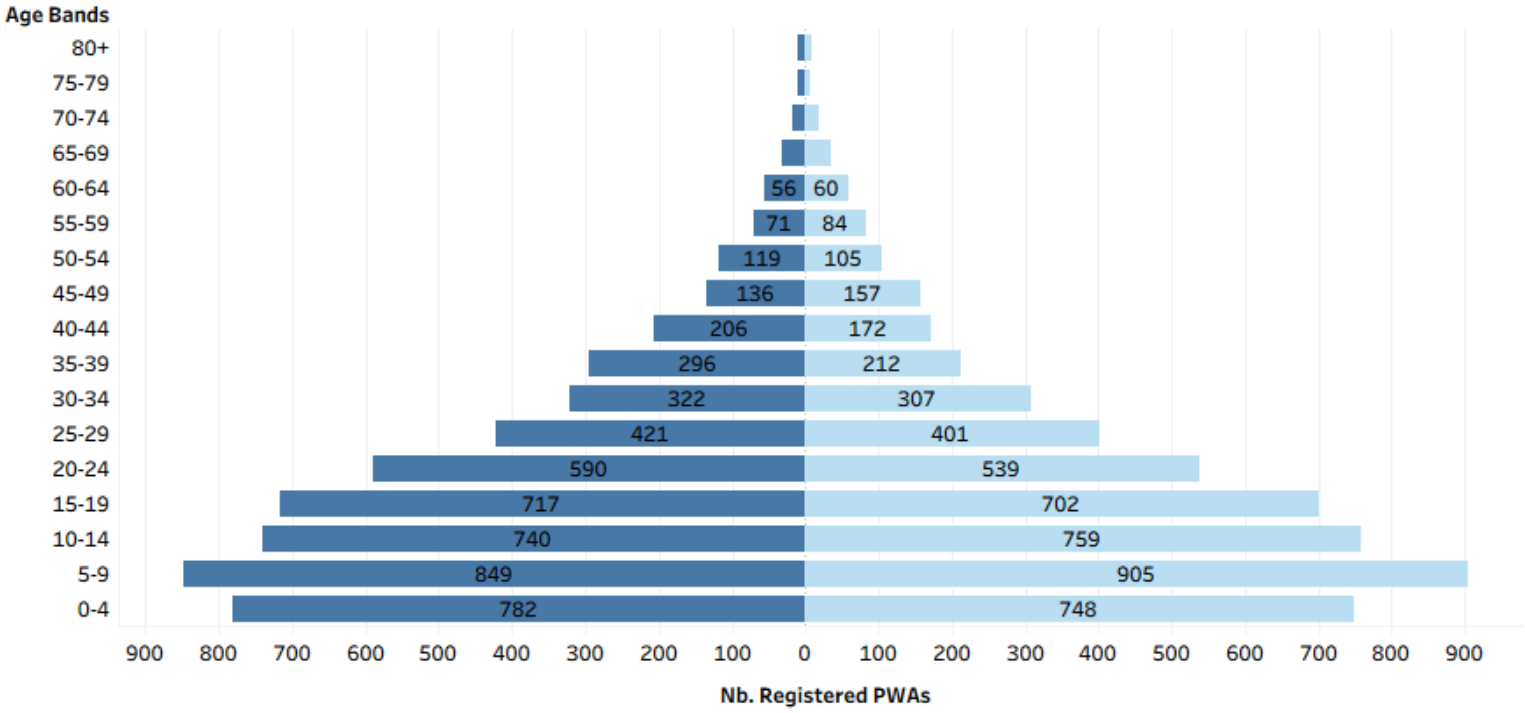
Across both countries, 10,929 people, representing 77.6% of the total registered population are under the age of 29, with 58.7% aged 19 or younger. By contrast, only 11.6% of people are over 40, and just 5.4% are over 50. This sharp decline in representation among older age groups reflects both the elevated risk of early mortality from skin cancer among persons with albinism and the overall youthful demographic we serve.

This trend is particularly stark in Malawi, where only 9.6% of persons with albinism registered in the SCPP are over the age of 40.

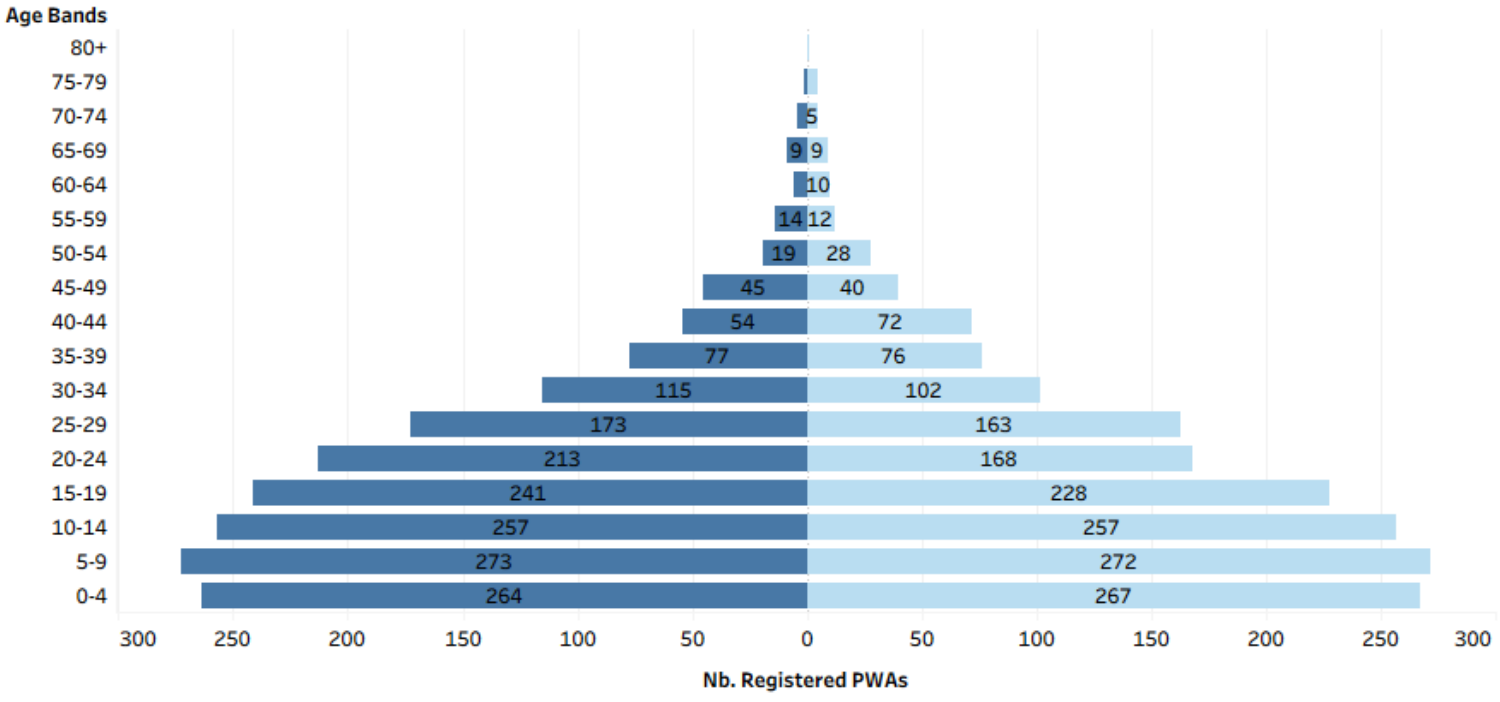
3.2 Population Pyramids - all heath programmes

The population pyramids below further illustrate this age distribution of people with albinism enrolled in the skin cancer prevention programme in both Tanzania and Malawi on the 31st December 2025.

Distribution of Registered people with albinism in Tanzania



Distribution of Registered people with albinism in Malawi



4. SKIN CANCER PREVENTION

4.1 Reach and Growth

To address the high burden of skin cancer among people with albinism in Africa, Standing Voice run a Skin Cancer Prevention Programme (SCPP) since 2013. The programme now reaches 13,323 people with albinism across Tanzania and Malawi through a growing network of dermatology clinics. Recognised by the United Nations as a best practice in 2016, the SCPP is delivered in partnership with the Governments of Tanzania and Malawi, the Regional Dermatology Training Centre, and more than 2,000 health professionals and civil society actors. With support from Fondation Pierre Fabre, the European Commission, the Croda Foundation and the International League of Dermatology Societies, the SCPP has grown into the largest skin cancer prevention programme for people with albinism globally.

Each clinic provides health education, skin examinations, cryotherapy, and referral for surgery where required. Participants also receive sunglasses, locally made sun hats, and a fresh supply of sunscreen at every clinic. Our long-term objective is to strengthen national health systems by supporting governments and civil society to deliver sustainable skin cancer prevention services that reach people with albinism in every region.

During 2025, we expanded the SCPP into two new regions of Tanzania (Lindi and Mtwara) and one additional district in Malawi (Nsanje). We carried out mapping exercises, delivered training, and held engagement meetings with government and civil society partners to support the mobilisation of people with albinism and strengthen local ownership of the programme. We also continued to train health professionals and community advocates who are leading the programme's expansion across both countries. Patient enrolment continued to grow steadily during the year, and the programme remains on track to achieve national coverage in Tanzania and the majority of Malawi by the end of 2027.

Indicator	Tanzania			Malawi		
	Target	Achieved	Difference	Target	Achieved	Difference
Nb regions/districts covered by SCPP	23	23	0	19	19	0
Nb clinic sites	144	154	10	95	140	41
Nb clinics delivered during reporting period	288	306	18	190	210	20
Nb MA led clinics delivered	0	0	0	78	83	5
Nb patients registered in SCPP	8,400	9,865	1,465	3,050	3,458	418
Nb patients seen in this period	6,100	6,807	707	2,400	2,510	110
New patients seen in this period	282	1,317	1,035	100	408	308

By the end of 2025, the Skin Cancer Prevention Programme had met or exceeded all its targets for patient reach and geographical expansion. A total of 13,323 people with albinism were enrolled across Tanzania and Malawi, exceeding our combined target of 11,450 by 14%. This included 9,865 people in Tanzania and 3,458 in Malawi.

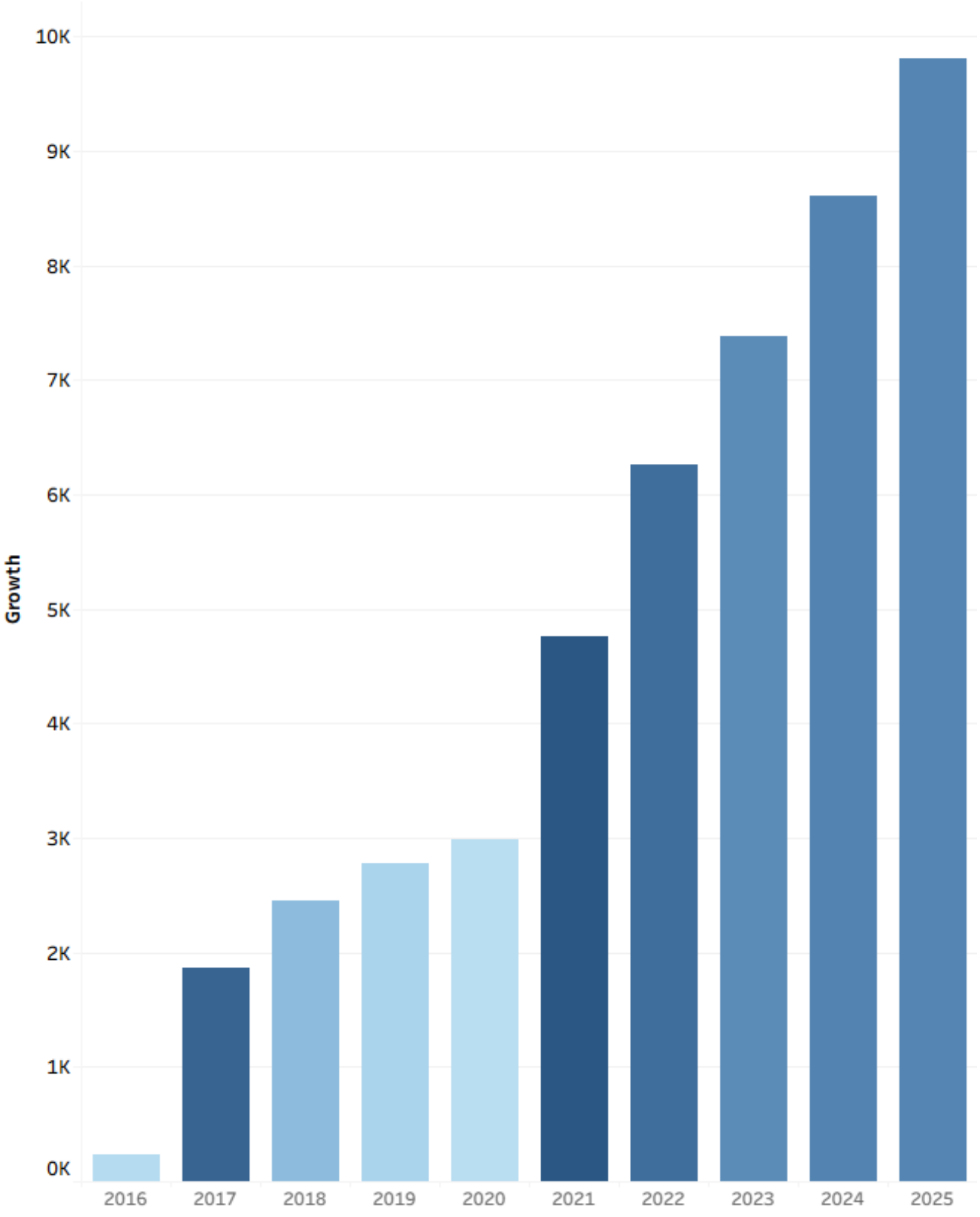
The programme reached 23 regions in Tanzania and 19 districts in Malawi, meeting our geographical expansion targets for the year. As a result, the SCPP is now operational in 75% of Tanzania's regions and 68% of Malawi's districts, delivering services through 294 hospitals and health facilities. During 2025, 599 dermatology clinics were held across the two countries.

The programme also continued to grow its patient base, with 1,725 people with albinism registering for the first time during the year. This represented annual growth of 15.4% in Tanzania and 13.4% in Malawi, demonstrating continued demand for specialist skin cancer prevention services as the programme expands towards national coverage.

The graph illustrates the steady growth in the number of registered patients enrolled in the Skin Cancer Prevention Programme in Tanzania between 2016 and 2025.

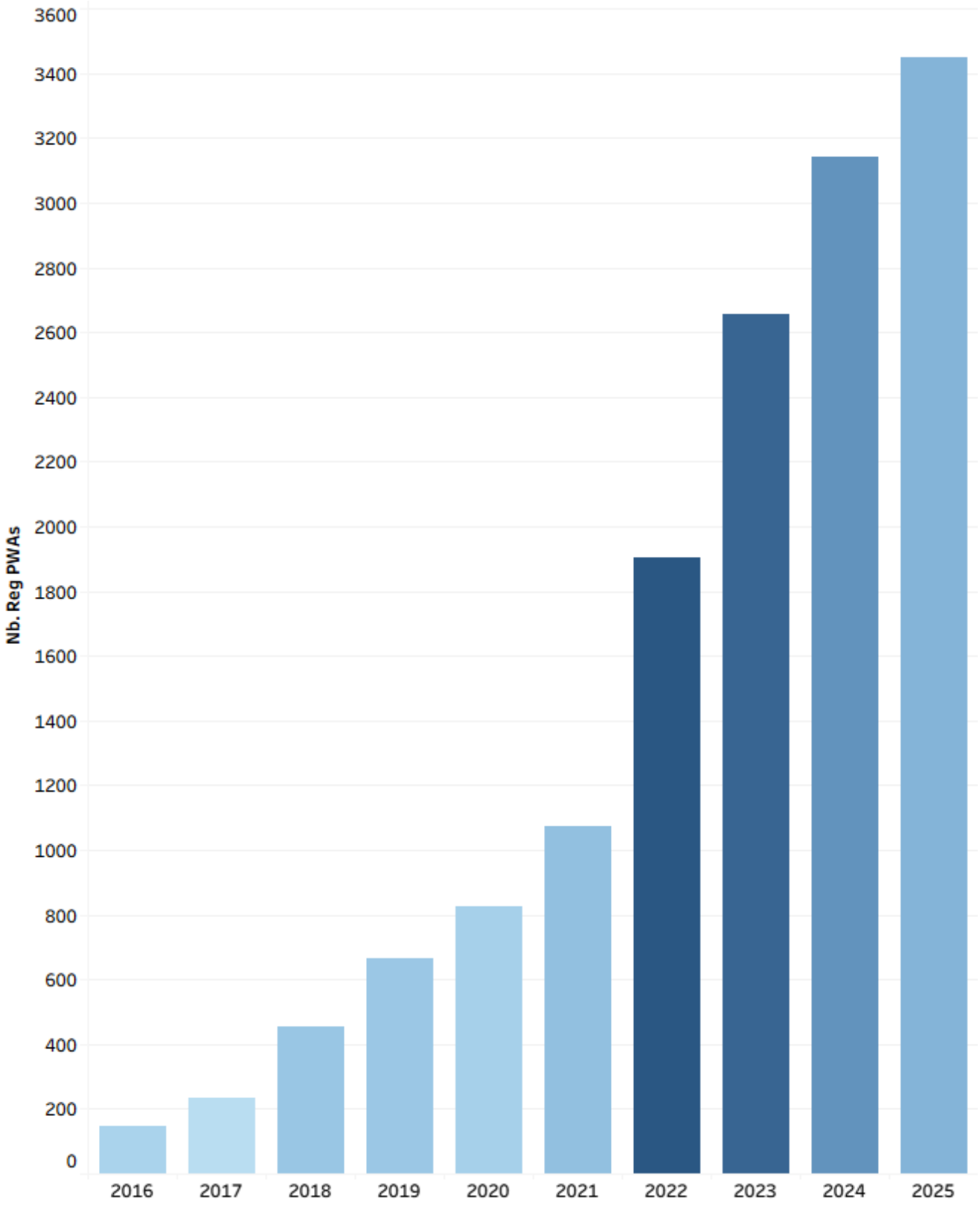
The darker bars highlight the years that recorded the highest annual growth in patient enrolment. The most significant increase occurred between 2021 and 2022, following the launch of Phase II of the partnership with the Fondation Pierre Fabre. This period marked a substantial expansion of the SCPP activities, resulting in a notable rise is geographical coverage and new enrolment.

Paper-based records from 2013–2017 have not been uploaded to the electronic health system. As a result, the data shown for 2016 in both Tanzania and Malawi is incomplete and does not represent the full dataset for that



The graph illustrates the steady growth in the number of registered patients enrolled in the Skin Cancer Prevention Programme in Malawi between 2016 and 2025.

The darker bars highlight the years that recorded the highest annual growth in patient registrations. As with the Tanzania expansion on the previous page, the most significant increase occurred between 2021 and 2022, following the launch of Phase II of the partnership with the Fondation Pierre Fabre. This period marked a substantial expansion of SCPP activities, resulting in a notable rise is geographical coverage and patient enrolment.



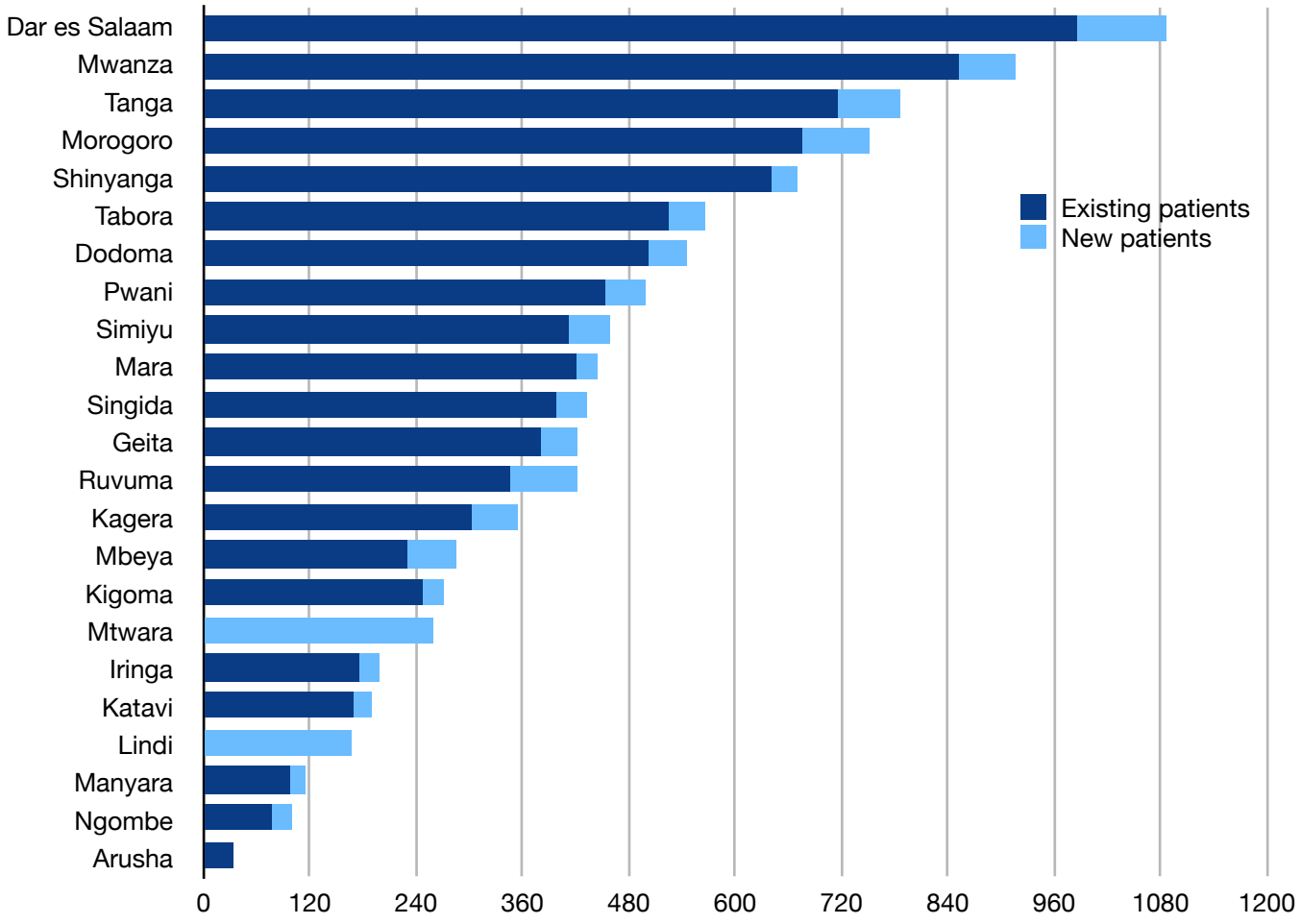


4.2 Geographic Breakdown SCPP

TANZANIA	Registered Patients - Disaggregated by Region, Gender, and New/Existing											
Region	Existing patients			New patients						Total patients		
	M	F	Total	M	Growth in M (%)	F	Growth in F (%)	Total	Total Growth (%)	M	F	Total
Dodoma	263	239	502	25	9.5%	19	7.9%	44	**8.8%**	288	258	546
Katavi	74	95	169	9	12.2%	13	13.7%	22	**14.2%**	83	108	191
Tabora	247	277	524	26	10.5%	17	6.1%	43	**8.2%**	273	294	567
Geita	189	193	382	21	11.1%	19	9.8%	40	**10.5%**	210	212	422
Singida	173	225	398	14	8.1%	20	8.9%	34	**8.5%**	187	245	432
Mara	188	211	422	8	4.3%	15	7.1%	23	**5.8%**	196	226	422
Simiyu	228	184	412	29	12.7%	19	10.3%	48	**11.7%**	257	203	460
Kagera	154	149	303	28	18.2%	25	16.8%	53	**17.5%**	182	174	356
Kigoma	129	119	248	14	10.9%	9	7.6%	23	**9.3%**	143	128	271
Mwanza	406	445	851	34	8.4%	32	7.2%	66	**7.8%**	440	477	917
Shinyanga	354	286	640	15	4.2%	16	5.6%	31	**4.8%**	369	302	671
Dar es Salaam	468	517	985	57	12.2%	45	8.7%	102	**10.4%**	525	562	1087
Tanga	327	390	717	39	11.9%	30	7.7%	69	**9.6%**	366	420	786
Arusha	12	21	33	0	0%	0	0%	0	**0%**	12	21	33
Manyara	47	49	96	11	23.4%	8	16.3%	19	**19.8%**	58	57	115
Morogoro	293	292	585	40	13.7%	35	12.0%	75	**12.8%**	333	327	660
Pwani	218	234	452	26	11.9%	22	9.4%	48	**10.6%**	244	256	500
Iringa	73	102	175	10	13.7%	13	12.7%	23	**13.1%**	83	115	198
Mbeya	121	110	231	22	18.2%	32	29.1%	54	**23.4%**	143	142	285
Ruvuma	163	183	346	38	19.7%	36	19.7%	74	**21.4%**	201	219	420
Ngombe	35	42	77	13	37.1%	11	26.2%	24	**31.1%**	48	53	101
Mtwara	0	0	0	121	100%	137	100%	258	**100%**	127	137	258
Lindi	0	0	0	88	100%	79	100%	167	**100%**	88	79	167
Total	**4,171**	**4,377**	**8,548**	**671**	**16.1%**	**646**	**14.8%**	**1,317**	**15.4%**	**4,842**	**5,023**	**9,865**

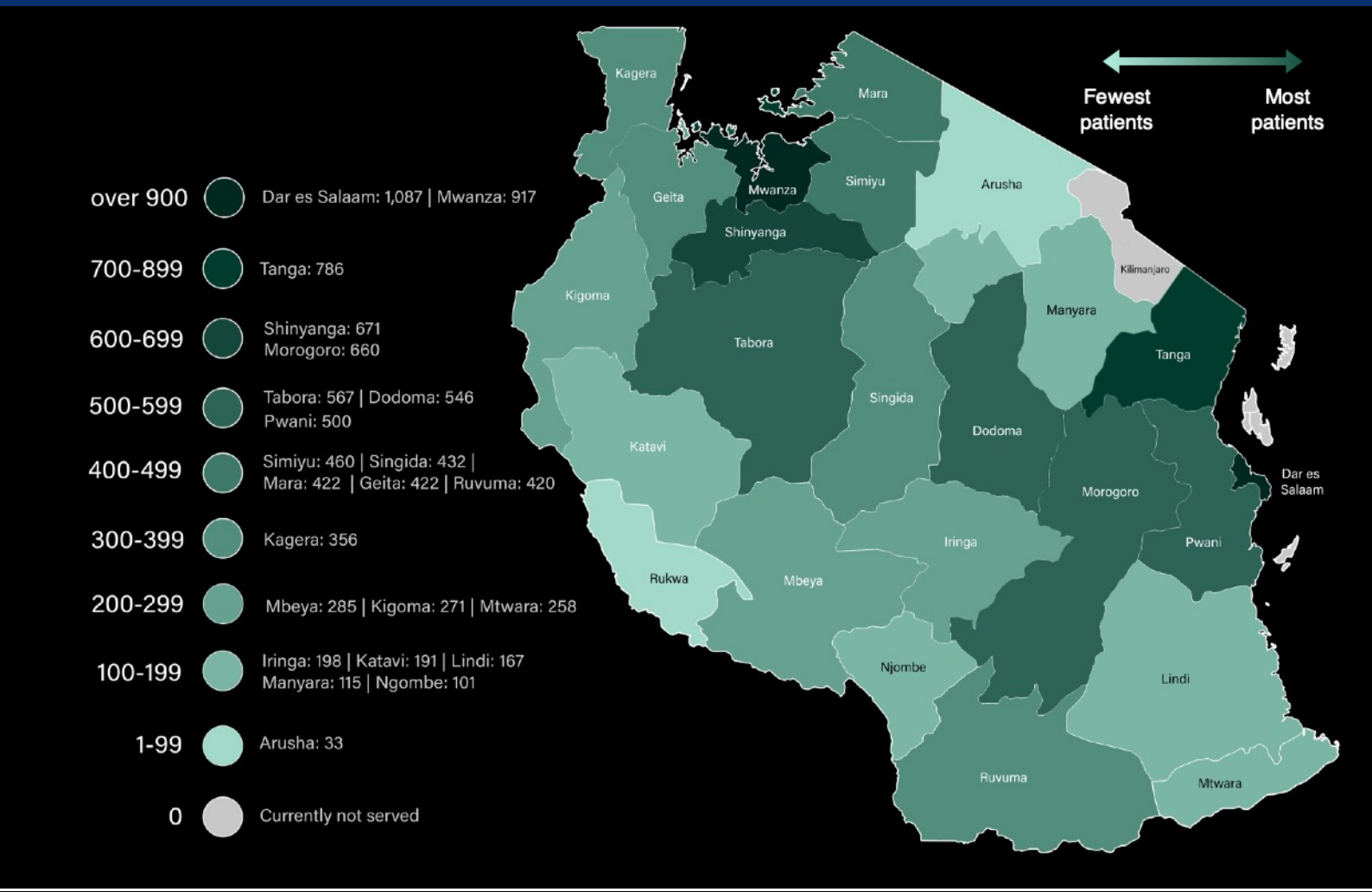


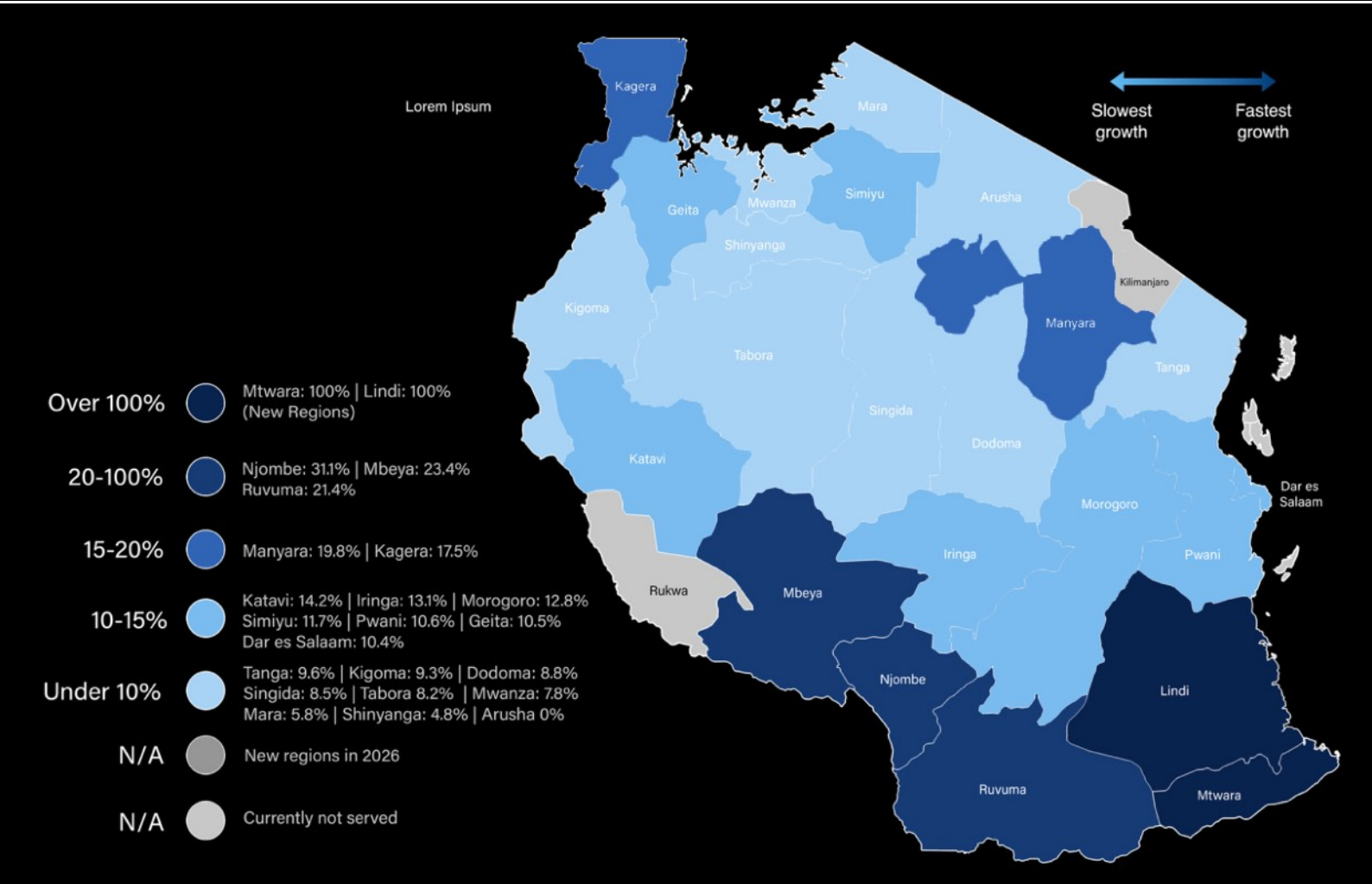
Annually, we recorded a 16.1% increase in registered male patients and a 14.8% increase in registered female patients across Tanzania. Our fastest-growing regions were Ngombe (31.1%), Mbeya (23.4%) and Ruvuma (21.4). In contrast, the slowest growth was observed in regions where the SCPP has been active the longest: Shinyanga (4.8%), Mara (5.8%) and Mwanza (7.8%).





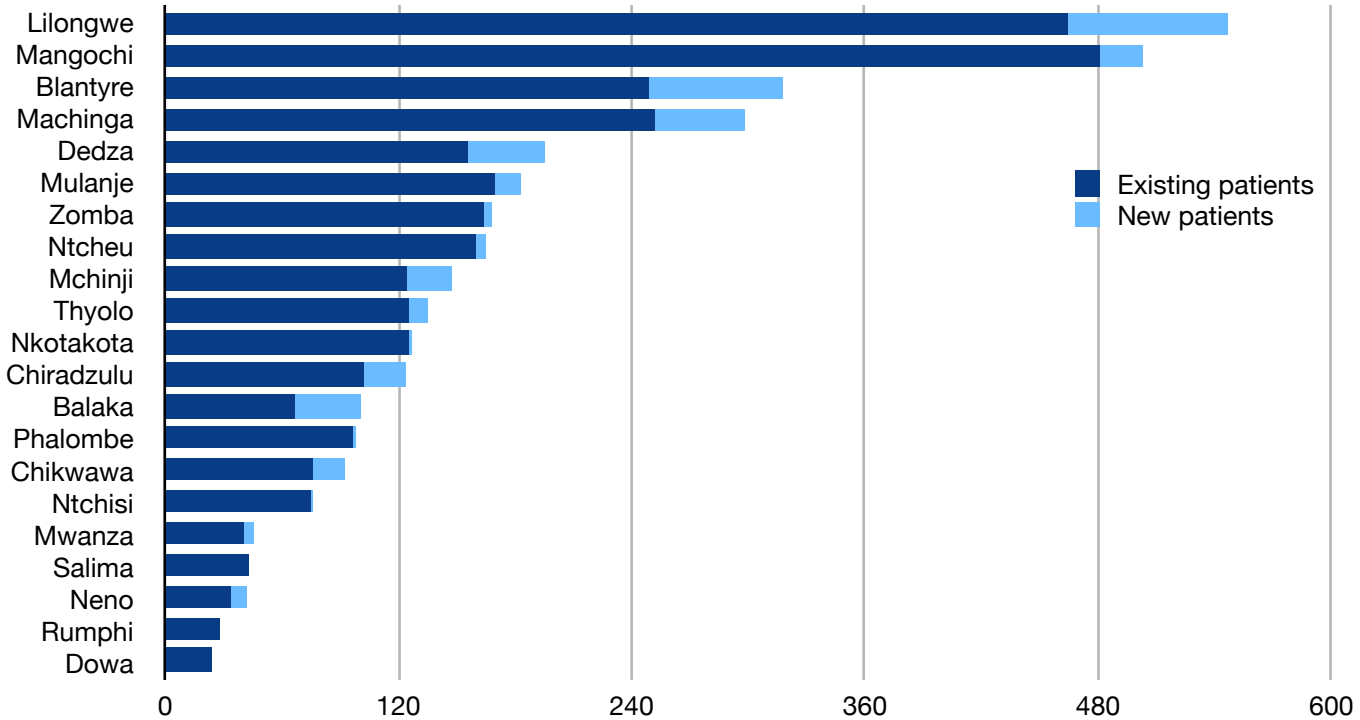
The top map indicates the distributional density of our registered patients in Tanzania: Dar es Salaam has the most registered patients (1,087) while Arusha has the fewest (33). The bottom map indicates regional growth rates in registered patients: Expectedly Ngombe, a new region as of 2024 grew the most in 2025 (31.1%), while Shinyanga saw the least growth (4.8%).



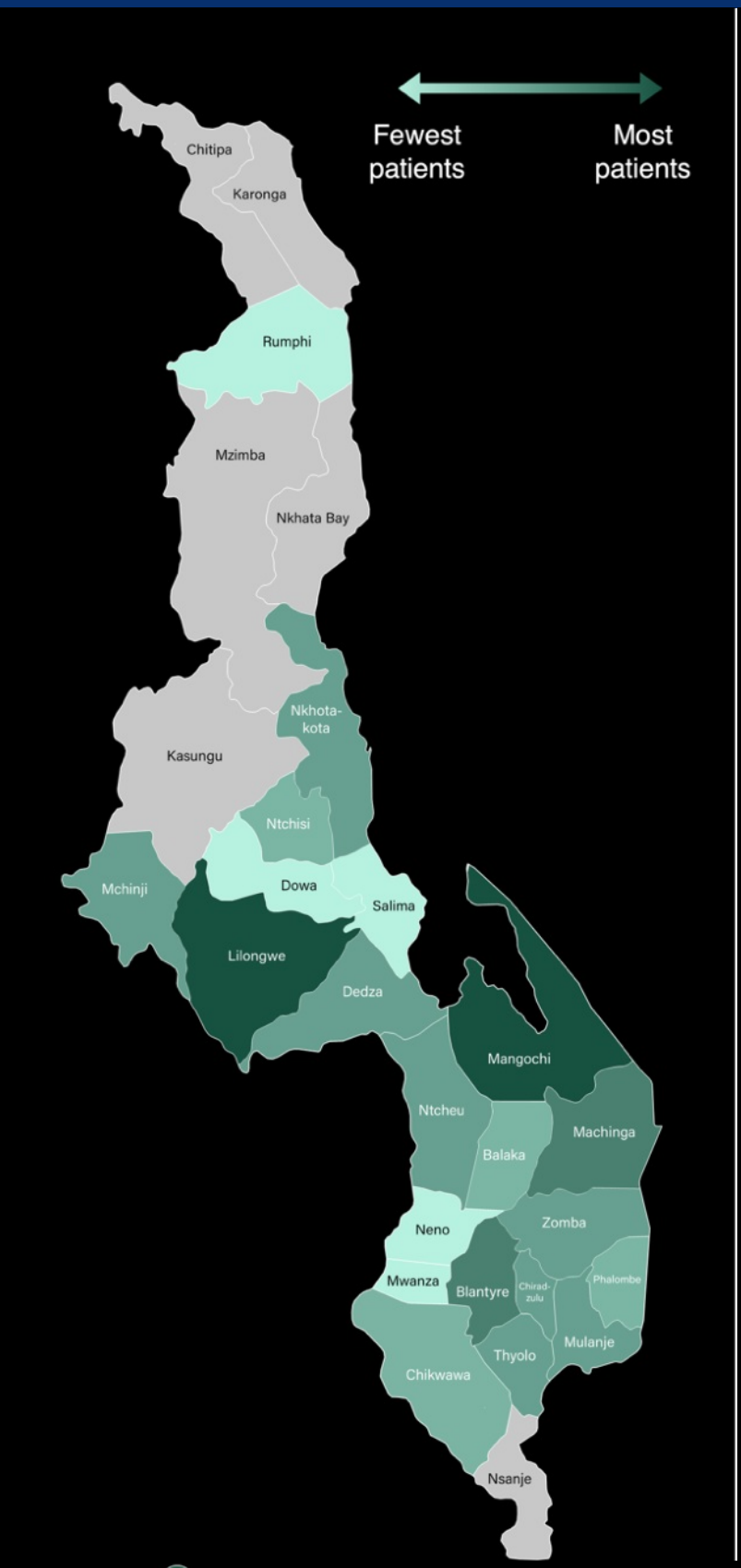


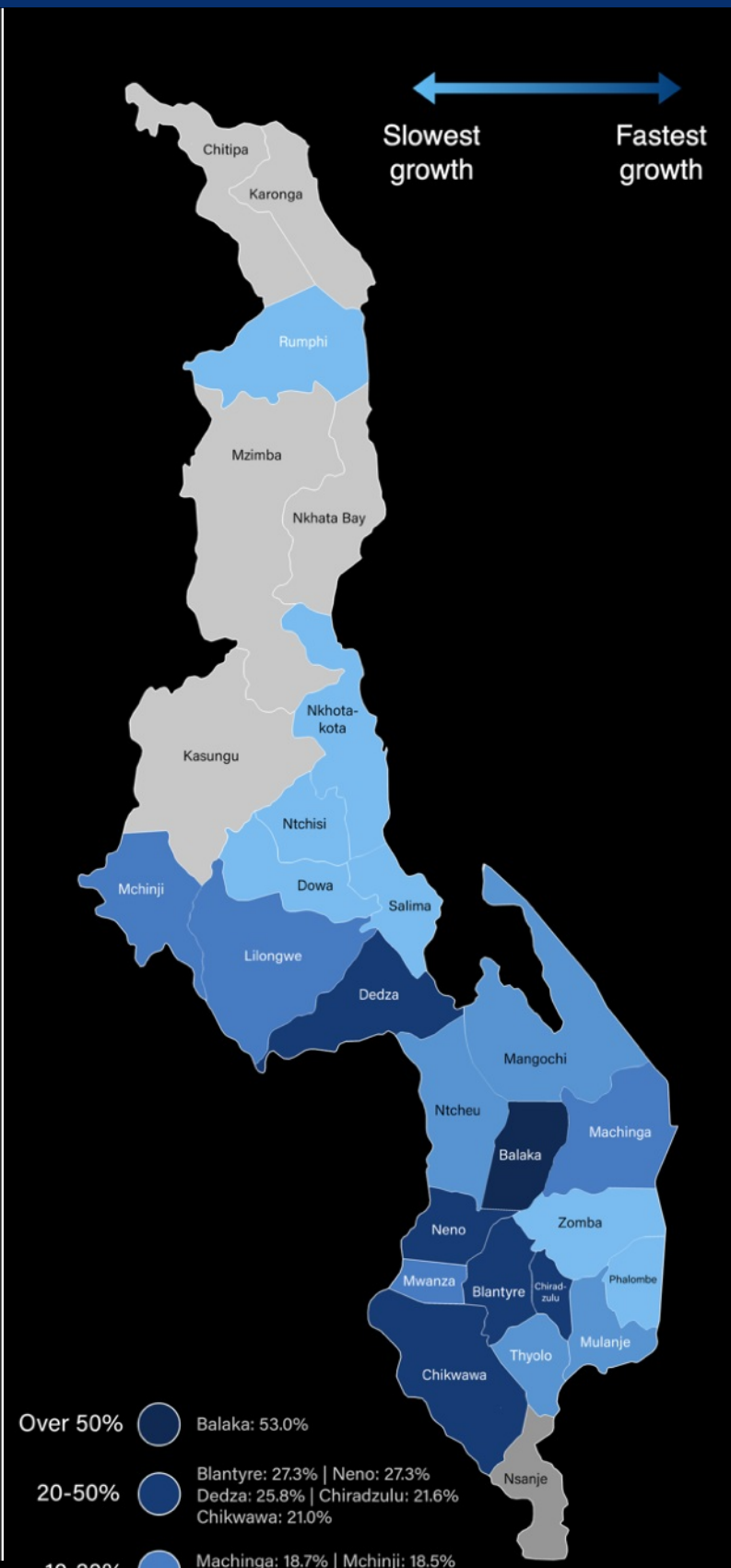
MALAWI	Registered Patients - Disaggregated by Region, Gender, and New/Existing											
District	Existing patients			New patients						Total patients		
	M	F	Total	M	Growth in M (%)	F	Growth in F (%)	Total	Total Growth (%)	M	F	Total
Machinga	133	118	251	6	14.3%	41	34.7%	47	**18.7%**	139	159	298
Mangochi	213	268	481	11	3.3%	11	4.1%	22	**4.6%**	224	279	503
Zomba	85	79	164	2	2.4%	2	2.5%	4	**2.4%**	87	91	169
Phalombe	44	52	96	2	4.5%	0	0.0%	2	**2.1%**	44	52	96
Mulanje	81	88	169	6	7.4%	8	9.1%	14	**8.3%**	87	96	183
Balaka	36	30	66	18	50.0%	17	56.7%	35	**53.0%**	54	47	101
Dedza	82	73	155	22	26.8%	18	24.7%	40	**25.8%**	104	91	195
Ntcheu	86	74	160	2	2.3%	3	4.1%	5	**3.1%**	88	77	165
Blantyre	120	129	249	34	28.3%	34	26.4%	68	**27.3%**	154	163	317
Mchinji	66	58	124	6	9.1%	17	29.3%	23	**18.5%**	72	75	147
Lilongwe	231	233	464	33	14.3%	49	21.0%	82	**17.7%**	264	282	546
Chikwawa	39	37	76	4	14.8%	5	31.3%	9	**21.2%**	46	46	92
Thyolo	59	66	125	5	8.5%	5	7.6%	10	**8.0%**	64	71	135
Chiradzulu	52	50	102	12	23.1%	10	20.0%	22	**21.6%**	64	60	124
Salima	27	16	43	0	0.0%	0	0.0%	9	**0.0%**	27	16	43
Nkotakota	66	59	125	0	0.0%	2	3.4%	2	**1.6%**	66	61	127
Ntchisi	39	36	75	1	2.6%	0	0.0%	1	**1.3%**	40	36	76
Neno	14	19	33	4	28.6%	5	26.3%	9	**27.3%**	18	24	42
Mwanza	14	26	40	1	7.1%	5	19.2%	6	**15.0%**	15	31	46
Rumpi	13	15	28	0	N/A	0	N/A	0	**N/A**	13	15	28
Dowa	11	13	24	0	N/A	0	N/A	0	**N/A**	11	13	24
Total	**1,511**	**1,539**	**3,050**	**172**	**11.4%**	**236**	**15.3%**	**408**	**13.4%**	**1,683**	**1,775**	**3,458**

In 2025, we recorded an 11.4% increase in registered male patients and a 15.3% increase in registered female patients in Malawi. The fastest-growing district was Balaka, which saw a 53.0% increase, followed by Blantyre at 27.3%). In contrast, the districts with the slowest growth were Salima, which recorded a 0.0% increase, Ntchisi, 1.3%, Nkhotakota (1.6%) and Phalombe (2.1%). Growth data is not applicable for Rumphi and Dowa, as these districts are not in operation, but rather have had people living in these areas visiting clinics during International Albinism Awareness Day only.



The map on the left indicates the distributional density of our registered patients in Malawi: Lilongwe has the most patients (546) while Neno has the fewest (42). The map on the right indicates district growth rates in registered patients: the fastest growth was in Blake (53.0%), while Salima saw the slowest growth (0.0%).

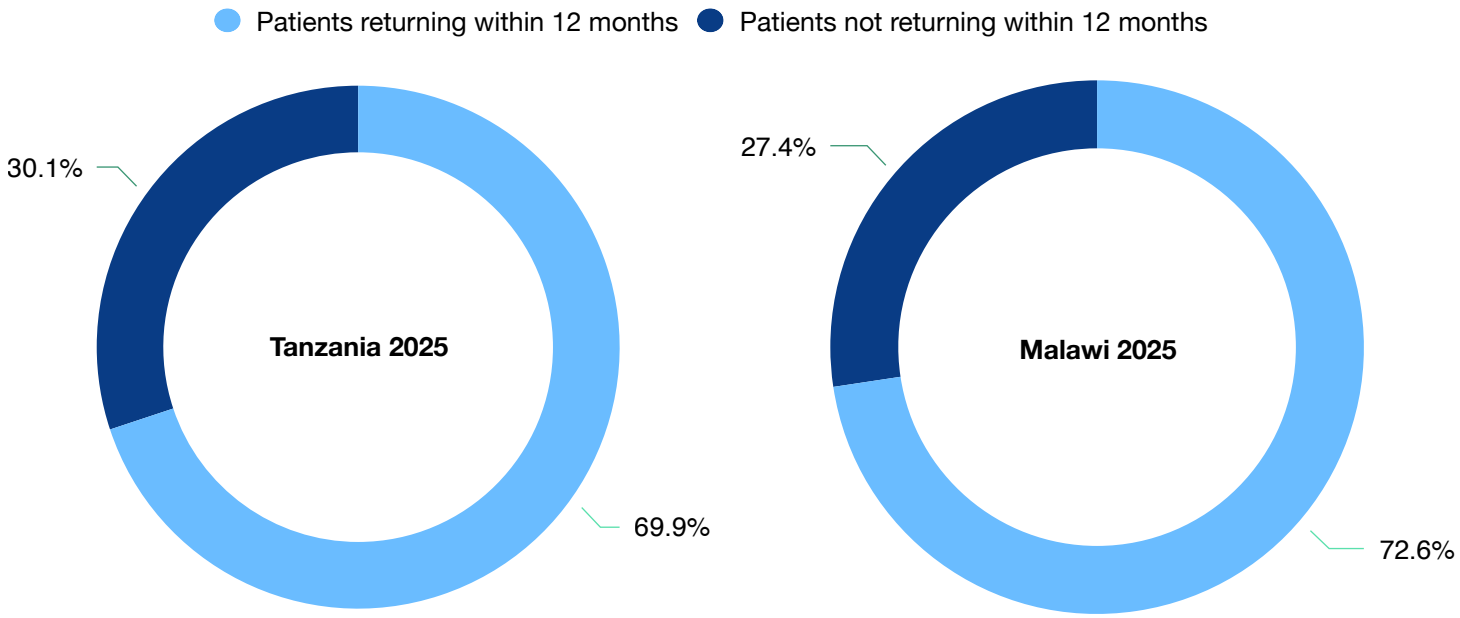




3.3 Retention

Patient retention is a key indicator of the effectiveness of the Skin Cancer Prevention Programme (SCPP), reflecting sustained engagement in care and continued access to services that help prevent skin cancer among people with albinism.

Retention has remained strong and stable as the SCPP has expanded. Across all clinic sites in Tanzania and Malawi, annual retention has consistently been maintained at approximately 68–75%, demonstrating the strength of established community mobilisation efforts and healthcare delivery systems.



Retention is influenced by a range of practical and personal barriers, including seasonal work commitments, climate-related disruptions such as flooding and poor road access, transport costs, childcare responsibilities, fear or anxiety related to clinical care, mistrust of health services, and competing healthcare needs.

Understanding these challenges is essential to strengthening service delivery. It enables us to adapt our approach, reduce barriers to access, and ensure that care remains both consistent and responsive to the realities faced by the communities we serve. Throughout 2025, we continued to monitor retention trends closely and identify variations across locations and population groups. This ongoing analysis supports targeted outreach and follow-up for patients who may be at risk of disengaging from care.

We continued to strengthen patient engagement through structured feedback collection within CommCare, alongside SMS reminders and follow-up communications designed to support attendance and ongoing participation in care.

While significant progress has been made in improving data quality, retention analysis continues to be affected by historical paper-based records that were entered prior to the introduction of CommCare. We are continuing to refine data management processes, including exploring the potential use of AI-assisted approaches to identify and prevent duplicate patient records, with the aim of further improving the accuracy of retention reporting.

Mobilisation Strategies and Evaluation

To ensure strong patient turnout at clinics, we implement a diverse and targeted range of mobilisation strategies designed to reach people with albinism (PWA) and their families. These efforts are coordinated in close partnership with local Albinism Associations Leaders, Government Social Welfare Departments, and schools, who play a vital role in community outreach. In addition to these grassroots efforts, we utilise mass communication channels, including radio broadcasts, social media platforms, and direct SMS messaging to broaden our reach and ensure timely awareness of upcoming clinics. To assess the effectiveness of these mobilisation efforts, clients are asked a series of questions during clinic registration about how they heard about the service. The table below presents an analysis of the most effective mobilisation channels used during 2025.

How did you hear about the clinic?	Tanzania 2025		Malawi 2025		Total	
Number of people surveyed	11,378		4,324		15,702	
Total responses	18,231		5,211		23,442	
MSN message	5,880	32.3%	275	5.3%	6,155	26.3%
Albinism Associations	8,092	44.4%	2,322	44.6%	10,414	44.5%
Social Welfare Officers / Health Surveillance Assistants	2,278	12.5%	1,988	38.2%	4,266	18.2%
Teacher / School	1,702	9.3%	227	4.4%	1,929	8.2%
Relative / Neighbour	191	1.0%	349	6.7%	540	2.3%
Radio advert	7	0.03%	12	0.2%	19	0.08%
Other	81	0.5%	38	2.1%	119	0.5%

From the table above, we observe a similar pattern of success across the different mobilisation methods deployed in both countries. The most common way people with albinism reported hearing about clinics was through their albinism association leaders, accounting for 44.4% of all persons with albinism (PWA) mobilised in Tanzania and 44.6% in Malawi. Social Welfare Officers and Health Surveillance Assistants also played a significant role in patient mobilisation, with 12.5% of patients in Tanzania and 38.2% in Malawi hearing about clinics through these government actors. The education system continued to be a key channel for reaching PWA in both countries, with 9.3% of patients in Tanzania and 4.4% in Malawi reporting that they were referred by teachers or schools. In 2022, Standing Voice introduced direct MSN messaging to patients' phones in Tanzania. Its impact has continued to grow into 2025, with 32.3% of PWA in Tanzania and 5.3% in Malawi citing this method as how they learned about clinic services. The lower figure in Malawi is attributed to both reduced access to mobile phones and the later rollout of MSN messaging, which began in late 2023.



4.4 Screening and Medical Management

2025 Indicator	Tanzania		Malawi		Total	
Total individual patients seen	6,807		2,510		9,317	
Nb of examinations	11,378		4,324		13,709	
Nb of cryotherapy procedures[7]	8,538	N/A	5,398	N/A	13,936	N/A
Nb of individuals receiving cryotherapy	1,233	18.1%	556	22.2%	1,789	19.2%
Nb individuals with multiple AKs identified	763	11.2%	531	21.6%	1,669	17.9%
Nb individuals with single AKs identified	475	7.0%	147	5.9%	1,484	15.9%
Nb patients referred for surgical procedures	290	4.3%	88	3.5%	378	4.1%
Nb of examinations where patients present with…						
Severe erythema	51	0.4%	44	1.0%	95	0.7%
Moderate erythema	249	2.2%	242	5.6%	491	3.6%
Mild erythema	3,994	35.1%	3,099	71.7%	7,094	51.7%
Ectropion	186	1.6%	122	2.8%	308	2.2%
Chelitis	978	8.6%	920	21.3%	1,898	13.8%
Single AKs	515	4.5%	149	3.4%	664	4.8%
Multiple AKs	1,027	9.0%	538	12.4%	1,556	11.4%

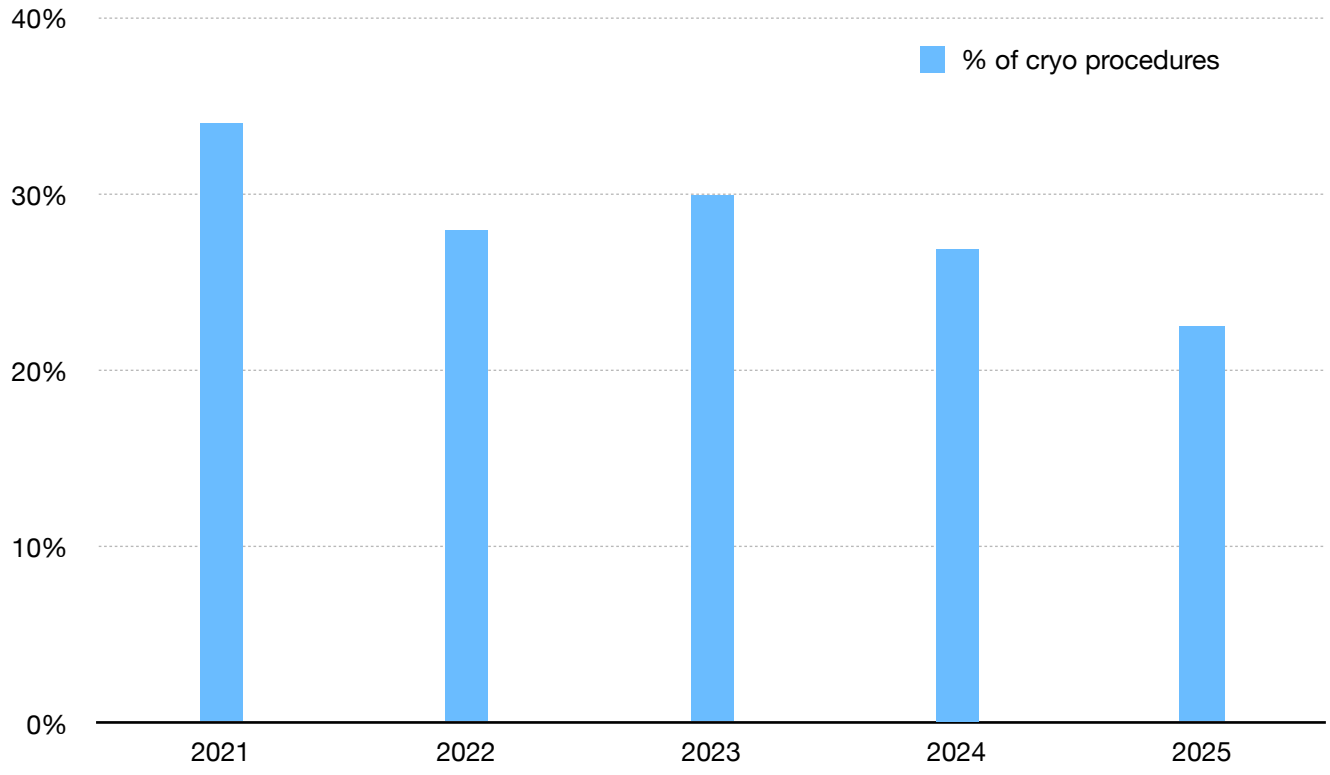
Clinical data from this reporting period show a higher prevalence of skin conditions among patients in Malawi compared with Tanzania. When measured as a proportion of the total number of people seen, 18.1% of individuals attending clinics in Tanzania in 2025 required cryotherapy, compared with 22.2% of individuals seen in Malawi.

Across both countries, 13,709 consultations were conducted in 2025. Of these, 95 examinations identified severe erythema (sunburn), 491 identified moderate erythema, and 7,094 identified mild erythema. Across all three erythema severity categories—mild, moderate, and severe—rates were approximately twice as high in Malawi as in Tanzania. This disparity is consistent with expectations, given the longer operational history of the SCPP in Tanzania. The programme's longer presence has helped establish a stronger baseline of awareness and understanding of skin cancer prevention and sun-protective behaviours among people with albinism.

Ectropion (outward turning of the eyelids) was identified in 186 examinations (1.6%) in Tanzania and 122 examinations (2.8%) in Malawi. Cheilitis (thickening and damage to the lips caused by sun exposure) was identified in 978 examinations (8.6%) in Tanzania and 920 examinations (21.3%) in Malawi.

Multiple actinic keratoses (AKs) were identified in 1,027 examinations (9.0%) in Tanzania and 538 examinations (12.4%) in Malawi.

Percentage of people receiving cryotherapy against patient population in Malawi



Despite presentations of skin conditions being higher in Malawi, there appears to be a steady decline in the number of cryotherapy procedures being administered against the patient population.

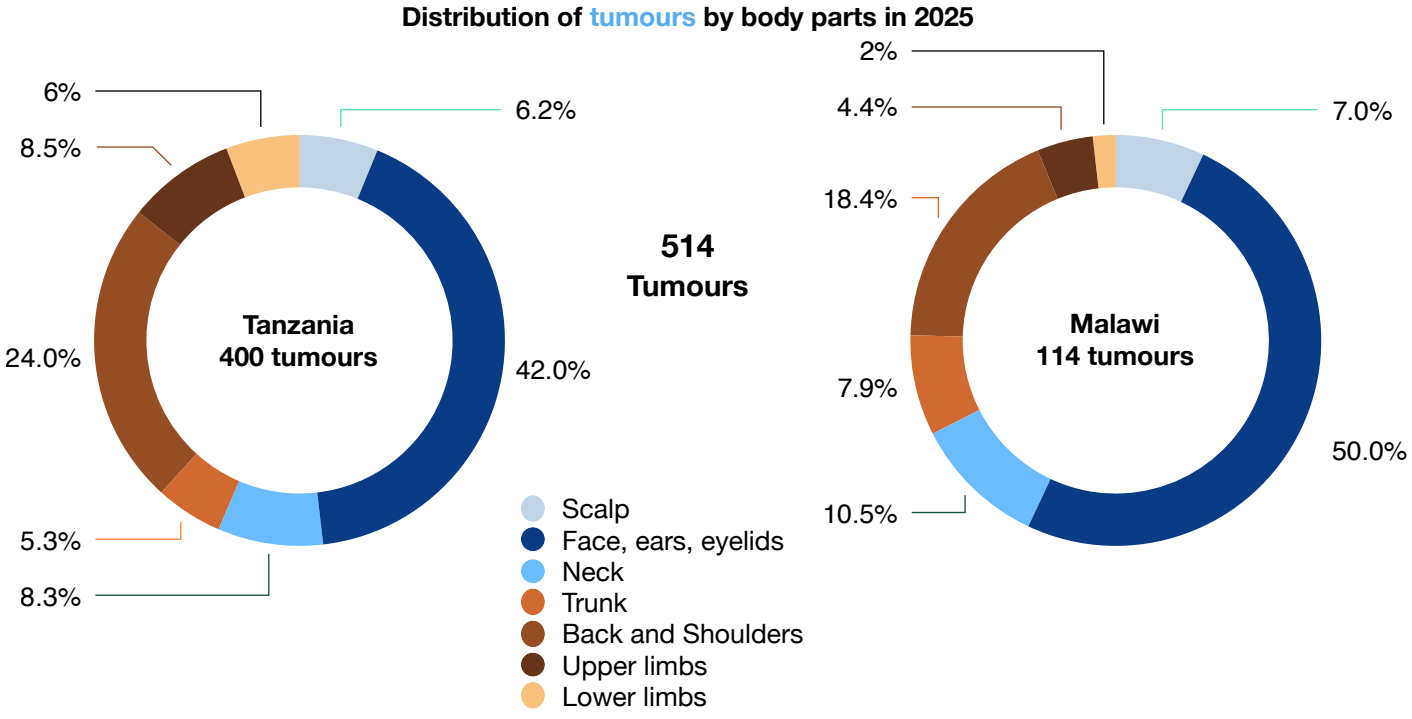


Provisional doctor's diagnosis during clinics 2025				
Indicator	Tanzania		Malawi	
Referrals made	290		88	
Possible tumours identified during clinics	400		114	
SCC	190	47.5%	51	44.7%
BCC	132	33.0%	38	33.3%
Unknown / other condition	78	19.5%	25	22.0%
Distribution of possible tumours by body part	400		114	
Scalp	25	6.2%	8	7.0%
Face, ears, eyelids	168	42.0%	57	50.0%
Neck	33	8.3%	12	10.5%
Trunk	21	5.3%	9	7.9%
Back and shoulders	96	24.0%	21	18.4%
Upper limbs	34	8.5%	5	4.4%
Lower limbs	23	6%	2	1.8%

A total of 514 possible tumours were identified during SCPP clinics across Tanzania and Malawi in this reporting period. In Tanzania, clinicians identified 400 possible tumours in 290 patients (an increase from 322 possible tumours identified in 2024, but a decrease in the number of individuals with tumours from 335 in 2024). Of these, 47.5% of possible tumours were identified as squamous cell carcinomas (SCCs), up from 34.5% in 2024. Basal cell carcinomas (BCCs) accounted for 33.0% of cases, down from 54.7% in the previous year. The remaining 19.5% were classified as unknown or other conditions, up from 10.9% in 2024.

In Malawi, doctors identified 114 possible tumours in 88 patients, a decrease from 128 tumours identified in 2024. Of these, 44.7% were provisionally diagnosed as SCCs (down from 55.5% in 2024), 33.3% as BCCs (slightly up from 32.0% in 2024), and 22.0% as other or unspecified conditions (up from 12.5% in 2024).

The distribution of tumours by body part was similar across both countries. The majority were located on sun-exposed areas, with the face, ears, eyelids, neck and scalp accounting for 56.5% of all tumours in Tanzania and 67.5% in Malawi.

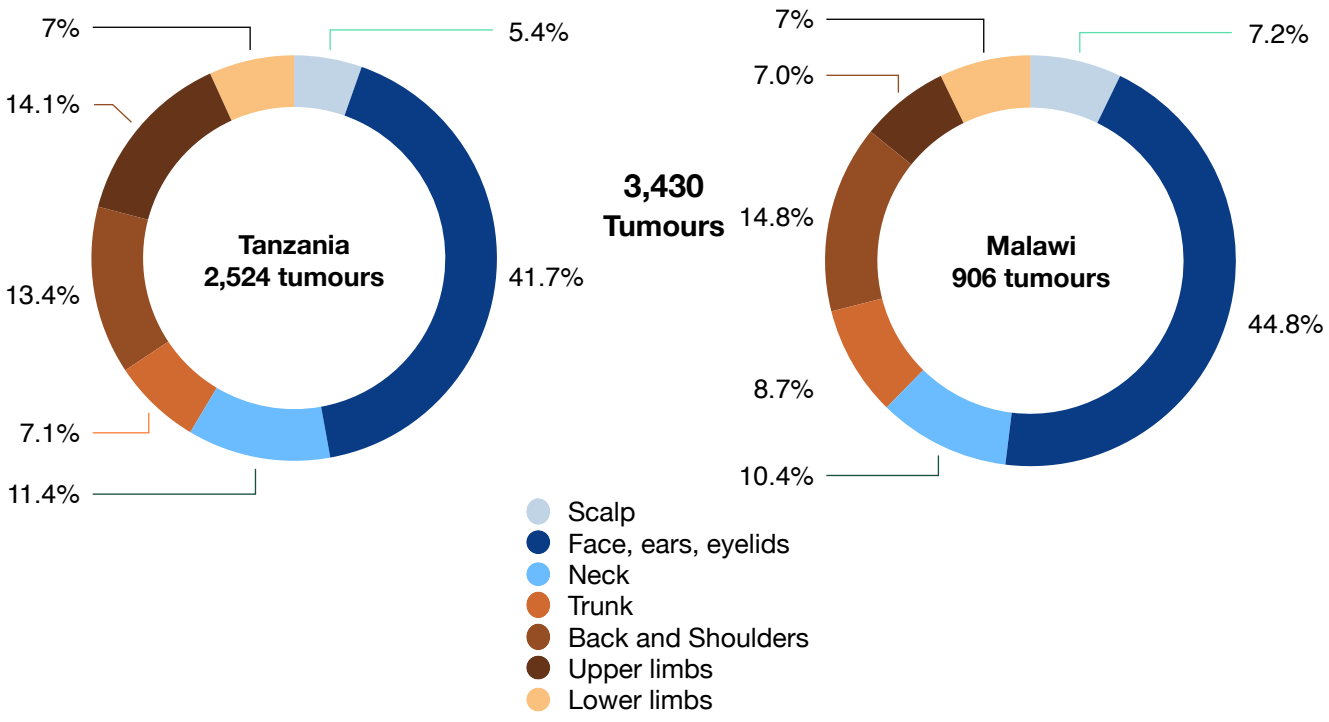


Provisional doctor's diagnosis during clinics since 2017				
Indicator	Tanzania		Malawi	
Possible tumours identified during clinics	**2,524**		**906**	
SCC	914	36.2%	507	56.0%
BCC	921	36.5%	254	28.0%
Unknown and other conditions	689	27.3%	145	16.0%
Distribution of possible tumours by body part	**2,524**		**906**	
Scalp	137	5.4%	65	7.2%
Face, ears, eyelids	1,053	41.6%	406	44.8%
Neck	288	11.4%	94	10.4%
Trunk	180	7.1%	79	8.7%
Back and shoulders	339	13.4%	134	14.8%
Upper limbs	355	14.1%	63	7.0%
Lower limbs	172	6.8%	65	7.2%

A total of 3,430 possible tumours were identified at clinics across Tanzania and Malawi since 2017. In Tanzania, clinicians have identified a total 2,524 possible tumours. Of these, 36.2% of possible tumours were identified as squamous cell carcinomas (SCCs), 36.5% as basal cell carcinomas (BCCs) and 27.3% were classified as other conditions. In Malawi, doctors identified 906 possible tumours, of which, 56.0% were diagnosed as SCCs, 28.0% as BCC and 16.0% as other or unspecified conditions.

The distribution of tumours by body part was similar across both countries. The majority were located on sun-exposed areas, with the face, ears, eyelids, neck, and scalp accounting for 58.5% of all tumours in Tanzania and 62.4% in Malawi.

Distribution of tumours by body parts in 2017-2025



From January to December 2025, 378 patients were referred for skin cancer treatment by dermatologists at SCPP clinics. This included 290 people in Tanzania and 88 in Malawi.

Referral Results 2025						
Indicator	**Tanzania**		**Malawi**		**Total**	
Patients for whom histology results are available	290		88		378	
Confirmed diagnoses[5]	**302**		**187**		**489**	
SCC	117	38.7%	35	18.7%	152	31.1%
BCC	98	32.5%	81	43.3%	179	36.6%
Melanoma	2	0.7%	0	0.0%	2	0.4%
Ophthalmological referrals	11	3.6%	2	1.1%	13	2.7%
Other conditions e.g. ulcers, benign lesions, warts, cysts	74	24.5%	69	36.9%	143	29.2%

In 2025, histology results were received for 489 biopsies: 302 from Tanzania and 187 from Malawi.

In Tanzania, 38.1% of cases were confirmed as squamous cell carcinomas (SCCs), down from 43.1% in 2024. Basal cell carcinomas (BCCs) accounted for 32.5% of cases, compared with 32.8% the previous year. Melanoma represented 0.7% of cases, up from 0% in 2024. Benign or non-cancerous conditions increased to 24.5% from 17.2%, while 3.6% of cases were referred for ophthalmological assessment.

In Malawi, 18.7% of biopsy results were confirmed as SCCs, up slightly from 14.2% in 2024. BCCs accounted for 43.3% of cases, down from 59.4% the previous year, while other conditions increased to 36.9% from 24.5%. Two patients were referred for ophthalmological assessment.

"I remember before attending clinics I was not aware about skin cancer. This made me live without protection and the wounds on my skin were like any wounds to me. Even my parents didn't know anything about albinism or skin cancer."

Eunice Peter, Kinondoni, Dar es Salaam, Tanzania



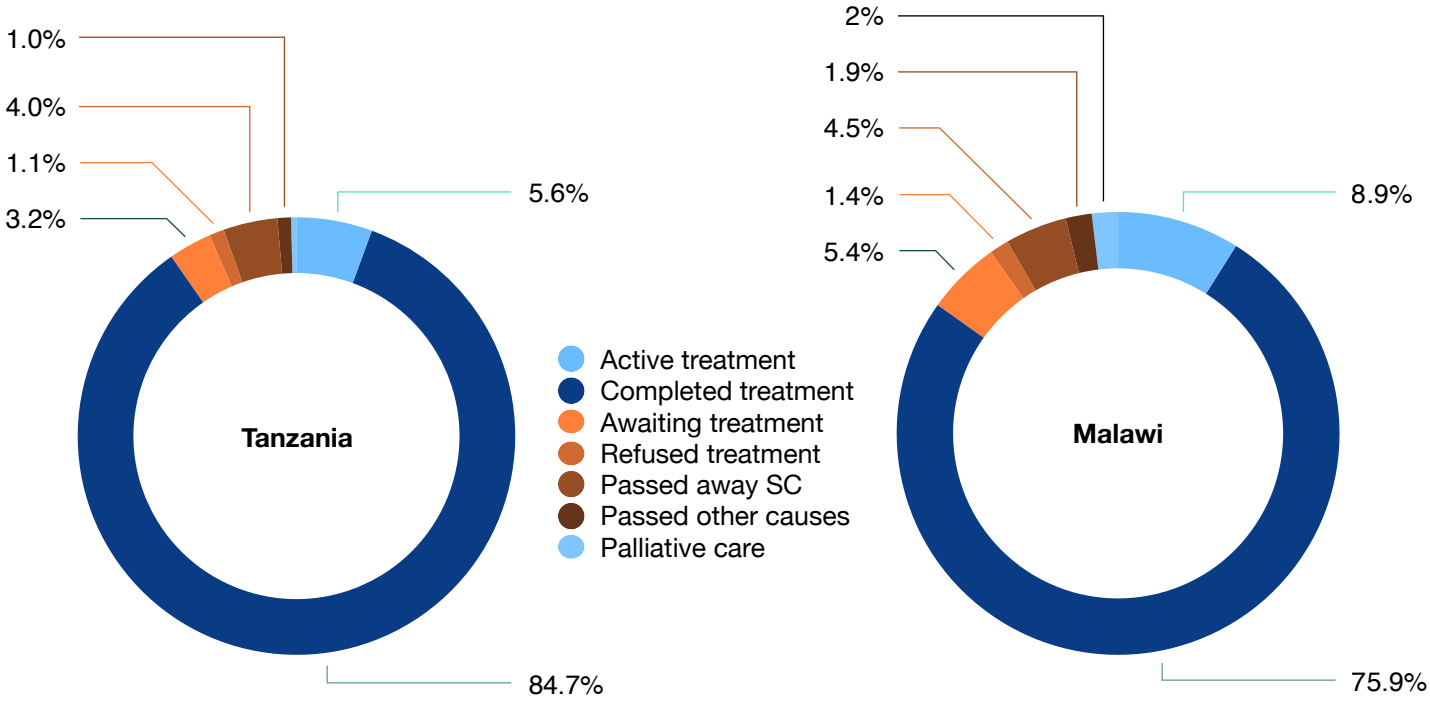
Total patient referrals and status since 2017						
Indicator	Tanzania		Malawi		Total	
Total number of patients referred for surgery	**1,616**		**628**		**2,244**	
Completed treatment	1,388	85.9%	482	76.8%	1,870	83.3%
Active treatment	91	5.6%	56	8.9%	147	6.6%
Waiting for treatment	32	2.0%	29	4.6%	61	2.7%
Refused treatment	18	%	9	1.4%	27	1.2%
Undergoing palliative care	7	0.4%	12	1.9%	19	0.8%
Passed away from skin cancer	64	4.0%	28	4.5%	92	4.1%
Passed away from other causes	16	1.0%	12	1.9%	28	1.2%

Since 2017, a total of 2,244 referrals have been made through the SCPP across Tanzania and Malawi, with 1,616 referrals in Tanzania and 628 in Malawi. The majority of patients referred for skin cancer treatment have successfully completed their treatment, representing 85.9% of patients in Tanzania and 76.8% in Malawi. Currently, 147 patients are undergoing active skin cancer treatment, accounting for 5.6% of patients in Tanzania and 8.9% in Malawi. In addition, 7 patients in Tanzania and 12 patients in Malawi are receiving palliative care.

Since 2017, 92 patients registered with the SCPP have died from skin cancer, including 64 patients in Tanzania and 28 in Malawi. A further 28 patients have died from other causes, comprising 16 patients in Tanzania and 12 in Malawi.

Despite receiving counselling, a small minority of patients have declined treatment for a variety of reasons. Common factors include fear of surgery, as well as the financial and logistical challenges associated with travelling for treatment and being away from their homes, employment, and families.

Patient referral status 2017-2025

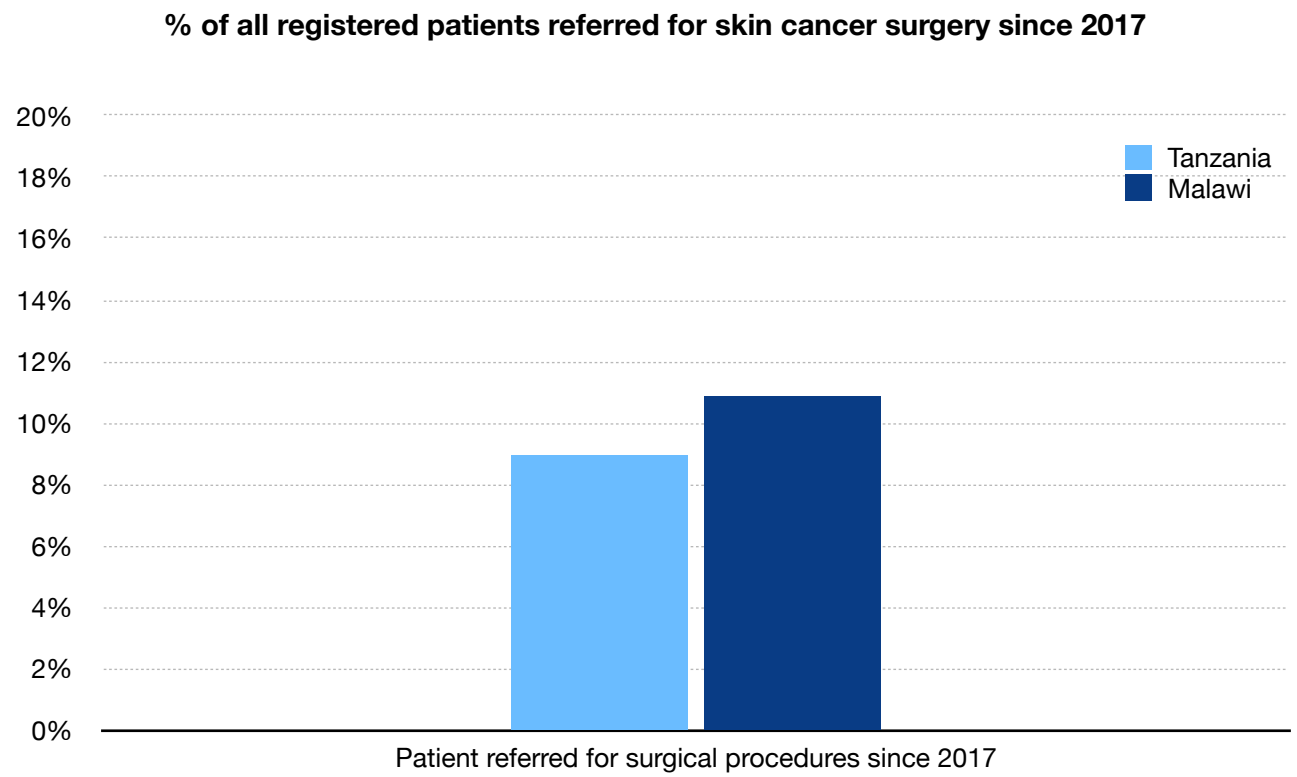


"After being diagnosed with [skin] cancer, I was sent to Hospital for surgery and later to Ocean Road Cancer Institute for further treatment.

"There were moments when I thought survival was impossible. It is hard to explain how I am alive today, but I am deeply grateful for the care, support, and treatment that gave me a second chance at life."

Eunice Peter, Kinondoni, Dar Es Salaam , Tanzania

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9.0% of all registered patients in Tanzania and 10.9% of all registered patients in Malawi have been referred for skin cancer treatment since 2017. These high percentages demonstrate the scale of the skin cancer crises facing people with albinism in Africa.

"I remember before attending clinics I was not aware about skin cancer. This made me live without protection and the wounds on my skin were like any wounds to me. Even my parents didn't know anything about albinism or skin cancer."

Barnabas Magashi Shilinde, Biharamulo, Kagera district, Tanzania





4.5 Sun Protection Measures

Indicator	Tanzania					Malawi					Total all years
	S2 2021	2022	2023	2024	2025	S2 2021	2022	2023	2024	2025	
Nb of jars of sunscreen distributed	8,894	14,816	22,093	30,108	106,528	1,722	12,300	13,839	16,592	12,611	239,503
Nb of sunglasses distributed	0	3,795	5,214	2,570	347	15	269	177	198	1,237	13,822
Nb of hats produced locally	4,381	7,458	13,350	17,676	17,287	N/A	N/A	N/A	N/A	N/A	60,152
Nb of hats distributed	3,269	7,290	8,345	9,685	11,378	238	1,431	2,620	3,235	4,095	51,586
Nb of umbrellas distributed	192	505	692	987	1,126	0	29	20	2	15	3,568
Nb UV protective lip balm	N/A	N/A	N/A	N/A	N/A	0	567	876	503	7	1,953

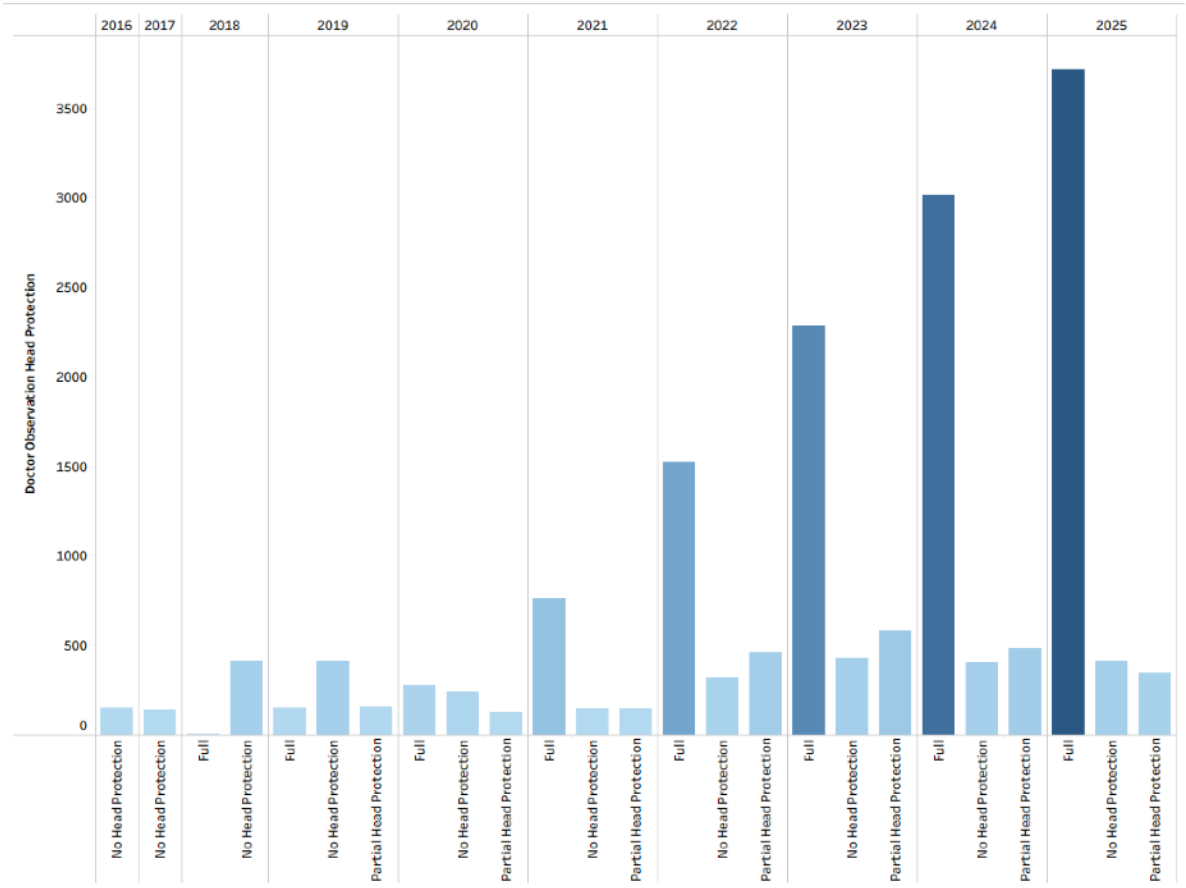
In 2025 the SCPP distributed thousands of essential sun-protective items across Tanzania and Malawi, including over 119,000 bottles of sunscreen, over 15,000 wide-brimmed hats, over 1,000 umbrellas, and over 1,500 pairs of sunglasses.

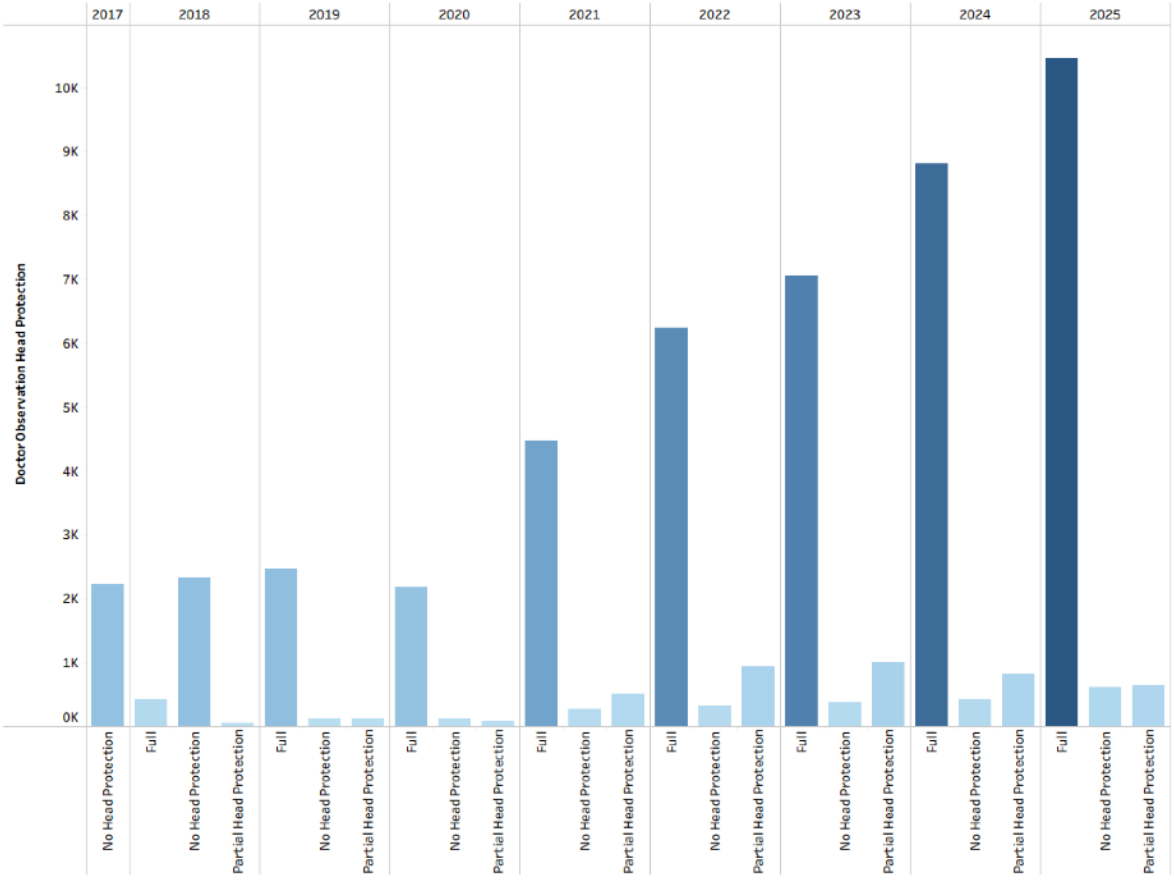
Since July 2021, a total of 310,432 sun-protective items have been distributed to people with albinism across both countries. As part off these efforts, 60,152 wide-brimmed hats have been made locally by tailors with albinism at the SV Umoja Training Centre in Tanzania and distributed free of charge through the SCPP clinical network. In 2025, we continued to expand the production and export of these hats to Malawi, deepening our regional impact while further empowering people with albinism through inclusive, skills-based employment.



Photo: A women demonstrates how to apply sunscreen effectively during a education awareness session in a clinic in Shinyanga Region

The graph presents doctors' observations of adherence to adequate head protection among persons with albinism (PWA) attending clinics from 2016 to 2025. Three categories were assessed: no protection, partial protection, and full protection. The findings indicate a steady increase in the proportion of individuals using full head protection over the study period, accompanied by corresponding declines in partial or no protection. This positive trend coincided with the rapid expansion of the programme in both countries, suggesting improved uptake of recommended sun-protective practices among clinic attendees.



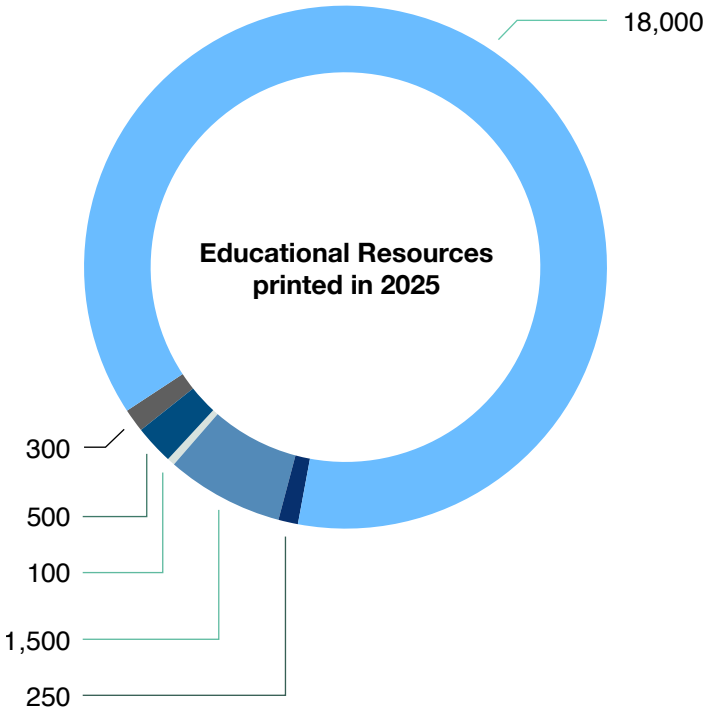


4.6 Educational resources

The SCPP serves as a key platform for disseminating specialist educational resources. Standing Voice has developed a diverse range of resources including booklets, training manuals and films to educate patients, communities, and service providers. In 2025, we printed 20,650 educational materials, of which 16,577 were distributed across all programme areas: 12,004 in Tanzania and 4,573 in Malawi.

To strengthen healthcare capacity, we continued to distribute and apply the *Manual of Best Practice in Dermatological Care for Persons with Albinism* to support professional training and enhance service delivery.

Total educational resources printed in 2025: 20,650



Educational Resources	Tz	Mw	Total
Understanding Albinism Booklet	12,000	6,000	18,000
Moon Shining Bright Picture Book	250	0	250
Teacher training booklet	1,000	500	1,500
Manual of best practice	50	50	100
Human Rights booklets	0	500	500
Communicate Advocate booklets	0	300	300
Total	13,300	7,350	20,650

- Understanding Albinism Booklet
- Moon Shining Bright booklet
- Teachers' Booklet
- Manual of Best practice
- Human rights booklets
- Community Advocate Booklet

In 2025, we continued to strengthen access to information on albinism, skin health, and rights through integrated education and advocacy resources delivered across Tanzania and Malawi. Materials were distributed through clinics, counselling sessions, training workshops, and schools, ensuring reach across both health and community settings. These included multilingual information booklets for people with albinism, families, teachers, and community advocates; the illustrated children's book *Moon, Shining Bright!*; and the *Manual of Best Practice* for the management of skin cancer in persons with albinism.

Audiovisual materials also remained central to our approach. Films were screened in clinics and at advocacy events, including an animated version of *Moon, Shining Bright!* and *Jikubali*, a documentary co-produced by Standing Voice and local partners. A new EU-commissioned documentary was launched in Lilongwe in March 2025 and later screened at the World Forum on Skin Cancer Prevention and Management in Cape Town in October.

Together, these resources support improved understanding of albinism, strengthen engagement with health services, and contribute to reducing stigma and promoting inclusion across communities in Tanzania and Malawi.


Hatua za kuharibika kwa ngozi
Kuungua na jua
Vidonda vya saratani ya ngozi
Madhara yatokanayo na jua ya zambarau
Yakinge macho yako
Tumia matuta ya kuteleza na mionzi ya jua
KUMBUKA:
Kinga ya jua


Ualbino
Ualbini Na Maana Kwa Watu Wenye Ualbino, Familia Na Walezi

4.7 Community Knowledge

Indicator	Tanzania	Malawi	Total
Nb of clinic education awareness sessions delivered	534	295	829
Nb times PWA and relatives attended awareness sessions	12,863	8,165	21,028
Nb of communication tool(s) used for the general public	4	5	9
Nb of communication tools distributed in the form of a brochure	11,649	4,684	16,333
Nb of new Regions / Districts	2	1	3
Nb of stakeholder mapping and engagement workshops	12	6	18
Number of 'community advocates' trained	71	26	97

Over the past 12 months, the SCPP delivered 829 health awareness sessions across Tanzania and Malawi, reaching a total of 21,028 people, including people with albinism, their family members, teachers, and community representatives. In Tanzania, 534 sessions were delivered to 12,863 participants, averaging 1.7 sessions per clinic. In Malawi, 295 sessions reached 8,165 people, with an average of 1.4 sessions per clinic. Additionally, 16,333 educational booklets were distributed to people with albinism in both countries.

In 2025, we conducted eighteen stakeholders mapping and engagement Workshops events in two new regions of Tanzania (Mtwara and Lindi), and one district of Malawi (Nsanje). These workshops engaged Community Leaders, Health Surveillance Assistants, Social Welfare Officers, and District Committee members of Albinism Associations, equipping them to support the SCPP's expansion and better advocate for the health and wellbeing of people with albinism in their communities.

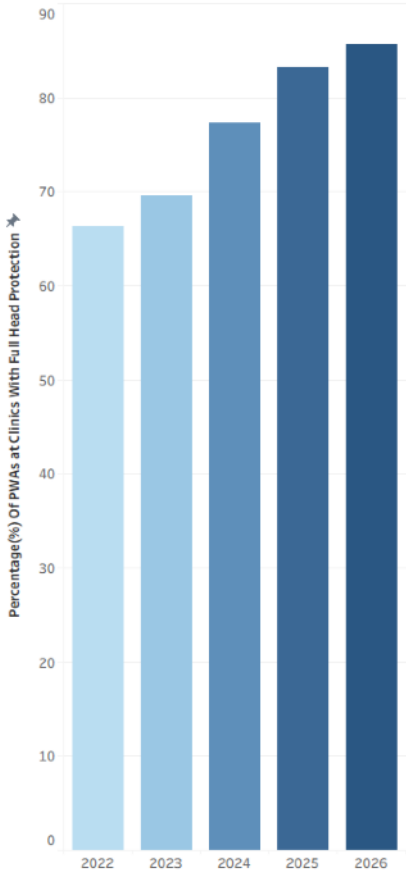


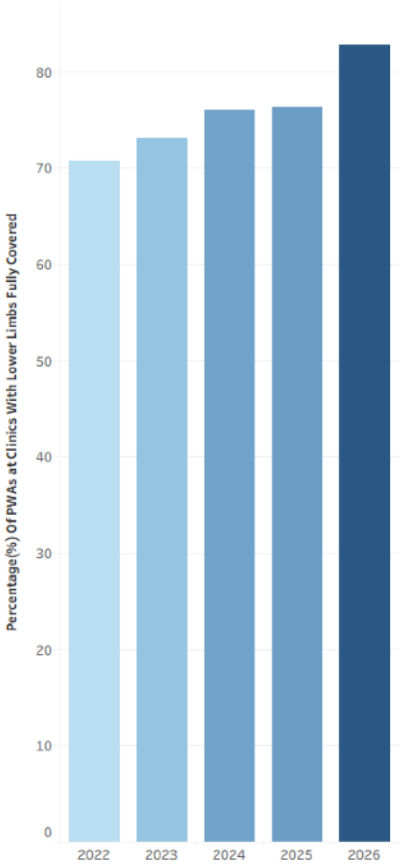
Dr Mosha leads a health education awareness session for people with albinism and their families during a clinic in Mwanza, Tanzania.

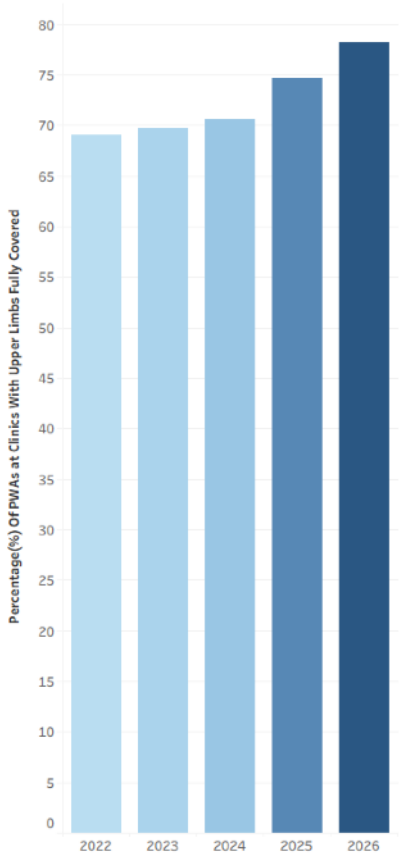


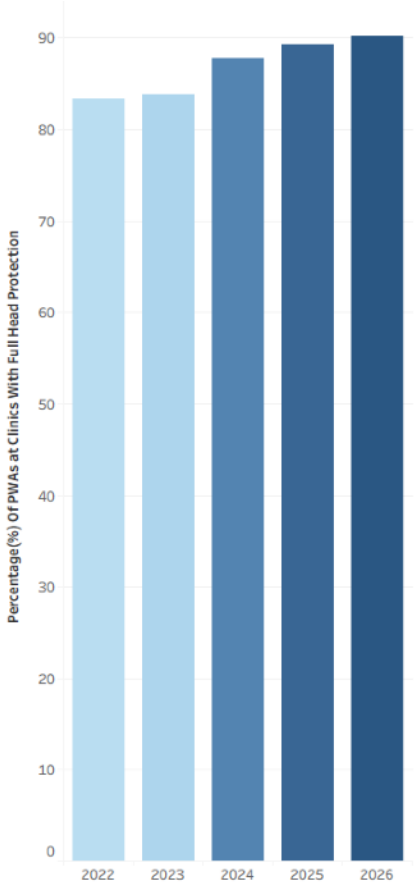
A mother stands proudly with her daughter while attending her local dermatology clinic in Mwanza, Tanzania

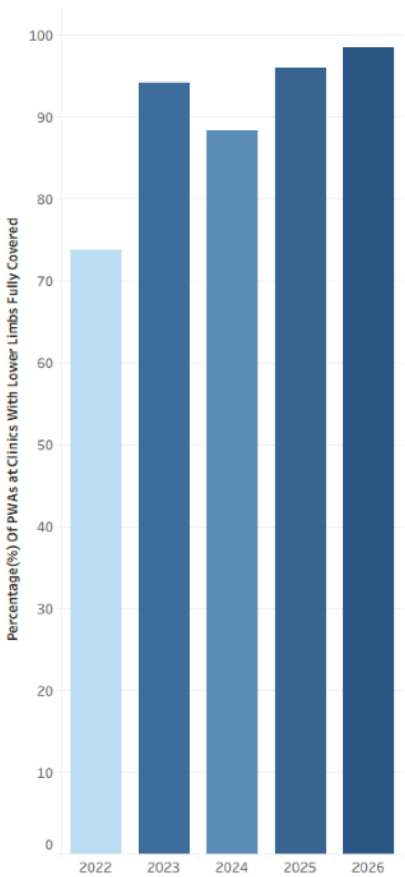
We have observed significant improvements in sun protection behaviours among people with albinism in Tanzania and Malawi, reflecting the impact of sustained education, improved access to resources, and community engagement. Clinician observations from 2022–2026 show increased use of protective hats and greater coverage of upper and lower limbs. These trends indicate stronger adherence to sun protection practices, a growing culture of self-care, and progress toward reducing skin cancer risk and improving long-term health outcomes. The three top graphs show Malawi, and the bottom three graphs show Tanzania.

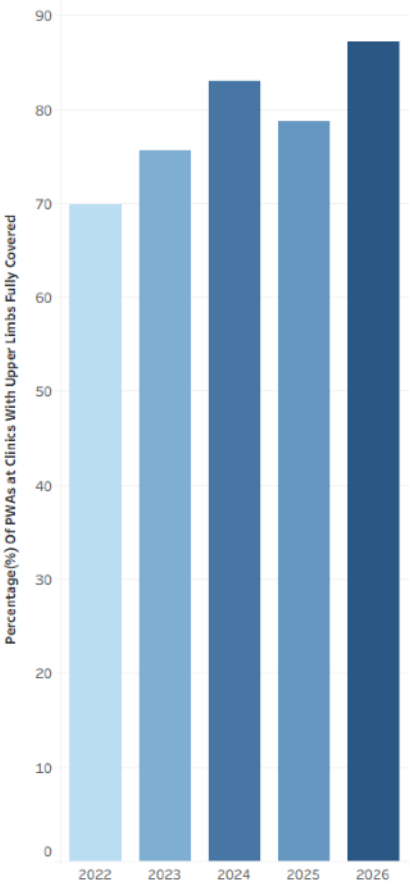












4.8 Stakeholder Training

In addition to delivering direct health education to people with albinism and their families, the SCPP drives systemic change in Tanzania and Malawi by strengthening the capacity of key duty bearers. These individuals, such as health professionals, educators, and government stakeholders, play a vital role in improving the health, wellbeing, and inclusion of people with albinism, particularly in the prevention and treatment of skin cancer.

In 2025, prior to launching new SCPP clinical services in new Regions and Districts across Tanzania and Malawi we conducted eighteen stakeholder engagement workshops, 12 of these were in Tanzania and 6 were in Malawi. These workshops introduced the programme to key stakeholders, mapped local hospitals, health centres, and patient populations, and identified optimal clinic locations. Sessions also covered understanding albinism, delivering effective health education, clinic setup, data collection, and referral management. Participants included Regional Administrative Secretaries, District Medical Officers, Social Welfare Officers, Special Education Officers, facility heads, and district and regional representatives of the Tanzania Albinism Society (TAS) and the Association of Persons with Albinism in Malawi (APAM). In total, these workshops engaged 139 stakeholders, 71 in Tanzania and 68 in Malawi. In Malawi expansion has slowed and our focus is on consolidation.

During the same period, clinical training was delivered to 86 frontline health professionals, 37 individuals in Tanzania and 49 in Malawi, including Dermatology Officers, Surgical Officers, Medical Assistants, nurses, and Health Surveillance Assistants. Training consisted of one to two days of classroom-based instruction followed by three to five days of hands-on clinical or theatre-based practice for dermatology and surgical staff.

Across all training initiatives in 2025, the SCPP strengthened the capacity of 225 key duty bearers: 108 in Tanzania and 117 in Malawi.

Photo: Surgical training in Malawi



4.8.1 IN FOCUS: Building Malawi's Capacity for Skin Cancer Surgery

Training the Next Generation of Surgical Officers

Before the Skin Cancer Prevention Programme (SCPP), access to specialist skin cancer surgery was extremely limited across Malawi. To address this challenge, Standing Voice combines life-saving surgical services with practical training for Malawian surgical officers and clinicians, helping to build the expertise needed to diagnose and remove skin cancers locally before they progress.

In 2025, two surgical training camps were held at Zomba Central Hospital, bringing together international specialists alongside Malawian surgeons, consultant dermatologists, anaesthetists, nurses, and surgical trainees from across the country. While providing essential treatment for people with albinism affected by skin cancer, the camps also served as a unique learning environment where trainees could develop specialist surgical skills through direct mentorship and hands-on surgical experience.

Every surgical officer trained through the SCPP represents an important step towards strengthening Malawi's capacity to deliver specialist skin cancer care and ensuring that more people with albinism can access timely treatment closer to home.

Training in theatre

The surgical training camps were designed to deliver specialist care while simultaneously strengthening Malawi's surgical workforce. Across the March and October camps, ten surgical officer trainees from district hospitals across the country received 14 days of intensive training from visiting and Malawian surgical specialists. The programme combined four days of classroom-based teaching and case discussions, two days of pre-operative assessments, and eight days of extensive supervised surgical practice in theatre. Structured pre- and post-training assessments were used to measure learning outcomes across the training period.

Unlike traditional training programmes, a large proportion of learning took place through supervised participation in direct patient care under the mentorship of experienced plastic surgeons and specialist clinicians. Trainees worked through the full surgical pathway, including patient assessment and counselling, theatre preparation, tumour excision, wound management, and post-operative follow-up. This approach enabled them to build practical competence in managing complex skin cancer cases that are rarely encountered in routine district-level practice, while also strengthening their understanding of multidisciplinary collaboration between dermatology, surgery, pathology, anaesthesia, and nursing teams.

The camps also strengthened the skills of 41 hospital staff, including nurses, anaesthetists, laboratory personnel, theatre attendants, and other frontline healthcare workers. Working alongside international dermatologists, surgeons, nurses, and local specialists, these participants gained valuable experience in surgical safety, diagnostic processes, multidisciplinary teamwork, and patient management.

By bringing together expertise from Malawi, Ireland, and the UK, the training camps created a collaborative learning environment that extends beyond individual training sessions. The relationships and professional networks established through the programme continue to support knowledge sharing, mentorship, and ongoing skills development long after the camps have ended.

Strengthening Skills and Systems

The camps exposed trainees not only to surgical techniques but also to the wider systems required to deliver high-quality care. Participants learned how digital patient records captured through CommCare support case identification, surgical planning, pathology tracking, and long-term follow-up.

Patients were screened before surgery using clinical information and photographs collected during SCPP outreach clinics, enabling surgeons to prioritise urgent cases and plan procedures effectively. Through this process, trainees gained valuable insight into how data systems, referral pathways, and coordinated care contribute to improved patient outcomes.

2025 Surgical Camps at a Glance

- 45 people with albinism received specialist surgical treatment for suspected skin cancers.
- 151 suspicious lesions were excised and submitted for laboratory analysis.
- 10 surgical trainees received intensive practical training.

Photo: Plastic Surgeons Tilende Chokotho and Patricia Eadie providing mentorship during a surgical training camp in Zomba, Malawi in March 2025



Lasting Impact

Impact from the training camps is already evident at district level. Surgical officers who have participated in the SCPP and subsequent training workshops are now independently performing minor skin cancer surgeries within their own facilities, reducing the need for referral and enabling earlier intervention. As their skills continue to develop, they are increasingly able to identify and manage skin cancers at earlier stages, improving treatment outcomes and reducing delays in care for people with albinism across Malawi.

This progress reflects strong collaboration between Standing Voice, Zomba Central Hospital, Queen Elizabeth Central Hospital, district health offices, international volunteer specialists. Together, these partnerships are helping to strengthen a more coordinated and sustainable system of care for people with albinism.

Investing in decentralisation of care remains one of the most effective ways to expand long-term access to specialist skin cancer treatment. Each trained clinician increases the health system's ability to detect, treat, and appropriately refer complex cases within routine services, ensuring more timely and equitable care.

> *"With only two plastic surgeons serving a population of approximately 17 million people, Malawi faces significant constraints in specialist surgical capacity. In this context, decentralising skin cancer services is critical to ensure that cancers are identified and removed early, before they progress to advanced stages where treatment options are limited and survival is significantly reduced.*
>
> *Through these surgical training camps, we are already seeing stronger coordination between health management teams and frontline clinicians, and a growing ability to manage and treat patients locally, bringing care closer to those who need it, when it matters most."*

Ndamiwe Kaseko, Health Manager, Standing Voice



Photo: Dr Aine Kelly guides trainee surgeons through a procedure during training in Malawi

4.8.2 IN FOCUS: Strengthening Healthcare Through Data-Driven Learning

Building Skills for Better Services

In October 2025, Standing Voice brought together 30 DVOs, clinicians, Ministry of Health representatives, and programme staff from across Malawi for a Monitoring & Evaluation (M&E) Workshop held ahead of the Dermatology Association of Malawi's annual Continuing Medical Education (CME) meeting in Dowa District.

The workshop was designed to strengthen participants' ability to use health data collected through the SCPP's digital health platform to improve clinical practice, monitor performance, and enhance the quality of care provided through the SCPP.

For many participants, the event provided an opportunity to step back from day-to-day clinical responsibilities and examine programme performance across the country. Through presentations, practical exercises, and peer discussions, participants reviewed data from clinics across 19 districts of Malawi, exploring trends in patient retention, referrals, skin conditions, precancerous lesions, tumour identification, and treatment outcomes.

The workshop demonstrated how routine health data can be transformed into a powerful tool for improving patient care. Participants reviewed rates of mild, moderate, and severe erythema, ectropion, actinic keratosis (AK), and possible tumours, as well as the use of cryotherapy and skin cancer referrals made through clinics.

A particular focus was understanding how clinical practice influences outcomes. By comparing consultation quality with screening times and referral patterns, participants gained insights into the factors that contribute to effective skin cancer prevention and early detection.

The sessions encouraged participants to move beyond simply collecting data to actively using it to identify challenges, measure progress, and guide decision-making within their districts.



Photo: Dr Mark Wheeler leads a training for Dermatology Officers in Malawi

Building Skills for Better Services

Throughout the workshop, DVOs strengthened their confidence and competence in interpreting health data and applying evidence to improve service delivery. Key areas of learning included

- Quality-of-care indicators and performance monitoring
- Identification and classification of skin cancer and precancerous lesions
- Effective referral processes using CommCare
- Clinical photography standards
- Patient follow-up and retention strategies; and
- The importance of accurate, timely data for informed decision-making.

By comparing district-level performance and sharing experiences between clinicians and clinic sites, participants were able to identify service gaps, learn from higher-performing districts, and develop practical solutions to improve patient outcomes.

Learning from Experience

The value of bringing practitioners together to review and reflect on programme data was evident throughout the workshop.

Rapson Chidothi, Dermatology Officer from Lilongwe, highlighted the practical benefits of the sessions

> "The programme's sustainability and expansion plans, as well as tumour identification and anatomical location, were most valuable. The session comparing provisional and confirmed diagnoses helped improve our diagnostic accuracy."

Fredrick Mtoto, Dermatology Officer from Zomba, also emphasised the importance of the data review process:

> *"All sessions were useful and highly interactive. Learning about average screening times across clinicians and the programme's future plans was impressive. The data review is a great motivation and helps us better understand our performance and achievements to date."*



Strengthening the Systems for the Future

Beyond building individual skills, the workshop reinforced the importance of continuous learning and quality improvement across the Skin Cancer Prevention Programme. Participants recognised the critical role of high-quality clinical photography in supporting referrals and diagnosis, while peer learning and analysis of real-world programme data helped strengthen both engagement and knowledge retention.

The discussions also generated practical recommendations for future programme development, including investment in additional cryotherapy equipment in health centres, strengthening clinical photography practices, exploring the introduction of Dermatoscopes to improve diagnostic accuracy, and integrating routine data review more systematically into future training activities.

Looking Ahead

As the Skin Cancer Prevention Programme continues to expand, ensuring that frontline health workers can effectively use data will be essential to maintaining high standards of care. The workshop demonstrated that when health workers are equipped with the skills to analyse and act on evidence, they are more motivated and better positioned to identify problems early, improve service delivery, and achieve better outcomes for patients. By investing in data-driven learning and continuous professional development, the SCPP is helping to ensure that people with albinism across Malawi receive timely, higher-quality, and evidence-based skin cancer prevention and treatment services.



Photo: Trainers use a model to teach the anatomical locations for skin surgery at a training workshop for Surgical officers in Zomba, Malawi in March 2025



The table below shows the large number of actors working across the programme. Today there are 2,321 people involved in delivering the SCPP.

By the end of 2027 we aim to have trained and mobilised over 2,500 frontline workers to lead the delivery of this programme.

SCPP stakeholders	Tanzania	Malawi	Total
Dermatologists and Dermatology Officers	56	28	84
Albinism Association leaders	276	140	416
Social Welfare Officers & Health Surveillance Assistants	184	101	285
Other health personnel: Clinicians, Medical Assistants, Nurses, Surgeons, Histopathologists	228	411	639
Regional & District Medical Officers	138	20	158
First responders / counsellors	24	30	54
Optometrists	20	12	32
Special Education Officers (Regional & District)	116	8	124
Teachers	451	-	451
Tailors	18	-	18
Pharmacists	8	19	27
Media	-	33	33
Total	**1,519**	**802**	**2,321**

5. VISION AND EDUCATION PROGRAMME

People with albinism commonly experience visual impairment, which can significantly affect educational attainment, employment opportunities, and independence. In Tanzania and Malawi, access to specialist low vision services remains limited, leaving many people without the care and support they need.

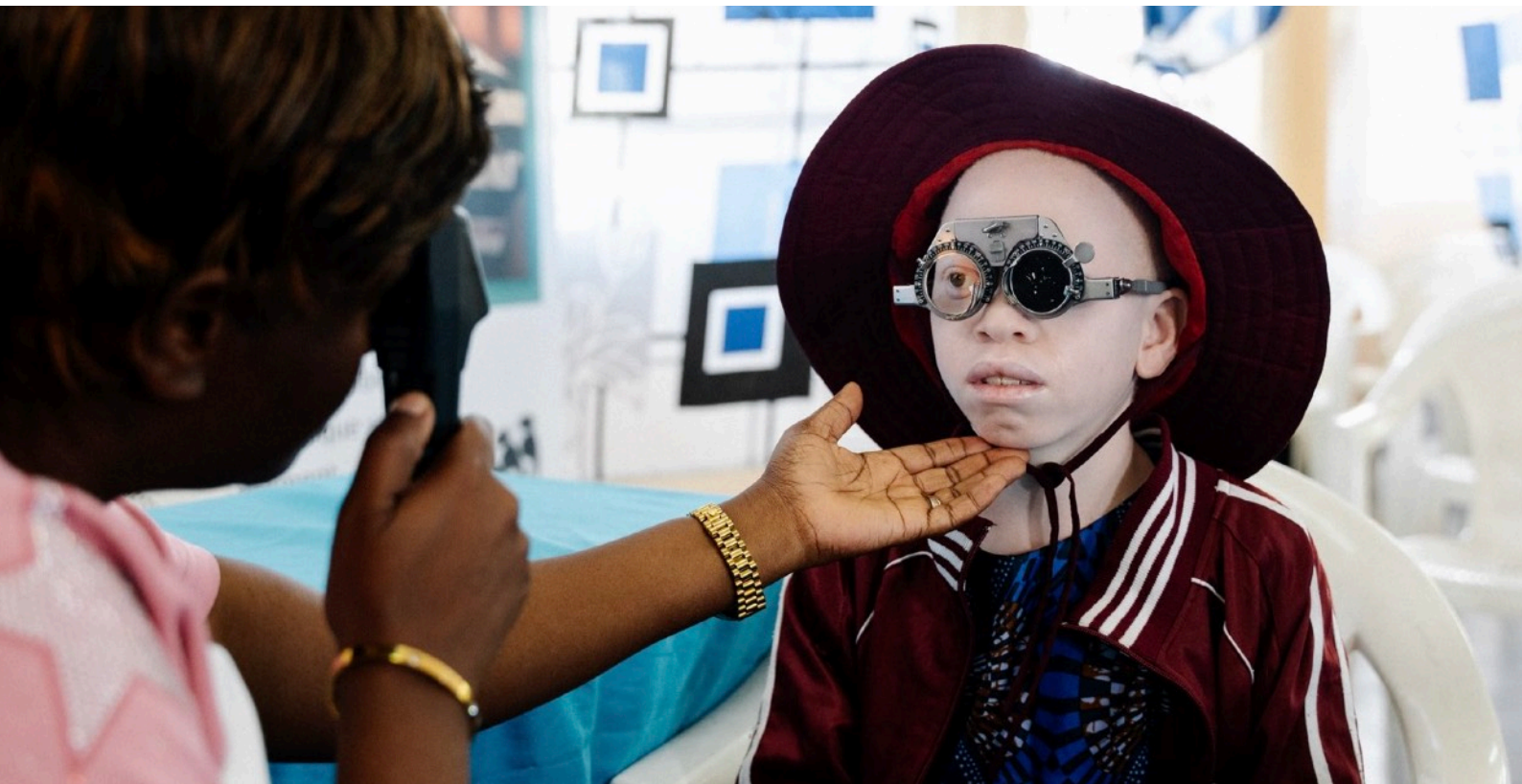
Since 2014, Standing Voice has delivered its Vision and Education Programme (VEP), providing specialist eye care, low vision assessments, assistive devices, and support for education professionals to improve outcomes for people with albinism. The programme is delivered in partnership with the Government of Tanzania and civil society organisations, with support from the OneSight EssilorLuxottica Foundation, Inside the Same, Manuli Ryco, and the Souter Charitable Trust.

During 2025, fewer eye clinics were delivered as preparations were made for a significant expansion of the programme in early 2026. This period focused on strengthening partnerships, procuring specialist equipment, and enhancing programme delivery. By the end of 2025, the programme had provided specialist eye care and educational support to more than 5,235 people with albinism since its inception, reaching fifteen regions of Tanzania and one district in Malawi. Many beneficiaries continue to receive regular eye assessments and follow-up care.

During 2025, 1,675 assistive vision devices were distributed, including 58 pairs of prescription glasses, 1,418 pairs of sunglasses, and 199 monocular telescopes.

Alongside clinical services, the programme delivered school awareness sessions that promoted greater understanding of albinism while encouraging inclusion and peer support within the classroom. Across all participating schools, 9,705 students with and without albinism took part in awareness activities during 2025. Surveys and focus group discussions indicated increased teacher confidence and improvements in the educational experience of students with albinism. Interactive talks, book readings, and film screenings encouraged positive attitudes towards people with albinism, while schools from across Ukerewe Island visited the Umoja Training Centre to access its community library and participate in inclusive learning activities.

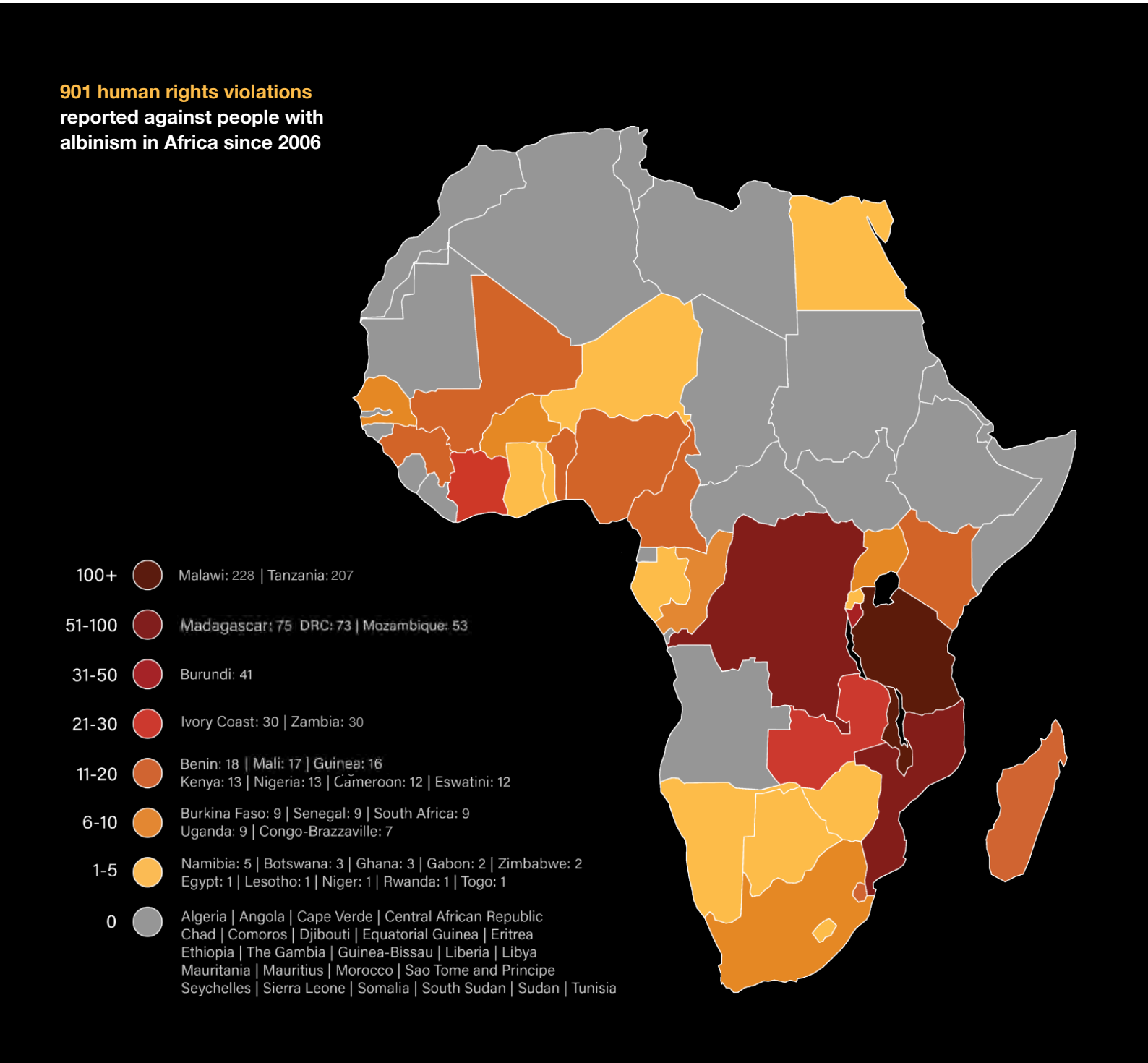
Standing Voice also provides direct educational support to children with albinism in Tanzania and Malawi. During the year, scholarships and school materials were provided to 33 children identified as being most at risk, helping them remain in education and learn in safe, supportive environments.

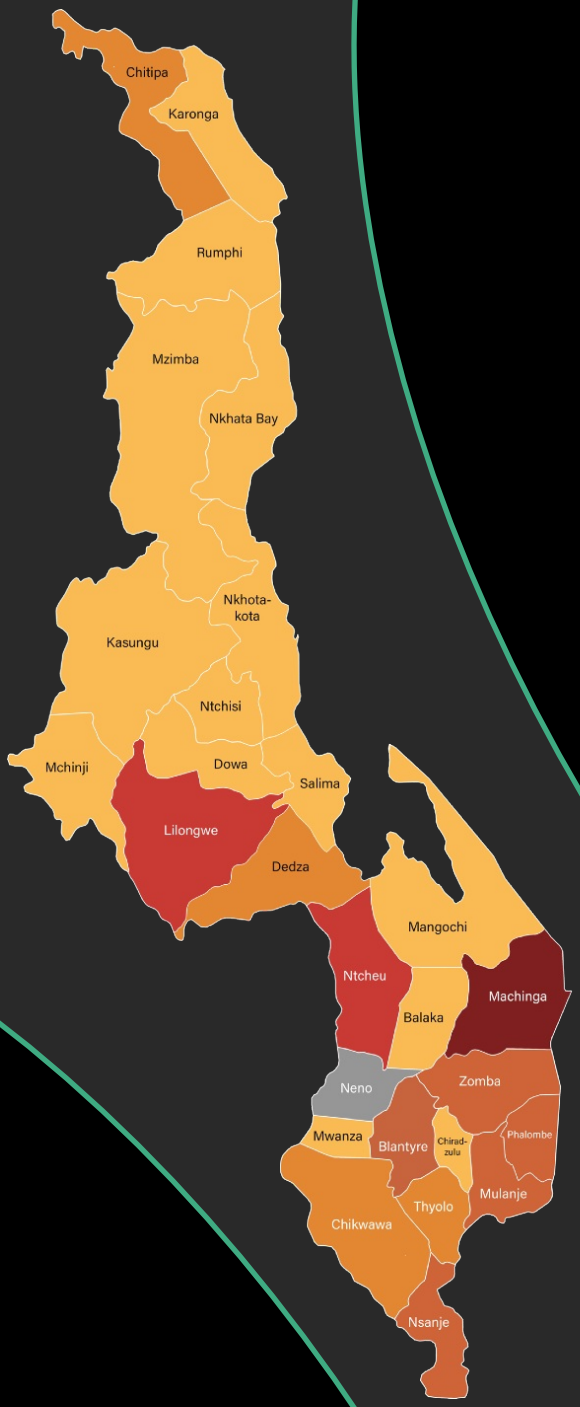


6. WELFARE AND SOCIAL PROTECTION PROGRAMME

6.1 The Issue

People with albinism are a violently persecuted minority in many African countries. Stigmatised for their unique appearance, many people with albinism are denied opportunities, excluded from services and subjected to damaging myths and misconceptions. In the worst cases, people with albinism are abducted, mutilated, raped and murdered: all because of the colour of their skin. As of December 2025 our records showed their were 901 documented human rights violations against persons with albinism in Africa since 2006. Tanzania and Malawi have been the epicentres of these atrocities, together accounting for half of all reported violations against people with albinism on the continent. In 2025, violent attacks in Malawi continued, with ten attempted abductions and other grave violations reported in the country's southern and central districts. In Machinga District, one in six people with albinism has experienced an attack.





MALAWI

228 human rights violations
reported against people with albinism since 2006

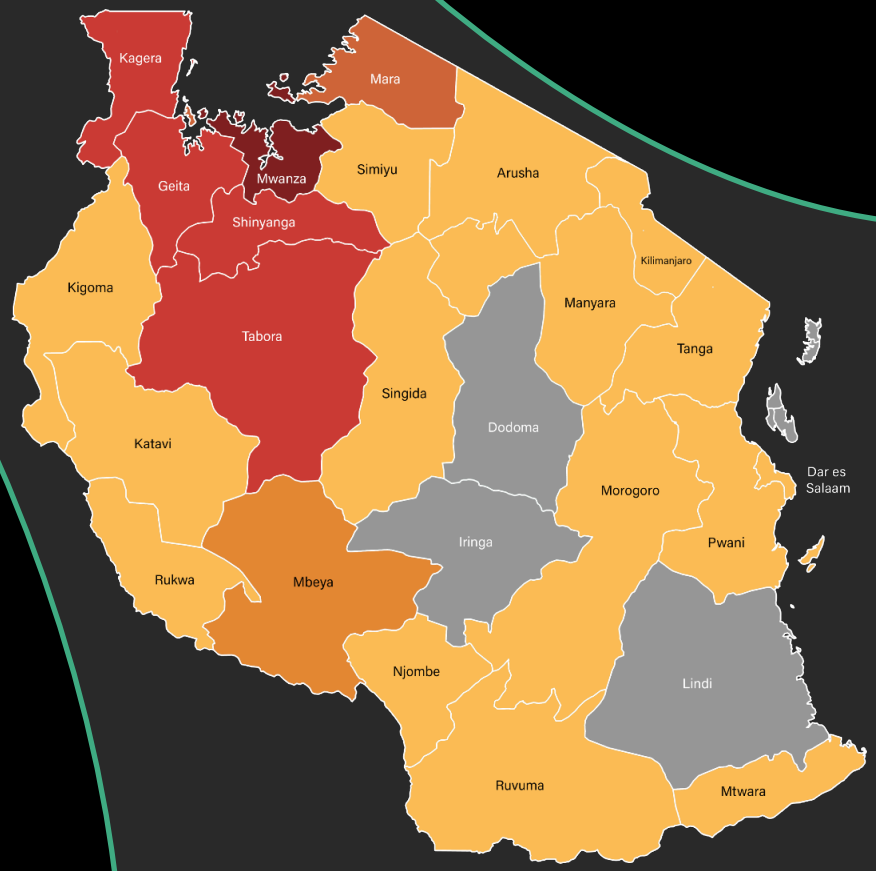
30+	Machinga: 39
16-30	Ntcheu: 17 | Lilongwe: 19
11-15	Zomba: 15 | Mulanje: 16 | Phalombe: 17 | Blantyre: 13 | Nsanje: 12
6-10	Dedza: 9 | Chitipa: 8 | Thyolo: 8 | Chikwawa: 7
1-5	Mangochi: 5 | Balaka: 6 | Salima: 4 | Chiradzulu: 5 | Karonga: 3 Mchinji: 3 | Mwanza: 4 | Ntchisi: 5 | Dowa: 4 | Kasungu: 2 Mzimba: 2 | Nkhata Bay: 2 | Nkhotakota: 2 | Rumphi: 1
0	Neno

Recent attacks:

There were 10 documented attacks against people with albinism in Malawi during 2025

Dec 2025
Grave violation of a women in Mangochi

March 2025
45 year old man went missing in Lilongwe Malawi. His body was found in May 2026



TANZANIA

207 human rights violations
reported against people with albinism since 2006

30+	Mwanza: 55
16-29	Kagera: 25 Geita: 17 | Shinyanga: 17 | Tabora: 16 Unknown locations 16
11-15	Mara: 14
6-10	Mbeya: 6
1-5	Rukwa: 5 | Kigoma: 4 | Morogoro: 4 | Pwani: 4 Arusha: 3 | Dar es Salaam: 3 | Simiyu: 3 | Tanga: 4 Njombe: 2 | Katavi: 1 | Kilimanjaro: 1 | Manyara: 1 Mtwara: 1 | Ruvuma: 1 | Singida: 1 | Songwe: 1
0	Dodoma | Iringa | Lindi | Zanzibar | Pemba

In addition to threats of violence and deeply rooted discrimination, most individuals with albinism whom we support in Tanzania and Malawi face significant barriers in accessing education, housing, employment and inclusion. Many have experienced profound trauma and require tailored, specialist support to navigate these intersecting challenges.

Across both countries, the Standing Voice First Response Team plays a crucial role in identifying, addressing, and preventing instances of abuse and discrimination against people with albinism and their families. This dedicated team is made up of local Standing Voice staff, social welfare professionals, and individuals with lived experience of albinism-related stigma. Over the past five years, they have undergone training and continuous mentorship from Dr. Mark Fish, a UK based psychotherapist and a member of the Standing Voice Advisory Board.

The First Response Team serves as a vital support system for some of the most at-risk individuals in our network. In 2025, its core areas of intervention under the partnership included:

6.2 Albinism Helpline

Indicator	Tanzania	Malawi
Regions where people with albinism have access to a helpline	25	19
Calls received through helpline	3,633	5,624

In 2025, Standing Voice continued to strengthen and operate two dedicated toll-free helplines, which are important lifelines for people with albinism and their families across Tanzania and Malawi. These helplines offer confidential platforms to report abuse, raise urgent health or welfare concerns, and seek support in situations of risk or uncertainty. Calls are handled by a trained team member in conducting rapid needs assessments and determining the appropriate course of action. Depending on the nature of the call, support may include immediate over-the-phone guidance, referral to a relevant programme including counselling, connection with specialist partner organisations, or, in cases of imminent danger, escalation to law enforcement or emergency services.

By the end of 2025, the helplines were accessible to people with albinism in 25 regions of Tanzania and 19 districts of Malawi, covering all areas where the Skin Cancer Prevention Programme (SCPP) is active, as well as additional sites in Tanzania where Vision and Education support is provided. Awareness about these services continues to be raised through literature, outreach clinics, school-based activities, and broader community engagement.

Since their inception in 2021, the helplines have received 9,257 calls. Of these 3,633 calls were Tanzania and 5,624 in Malawi. Callers seek support for a wide range of critical issues, most commonly:

- Reports of violence or abuse
- Anticipated or actual threats to personal safety
- Access to urgent medical care
- Psychosocial support
- Challenges related to education, food security, or livelihoods

Beyond their role in crisis response, these helplines are vital tools for ongoing case management and personalised care. They ensure that individuals at risk are supported in other ways, reinforcing our belief in holistic support and leaving no one behind.

6.3 Counselling and Emergency Tailored Support

Indicator	Tanzania 2025	Malawi 2025
Nb regions / districts where PWA have access to counselling at clinics	4	14
Nb PWA with access to counselling service at clinics	2,199	2,905
Nb of clinics with Counselling delivered	50	38
Nb people counselled through peer-to-peer counselling at clinics	123	159
Nb PWA receiving tailored and emergency support	176	122

During 2025 through the support of the Pierre Fabre Foundation, European Commission and United Nations Voluntary Fund for Victims of Torture we have been able to continue expanding peer to peer counselling and risk assessments at Dermatology clinics throughout Tanzania and Malawi, providing safe and confidential spaces for people with albinism and their families to speak freely about their needs and concerns, process trauma, build confidence and access referral for specialist services where required.

By the end of 2025, counselling was accessible to 5,104 people with albinism. This includes 2,199 people across four regions of Tanzania and 2,905 people in fourteen districts of Malawi. Since its inception 1,044 individuals have attended clinics based counselling sessions. 512 of these people were in Tanzania, and 532 people in Malawi.

During 2025 across both countries a total of 282 individuals sought counselling during 88 clinics. Of the 123 people visiting counselling stations during 2025 in Tanzania 68.3% were female and 31.7% Male. Of the 159 clients who received counselling in Malawi 44.7% were female and 55.3% Male.

For the most vulnerable people we work with, many of whom carry acute psychological trauma and have survived witchcraft-related atrocities, our Response Team provides a package of emergency support. This can include relocation to safe-housing, home security improvements; livelihood and food security support; urgent medical intervention; psychosocial, dermatological and palliative healthcare; facilitation of trauma recovery or family reconciliation; and direct advocacy interventions in situations of risk, conflict or exclusion. Across both countries 298 people with albinism were receiving some form of tailored support during 2025. This included ongoing support to 26 survivors of attack and 22 of their family members in Malawi.



- **10 attacks against PWA were documented in Malawi in 2025**
- **76.67% of survivors we are working with are under 15 years old**

6.4 Umoja Training Centre: Advancing Inclusion, Skills and Opportunity

Indicator	Tanzania 2025
Nb PWA receiving ongoing skills development or income generation support	57
Nb community members benefitting from the Umoja Training Centre (UTC)	10,274
Nb of school children reached by the UTC	9,705
Nb UTC tailors trained	18
Nb hats produced by UTC tailors	17,287
Nb hats produced since initiative begun (2021)	60,152

Since its establishment by Standing Voice in 2014, the Umoja Training Centre (UTC) on Ukerewe Island has grown into a thriving hub for inclusion, skills development, and community transformation. Designed to support people with albinism and their families, many of whom have been excluded from education and employment, the UTC offers a safe and vibrant space for learning, healing, and empowerment.

The UTC remains home to the Ukerewe Albinism Society and serves as a focal point for a growing network of community-based organisations and peer support groups. In 2025, the Centre continued to deliver life-changing opportunities for education, economic empowerment and inclusion through a broad range of formal training programmes, arts and cultural activities, and therapeutic support for survivors of discrimination and violence.

With the only public library on Ukerewe Island and a dynamic school outreach programme, the UTC plays a vital role in raising awareness of albinism and promoting inclusive education at the grassroots level. This year, the UTC supported the capacity development of numerous community groups and 58 individual trainees with albinism and their family members, offering practical training in: Tailoring, Soap-making, Batik, Radio production, Performing and visual arts, Music and storytelling

With the support of the Fondation Pierre Fabre and Croda Foundation, the Tunajitambua tailoring initiative has been able to continue scaling its impact, with UTC-trained artisans producing 17,287 wide-brimmed sun hats distributed free across 294 hospitals and health centres in Tanzania and Malawi. These protective hats form a vital part of Standing Voice's Skin Cancer Prevention Programme (SCPP), helping individuals with albinism manage sun exposure and reduce cancer risk. 10,274 people from across Ukerewe Island were directly engaged by UTC activities in 2025, through training sessions, community outreach, education campaigns, and public events, affirming the Centre's status as a beacon of inclusion and empowerment on the Island.



Florentina is pictured working in her factory producing sun hats, which are distributed across Tanzania and Malawi through the SCPP.

6.5 Women's Albinism Action Group: Empowering Women, Confronting Stigma

Women with albinism, and mothers of children with albinism, face compounded and intersecting forms of discrimination, rooted in gender, disability, and social stigma. In Sub-Saharan Africa, harmful myths persist, including the belief that sexual intercourse with a woman with albinism can cure infertility or HIV/AIDS. These dangerous misconceptions place women at heightened risk of sexual violence, coercion, and HIV infection. Meanwhile, mothers of babies born with albinism are frequently blamed and stigmatised, abandoned by their partners and families, and left solely responsible for their child's wellbeing. This not only increases their emotional and economic burden but also limits opportunities for income generation, exacerbating poverty and placing both mother and child in greater vulnerability.

In response, the Women's Albinism Action Group (WAAG) was founded in 2015 with the support of Standing Voice. Today, WAAG is a registered community-based organisation, led by and for women impacted by albinism. Based at the Umoja Training Centre on Ukerewe Island, the group began as an informal peer network and has since evolved into a powerful collective of change-makers advocating for dignity, inclusion, and justice for other mothers and their families.

WAAG provides a safe space for women to share experiences, build solidarity, and mobilise around shared goals. The group works in close partnership with Standing Voice and the Tanzania Albinism Society, offering peer counselling to new mothers of children with albinism via the Skin Cancer Prevention Programme's clinical network, and conducts homes visits and outreach in communities where stigma remains entrenched. Members travel widely to raise awareness, challenge myths, interrupt abandonment, promote positive narratives, particularly through direct engagement directly with families, in schools, health centres, and other public forums.

During 2025, the WAAG reached 5,452 individuals through its community outreach events designed to deepen public understanding of albinism. Throughout the year the WAAG continued to work with Standing Voice to provide peer-to-peer counselling for 84 women and girls attending dermatology clinics, and during 2025 provided ongoing tailored support to 176 people impacted by albinism and their families. WAAG's community support helpline received 758 calls in 2025, 365 of these calls related to women impacted by albinism. Since its launch in 2022, the helpline has provided vital over-the-phone counselling and advice to women on Ukerewe, with a total of 3,522 calls handled to date.

The WAAG plays a critical frontline role in protecting the rights, health, and wellbeing of women and families impacted by albinism. Through their leadership, lived experience, and collective voice, the women of WAAG are transforming attitudes and forging new pathways to safety, equality, and empowerment.



- **Established at the UTC** as a safety and support group for women impacted by albinism
- The WAAG registered as a **community-based organisation in 2021**
- The WAAG provides **peer counselling** and operates a **helpline** for women and mothers impacted by albinism; delivers **albinism training for welfare professionals**; and conducts **community outreach** to build public awareness of the rights and needs of people with albinism
- The WAAG has sensitised **27,885** people on albinism since 2021



Photo: Harry Freeland

Siwema

"My children no longer feel isolated — they can now play and be part of the community. Without this group, there would be very little understanding of albinism in our villages. Our work is helping to defeat stigma across schools, communities, and wider society. When we met for the first time, we saw our stories were the same. We are not alone anymore. Coming together as a group has helped us share our experiences and support each other through the challenges we have all faced."

Mama Kampala

"Since joining this group, my life feels more complete, and I feel empowered. My colleagues have opened my mind and deepened my understanding, and I now feel much more confident in my situation. This group of women is very important to me. It is empowering mothers in the village, raising awareness, so that other families understand albinism and have access to support that we never had."





Anneth

"When I joined this group, my self-confidence increased, and I have seen the same change in other mothers who are part of it. My baby has albinism, but that is just a condition and nothing more. Mothers of children with albinism need to stand up and speak out against stigma so that attitudes can continue to change.

"There was a time when I felt very alone, but this group has helped me make friends and feel more confident."

Neema

"Albinism is just a condition — there is nothing extra about it. I feel very empowered to be part of this group, and I no longer feel like I have a disability. Through our work, people in the community see that we can achieve the same as everyone else. We are having a strong impact, but this is just one small island and this country is huge. We have already helped establish another Mothers Group [in another part of Tanzania], but we will not stop until every corner of the country is reached."



Photo: Harry Freeland



Photo: Harry Freeland

Frolentina

"The work our group is doing is incredible. The level of understanding is so much higher than before, and today, my child feels more integrated and accepted than at any other point in her life. There is so much unity in the group. We understand each other, we share experiences, and our bond has grown stronger. When we go into communities, people thank us and tell us how eye-opening and educational our work is. That shows the impact this group is having."

Mbonamengi

"Just for giving birth to a baby with albinism, I have faced so many challenges in my life. But through the work of this group, we have seen real impact and many positive changes. We have achieved so much, but there is still more to do. We have not achieved everything yet."





Photo: Harry Freeland

Florentina

"When I look back, it was very difficult for mothers to have a child with albinism. Husbands rejected and abandoned them, and women were pushed out of their families and communities. Life was so hard. When this group was formed, we knew how important it was that we prevented this from happening to other women. Our confidence has grown so much – today, we go anywhere without fear. That change started the day we met at the UTC, and came together as a group."

Mama Veda

"When I gave birth to a child with albinism, some of my closer relatives were no longer interested in having a relationship with me and I had to move to another village. People did not even want to shake hands with my son. But now that has all changed. I am very grateful for Standing Voice, for the awareness raising, and for the knowledge I have gained. I am now happy and confident."



6.6 Titukulane Project: Economic Empowerment for People with Albinism in Malawi

The Titukulane (Empowerment) Project is a three-year partnership between Standing Voice, Beyond Suncare (BSC), and the Girls Empowerment Network (GENET) to advance the economic, social and cultural rights of people with albinism in Malawi. During its first year, the project made substantial progress in improving access to healthcare, strengthening protection systems, promoting economic inclusion, and addressing discrimination, violence, and social exclusion.

As part of the programme, a national barriers analysis report was commissioned and undertaken with the Malawi Human Rights Commission. The study identified key obstacles affecting access to healthcare, education, employment, and justice for people with albinism, providing an important evidence base for advocacy and policy reform over the remaining two years of the project.

Year 1 focused on strengthening health and protection systems to establish the foundations for improved economic security in Years 2 and 3. Across Malawi, 3,947 people with albinism now have access to project services, while 5,151 duty bearers, including family members, government officials, health workers, teachers, police officers, and community leaders, received training and sensitisation to improve understanding of albinism and promote inclusive service delivery. Within the 15 Titukulane priority districts, 2,930 people with albinism now have access to essential health, counselling, protection, and sexual and gender-based violence (SGBV) services.

The project also strengthened opportunities for women and young people. A total of 135 women and girls with albinism received leadership and entrepreneurship training, while targeted support was provided to survivors of attacks in four districts.

To promote long-term economic inclusion, 105 candidates were identified for vocational training, with the first cohort of 35 participants enrolled on courses commencing in Year 2. Eight vocational training institutions received to strengthen their capacity for inclusive education by developing inclusion plans and appointing Inclusion Ambassadors to promote access for learners with albinism.

Overall, the first year established strong partnerships, effective referral pathways, and sustainable service delivery mechanisms, laying a solid foundation for expanding vocational training, job placements, skills development, education, and advocacy over the remaining two years. The project is already demonstrating measurable progress towards improving the health, safety, dignity, and socio-economic inclusion of people with albinism across Malawi.



7. DATA MANAGEMENT AND ANALYSIS

In 2025, we continued to strengthen our digital health infrastructure through the ongoing development and optimisation of the CommCare platform, which supports service delivery, monitoring and evaluation across all our programmes in Tanzania and Malawi. Data is shared directly with the Government and fed into the national health information systems in Tanzania and Malawi. As the Skin Cancer Prevention Programme (SCPP) expands, the platform remains central to the collection and management of albinism health data from Government clinics and other SV outreach activities.

A major focus during the year was improving data quality, accessibility, and readiness for future research. One of the ongoing challenges of the programme is balancing service delivery, impact measurement, and workforce development. As new Government healthcare workers are trained and begin using the CommCare platform, maintaining consistent standards of data entry, security and record management requires regular training, supervision, and data quality reviews.

To address these challenges, a dedicated Data Analyst joined the UK team towards the end of 2025 to lead an ongoing programme of data cleaning, validation, and harmonisation across programme datasets. This substantial body of work will continue into 2026, strengthening the reliability of impact data and supporting planned operational and clinical research activities.

To improve data use and reporting, we have been working on developing a suite of live dashboards linked directly to our health information system. As these dashboards are rolled out and refined, they will provide government stakeholders and partners with real-time access to programme indicators, supporting more effective monitoring, analysis, and impact reporting.

Digital health training remained a priority throughout the year. Refresher training and ongoing technical support were provided to healthcare workers and programme staff to strengthen data quality, improve platform utilisation, and ensure consistent and accurate data collection across an expanding network of service delivery sites.

Together, these investments are helping to transform programme data into actionable insights that support decision-making, continuous service improvement, and the generation of evidence to inform future policy and practice.



8. SPECIAL EVENTS AND PARTNERSHIP VISIBILITY

During 2025, Standing Voice strengthened the visibility and reach of the partnership through national, regional, and international engagement. Across the year, teams participated in conferences, workshops, and advocacy platforms, sharing learning from across our Programme in Tanzania and Malawi while deepening collaboration across health, disability, and albinism-focused networks.

A key milestone was the final dissemination meeting of the EU and Fondation Pierre Fabre funded Ufulu Wanga Project in Malawi in March 2025. The event brought together government representatives, development partners, civil society organisations, health professionals, media, and persons with albinism to review achievements and identify future priorities. As part of the project, the European Union commissioned a documentary highlighting the rights, health, and lived experiences of persons with albinism in Malawi. The film premiered at the dissemination event and was later screened at the World Forum on Skin Cancer Prevention and Management in Persons with Albinism held in Cape Town, South Africa, in October 2025.

In April, Standing Voice participated in the GlobalSkin Conference in Prague, Czech Republic, presenting lessons from its programmes in Malawi and Tanzania and highlighting the impact of the Standing Voice–Pierre Fabre Foundation partnership to a global audience of patient advocates and skin health specialists.

In May, Standing Voice team members Chrispine Mabwenga from Tanzania and Daisy Chikowi from Malawi joined a regional workshop on albinism and mental health in Abidjan, Côte d'Ivoire, convened by the Fondation Pierre Fabre under the APPASAAS project. The workshop brought together partners from across Africa to strengthen mental health responses for people with albinism. Standing Voice contributed insights from its trauma-informed and community-led programming, emphasising the links between physical and mental health, economic empowerment, and social inclusion.

In June, the Standing Voice Tanzania team travelled to London for a strategic planning workshop focused on strengthening organisational coordination, sustainability and government engagement.

A major advocacy milestone was achieved in September 2025 when the World Health Organization (WHO) added broad-spectrum high factor sunscreen to its Model List of Essential Medicines. The decision followed sustained advocacy by the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, the Global Albinism Alliance, African Albinism Network, the Fondation Pierre Fabre, Standing Voice and other international partners, who jointly submitted a proposal to WHO and called for sunscreen to be recognised as an essential health intervention for persons with albinism. The inclusion represents an important step towards improving access to life-saving skin cancer prevention measures and strengthening recognition of sunscreen as a critical component of healthcare for persons with albinism worldwide.



October marked two important milestones. In Malawi, we launched the Titukulane Project, a new three-year initiative funded by the European Union. The project brings together government, civil society, and community stakeholders to advance the socioeconomic empowerment and inclusion of persons with albinism. It builds on the foundation established by the Skin Cancer Prevention Programme, recognising that good health is a prerequisite for accessing education, employment, and other opportunities for social and economic participation.

Later that month, Standing Voice joined the Pierre Fabre Foundation, the Global Albinism Alliance, and the International League of Dermatological Societies (ILDS) to deliver the World Forum on Skin Cancer Prevention and Management in Persons with Albinism in Cape Town, South Africa (See in-focus article on page 63).

Throughout the year, Standing Voice continued to engage government ministries and key stakeholders to strengthen national responses to albinism. In Malawi, the organisation contributed to consultations on the renewal of the National Action Plan for Persons with Albinism scheduled for renewal in 2026, while in Tanzania it supported ongoing implementation of the National Action Plan launched in 2024. Collaboration with Ministries of Health in both countries helped to further advance efforts to integrate skin cancer prevention and treatment into national health systems. These partnerships continue to play an important role in embedding albinism-related services and protections within national systems and policies.

Standing Voice also strengthened its communications work throughout 2025, including the redevelopment of its website to improve the visibility of the programme impact, amplify the partnership, and champion community stories to a wider audience.







8.1. IN FOCUS: Fondation Pierre Fabre Visit Malawi

In October 2025, Standing Voice welcomed Mélanie Reau, Head of Dermatology Programmes at the Pierre Fabre Foundation, to Malawi.

The visit, undertaken alongside Standing Voice Executive Director Harry Freeland, provided an opportunity to review programme progress in Malawi, meet implementation teams, and observe services supported by the Foundation's investment. In Lilongwe, the delegation engaged with the Standing Voice Malawi team at their office, visited key programme sites, including hospitals delivering skin cancer prevention services and safe housing supporting survivors of violence.

Across these visits, the delegation met individuals with albinism whose lives have been directly impacted by improved access to dermatological care, psychosocial support, counselling, and empowerment services. These engagements highlighted the role of integrated, community-based interventions in improving skin health, wellbeing, confidence, and social inclusion.

The programme also included visits to the World Health Organisation country office in Lilongwe, where discussions focused on broader collaboration in digital health and e-health systems, as well as the One Stop Centre at Kamuzu Central Hospital. Here, partners explored ongoing efforts to strengthen support services for survivors of sexual and gender-based violence, including persons with albinism.

A key feature of the visit was direct engagement with individuals and families supported through the programme. Their experiences demonstrated the value of a holistic, community-centred approach that combines clinical care, psychosocial support, and protection services to enable people with albinism to live safer and more independent lives.

The visit reaffirmed the shared commitment of Standing Voice and the Pierre Fabre Foundation to a systems-strengthening approach. Rather than delivering isolated interventions, the partnership continues to focus on building locally integrated services that are embedded within national systems and capable of delivering long-term impact.

It also provided an opportunity to reflect on lessons learned and to explore future priorities, including expanded research collaboration, strengthened community engagement, and deeper integration of services within national health and protection systems.

Reflecting on the visit, Mélanie Reau said: *"I am sincerely grateful to the Standing Voice team for the outstanding organisation of this first mission to Malawi. This experience was both insightful and deeply meaningful, offering a unique opportunity to engage directly with people living with albinism, community members, dedicated healthcare professionals, and local partners, while witnessing firsthand the impactful and long-standing work carried out by Standing Voice in Malawi."*





8.2 IN FOCUS: WORLD FORUM ON SKIN CANCER PREVENTION AND MANAGEMENT

In October 2025, global leaders, experts, researchers, clinicians and advocates gathered in Cape Town, South Africa, for a landmark meeting in the global fight against skin cancer in persons with albinism.

Co-organised by the International League of Dermatological Societies (ILDS), the Global Albinism Alliance (GAA), and Standing Voice (SV), and the Fondation Pierre Fabre, the inaugural World Forum on Skin Cancer Prevention and Management in Persons with Albinism brought together 70 delegates from more than 30 countries. The Forum represented the first dedicated global meeting focused exclusively on preventing and managing skin cancer in persons with albinism—a condition that remains one of the leading causes of preventable illness and premature death among people with albinism in many low-resource settings.

Over two days, dermatologists, researchers, policymakers, public health specialists, and representatives from organisations of persons with albinism shared experiences and best practices, identified key barriers to care, and explored practical solutions to strengthen prevention, early detection, treatment, and long-term management. As the first event of its kind, the Forum signalled a shift towards a more coordinated international response to one of the most urgent yet preventable health challenges affecting persons with albinism worldwide.

In a joint statement, the organising partners highlighted the importance of strengthening access to photo-protection, early diagnosis, and treatment, while addressing the systemic barriers that continue to prevent many people with albinism from accessing care.

“By convening this Forum, we have, for the first time, brought together a diverse range of stakeholders from around the world with expertise in addressing skin cancer in persons with albinism. This gathering created a unique space for these actors to connect, exchange expertise and learn from one another, laying the foundation for future collaboration and coordinated action. The Forum has fostered the emergence of a global community united by a shared commitment to improving skin cancer prevention and management in persons with albinism.”

The Forum formed part of a growing international effort, supported by the Pierre Fabre Foundation, to strengthen collaboration, evidence generation, and access to effective skin cancer prevention and management services for persons with albinism. Throughout the meeting, plenary sessions, expert panels, and workshops explored topics including scaling best-practice prevention models, photo-protection strategies, health worker training, screening and surgical approaches, epidemiology, health system integration, advocacy, community-led education, and the lived experiences of people with albinism. Discussions also built on the World Health Organisation’s recent decision to include sunscreen on its Essential Medicines List, a significant step forward for global advocacy efforts. This application submitted early in 2025 was backed by both Standing Voice and the Pierre Fare Foundation alongside other key partners in the albinism movement.




SCPP toolkit and patient information system
ILDS
World Forum


ND SAFETY
ILDS
League of
Societies


Ousmane Faye



A key outcome of the Forum was agreement to establish a shared global framework for skin cancer prevention and management in persons with albinism. The framework will guide future collaboration and action across advocacy, photo-protection, clinical capacity strengthening, service delivery, research, and policy development, while promoting stronger coordination between researchers, practitioners, governments, and organisations of persons with albinism.

The Forum marks an important step towards a more coordinated global response to skin cancer in persons with albinism, bringing together science, policy, programme experience, and lived expertise to improve prevention, strengthen access to care, and reduce avoidable deaths. To sustain this momentum, a post-meeting report has been published outlining the Forum's key discussions, priorities, and recommendations for future action.

You can read the full post-meeting report here: **Read the full report**



9. RESEARCH

During 2025, Standing Voice took an important step in strengthening the research function of the Skin Cancer Prevention Programme. Building on the programme's established health information system, we invested in dedicated analytical capacity to improve the use of routine programme data for monitoring, learning, and impact measurement.

A significant milestone was the launch of a new partnership between Standing Voice, the the International Agency for Research on Cancer (IARC) and Fondation Pierre Fabre (FPF). Together, the partners began developing a research programme to generate evidence on the health outcomes of people with albinism using data collected through the SCPP. Initial research protocols were developed during the year, with ethical approvals and the first analyses planned for 2026.

This partnership represents an important evolution of the programme, creating new opportunities to strengthen the global evidence base on albinism while informing future policy, practice, and skin cancer prevention services.



10. FUNDING MATTERS

GRANT-MAKING POLICY

Standing Voice provides grants to collaborating organisations that require funding to deliver services aligned with our mission. In some cases, the trustees may award grants to independent organisations not in formal partnership with Standing Voice, where there is clear alignment with our charitable objectives.

Grants are directed toward organisations or services that promote the wellbeing and social inclusion of people with albinism in Africa, particularly through initiatives in health, education, welfare, and community development. All grants are subject to strict conditions, including robust financial reporting and accounting standards, strong internal policies (covering safeguarding, finance, and procurement), a proven track record of successful implementation, and full compliance with relevant regulations and international standards, as outlined in Standing Voice's grant agreements.

FUNDRAISING ACTIVITIES

Standing Voice raises funds from a diverse portfolio of sources, including trust funds, grant-giving foundations and institutions, corporate donors, and individual philanthropists. Additional support is generated through public donations, direct appeals, and organised fundraising events and campaigns. In 2025, our principal sources of funding continued to be grants from charitable foundations and trusts, alongside generous contributions from individuals, corporate partners, and the wider public.

We are proud to have been supported throughout 2025 by a wide range of innovative and committed funders. These include the Fondation Pierre Fabre (FPF), the European Commission (EU), the International Foundation for Dermatology (IFD), the Croda Foundation, the International League of Dermatological Societies (ILDS), the United Nations Voluntary Fund for Victims of Torture (UNVFVT), the International Agency for Research on Cancer (IARC), the Bilton Charitable Foundation, the John Armitage Charitable Trust (JACT), Inside the Same, Glasgow University, The Edge, Wings of Support, the Irish Global Health Network, Global Green Grants, the Tara Getty Fund, Global Skin, Manuli Ryco, the Souter Charitable Trust, the Order of St'Lazarus and the Reed Foundation. We are also deeply grateful for the extensive in-kind support received from Altruist, the African Albinism Foundation, and ISDIN, OneSight Essilor Luxottica Foundation, along with many other generous partners, including those who have chosen to remain anonymous.

The trustees extend their heartfelt thanks to all donors and funding partners for their invaluable support, which continues to make our work possible and meaningful. Your commitment enables us to protect, empower and include people with albinism across Tanzania, Malawi, and beyond.

FINANCIAL PERFORMANCE

Income during the period 1st January 2025 to 31st December 2025 amounted to £1,528,990 (January 2024-December 2024: £1,445,587). Voluntary income for 2025 was £1,520,619 (2024: £1,438,922). Of the total income, £1,436,889 (2024: £1,338,180) was restricted and £92,101 (2024: £107,407) was unrestricted. The restricted income consists of donated funds from grant funders and individuals, as well as restricted gift in-kind support amounting the value of £482,375 (2024: £128,182). £647,245 (2024: £603,436) of restricted funding was carried forward. Total unrestricted funds carried forward totalled £234,521. Unrestricted income was mainly from individual donations.

Expenditure amounted to £1,470,660 (2024: £1,286,929) of which £1,420,125 (2024: £1,225,352) was project expenditure, £46,275 (2024: £57,301) was fundraising expenditure and £4,260 (2024: £4,276,) was governance costs. Of the total expenditure, 1,393,080 (2024: £1,218,520) was restricted expenditure and £77,580 (2024: £68,409) was unrestricted expenditure. Standing Voice exercises a policy of setting aside funds to cover 6 months of administration overheads as reserves (£329,253), to cover core costs in the event of the organisation encountering a period of reduced income.

At the end of the financial year ending 31st December 2025, the charity carried forward a balance of £881,766 (2024: £823,436), of which £329,253 was available for salaries and overheads. The organisation also awaited funding responses from major grant funders. The trustees deemed reserve funds held to be sufficient, keeping in consideration the overheads budget allocations in restricted funds held, and the status of committed funding from new and existing donors due for disbursement in 2026 amounting to over £1,200,000.

EXPENDITURE SUPPORTING KEY OBJECTIVES

Standing Voice increased expenditure on its life-saving programmes to £1,470,660 in 2025, up from £1,286,929 in 2024. This investment has been essential as the needs of the people we support continue to grow amid unstable global economic conditions in both Tanzania and Malawi, the increasing risk of climate change-related disasters, and the ongoing threat of attacks against people with albinism. The increase in programme expenditure of £183,731 compared with 2024 has been carefully planned and is considered sustainable, supported by existing funding commitments and the successful development of new multi-year funding partnerships secured during 2025 and into 2026. Expenditure on programmes that promote the health, wellbeing, and inclusion of people with albinism remains fully aligned with Standing Voice's charitable objectives as set out in its governing constitution.

People with albinism in Tanzania and Malawi continue to benefit from capacity development; improved dermatological and ophthalmological health services; psychosocial support interventions; increased access to education; and advancements in local and international awareness on albinism resulting from Standing Voice's project activities. Additionally, through training and coordination of health, social protection and education service providers we are building a sustained, scalable and locally driven response to this issue in both countries.

The charity's projects this year have grown substantially both in terms of geographical reach, and depth of the interventions being delivered across both countries of operation. Whilst growing the footprint of its work Standing Voice continues interlinking services, to ensure individual projects act as gateways for other essential services. Scaling up geographical reach, alongside investing in a holistic approach to our work has led Standing Voice to achieve its objective of combating human rights abuses against people with albinism by further advancing integration in society in 2025.





11. GOVERNANCE AND RISK

FUTURE PLANS OF THE CHARITY

In 2026, Standing Voice will continue to strengthen and expand its integrated programmes across Tanzania and Malawi, building on more than a decade of sustained growth. While the Skin Cancer Prevention Programme (SCPP) will continue its planned expansion towards national coverage in Tanzania and the majority of Malawi, with the continued support of the Fondation Pierre Fabre and the Croda Foundation emphasis will be on cementing the programmes integration within national health systems. We will also launch new partnership in Zimbabwe and Uganda in skin cancer prevention and management programmes.

Alongside dermatology and eye care services, we will continue to strengthen our welfare, education and livelihoods programmes, ensuring that people with albinism have access to the healthcare, psychosocial support, skills and opportunities needed to live healthy, safe and independent lives. In Malawi, our European Union-funded Titukulane project, will expand opportunities for economic empowerment through vocational training, entrepreneurship support, financial inclusion and pathways to employment for people with albinism.

We will also continue to invest in research, monitoring and evaluation, and digital systems to strengthen programme quality and generate evidence that informs policy and practice. New collaborations with the International Agency for Research on Cancer (IARC), Fondation Pierre Fabre, academic institutions and new funding partners will support research into the health outcomes of people with albinism and contribute to the global evidence base.

Across all areas of our work, Standing Voice will continue working in partnership with governments, organisations of persons with albinism, healthcare providers, civil society organisations and our donors to strengthen national systems, build local capacity and promote long-term sustainability. Our ambition remains to ensure that people with albinism can access high-quality healthcare, education, protection and economic opportunities, enabling them to live with dignity, safety and equal opportunity.



OPERATING CONTEXT, CHALLENGES AND RESILIENCE

In 2025, Standing Voice operated in an increasingly challenging environment. Political, economic and regulatory developments in both Tanzania and Malawi placed additional pressure on health systems, civil society organisations and the communities we serve.

In Tanzania, heightened political tensions and increased regulatory scrutiny of civil society organisations created a more complex operating environment. Standing Voice maintained close oversight of staff safety, travel and programme delivery while continuing to work collaboratively with government partners at national and regional levels. Our programmes continued without significant disruption, reflecting the strength of these partnerships and our established operational systems.

In Malawi, inflation, fuel shortages, foreign exchange constraints and reductions in international aid funding increased the cost and complexity of programme delivery and placed further strain on an already fragile health system. These conditions also created additional barriers for many people with albinism seeking access to healthcare.

Against this backdrop, organisational resilience remained a key priority. Standing Voice continued to invest in staff capacity, programme management, digital systems and financial oversight, ensuring services remained responsive and sustainable. Strong governance, prudent financial management and close collaboration between our teams in Tanzania, Malawi and the UK enabled the organisation to maintain services, continue planned programme expansion and strengthen the foundations for long-term government ownership of our programmes. Despite these challenges, the charity met or exceeded its principal programme objectives during the year.

Risk Management

The principal risk facing Standing Voice, and therefore the communities we serve, is ensuring sufficient organisational capacity to meet the increasing scale and complexity of our programmes. As our work continues to grow, responding to the evolving needs of people with albinism requires sustained investment in a skilled, adaptable and well-supported team.

We mitigate this risk through a diversified funding portfolio, continued grant fundraising and careful financial planning to ensure recruitment and organisational growth remain aligned with programme needs and available resources.

To manage operational and financial risks, Standing Voice maintains robust governance and oversight across its operations in Tanzania, Malawi and the UK. Comprehensive financial controls, regular monitoring and evaluation, and detailed programme and financial reporting support effective management and accountability. All significant fund transfers and disbursements are subject to dual-authorisation processes in both the UK and our country offices, with oversight from UK management and regular review by senior leadership and the Trustees through reporting and site visits.

The Trustees also monitor wider external risks, including political and regulatory change, foreign exchange and banking restrictions, donor dependency, security, technological limitations and climate-related disruption. These risks are reviewed regularly to ensure appropriate mitigation measures remain in place and that the charity can continue delivering its programmes effectively.

RESPONSIBILITIES OF THE BOARD OF TRUSTEES

The Trustees are responsible for managing the affairs of the CIO and may for that purpose exercise all the powers of the CIO.

It is the duty of each charity trustee:

1. to exercise his or her powers and to perform his or her functions in his or her capacity as a trustee of the CIO in the way he or she decides in good faith would be most likely to further the purposes of the CIO; and
2. to exercise, in the performance of those functions, such care and skill as is reasonable in the circumstances having regard in particular to:
    1. any special knowledge or experience that he or she has or holds himself or herself out as having; and,
    2. if he or she acts as a charity trustee of the CIO in the course of a business or profession, to any special knowledge or experience that it is reasonable to expect of a person acting in the course of that kind of business or profession.

The Board of Trustees are responsible for complying with the requirements of the Charities Act 2011 with regard to the keeping of accounting records, to the preparation and scrutiny of statements of account, and to the preparation of annual reports and returns for submission to the Charity Commission.

PUBLIC BENEFIT

In accordance with section 17 of the Charities Act 2011 the Trustees confirm that they have had regard to the Charity Commission's guidance in relation to public benefit. The Trustees have referred to the Charity Commission's general guidance on public benefit when reviewing the charity's aims and objectives and in planning the charity's future activities. In particular, the Trustees have considered how planned activities contribute to the aims and objectives they have set.

TRUSTEES' DECLARATION

There is no relevant information of which the auditor is unaware. Each Trustee has taken all the necessary steps that he/she ought to have taken as a Trustee in order to inform themselves of all relevant information, and to establish that the auditor is aware of that information.

Approved by the Board of Trustees and signed on its behalf by:



Chair of the Board of Trustees
30/06/2026



12. ACCOUNTS

12.1 Independent Auditor's Report to the Trustees of Standing Voice (UK)

Opinion

We have audited the consolidated financial statements of Standing Voice (UK) (the 'CIO') and its subsidiaries (the 'group') for the year ended 31 December 2025 which comprise the Consolidated Statement of Financial Activities, the Consolidated Balance Sheet and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 *The Financial Reporting Standard applicable in the UK and Republic of Ireland* (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the CIO's affairs as at 31 December 2025, and of group's and parent for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Charities Act 2011.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the group in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or

- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the group's and parent charity's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the trustees' report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the group and the parent charity and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' report.

We have nothing to report in respect of the following matters in relation to which the Charities (Accounts and Reports) Regulations 2008 require us to report to you if, in our opinion:

- the information given in the financial statements is inconsistent in any material respect with the trustees' report; or
- sufficient accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the trustees' responsibilities statement in trustees' report, the trustees are responsible for the preparation of financial statements which give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the group's and parent CIO's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the group and or parent CIO or to cease operations, or have no realistic alternative but to do so.

We have been appointed as auditor under section 151 of the Charities Act 2011 and report in accordance with the Act and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

- We obtained an understanding of the legal and regulatory frameworks that are applicable to the CIO and determined that the most significant are the Statement of Recommended Practice 'Accounting and Reporting by Charities' (SORP 2019), in accordance with the Financial Reporting Standard applicable in the UK (FRS 102) applicable to smaller entities and the Charities Act 2011.
- We understood how the CIO is complying with those frameworks via communication with those charged with governance, together with the review of the CIO's documented policies and procedures.
- The audit team, which is experienced in the audit of charities, considered the charity's susceptibility to material misstatement and how fraud may occur. Our considerations included the risk of management override.
- Our approach was to check that the income from grants and donations was properly identified, related expenditure was appropriately charged in accordance with any restrictions that may have been in place and that payments overseas were made to valid organisations. This included reviewing journal adjustments and unusual transactions.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of our report

This report is made solely to the CIO's trustees, as a body, in accordance with Part 4 of the Charities (Accounts and Reports) Regulations 2008. Our audit work has been undertaken so that we might state to the CIO's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the CIO and the CIO's trustees as a body, for our audit work, for this report, or for the opinions we have formed.

Knox Cropper LLP

Date 30 October 2026

Knox Cropper LLP
Statutory Auditor
65 Leadenhall Street
London
EC3A 2AD

Knox Cropper LLP is eligible for appointment as auditor of the charity by virtue of its eligibility for appointment as auditor of a company under section 1212 of the Companies Act 2006.

27.10.2026

12.2 Consolidated Statement of Financial Activities (SoFA)

Statement of Financial Activities (Incorporating an Income and Expenditure Account) for the period ended 31 December 2025:

		Chaity	Group	Group	Group
	Notes	Unrestricted funds (£)	Restricted income funds (£)	Total 2025 (£)	Total 2024 (£)
Income and endowments from:					
Donations and legacies		86,592	1,434,027	£1,520,619	1,438,922
Income from investments		5,509	2,862	8,371	6,665
Other income		-	-	-	-
Total income and endowments	**2**	**92,101**	**1,436,889**	**1,528,990**	**1,445,587**
Expenditure on:					
Raising funds		2,313	43,962	46,275	57,301
Charitable activities		71,007	1,349,118	1,420,125	1,225,352
Other expenditure		4,260	-	4,260	4,276
Total expenditure	**3**	**77,580**	**1,393,080**	**1,470,660**	**1,286,929**
Net income/(expenditure) and movement in funds for the year		14,521	43,809	58,330	158,658
Total funds brought forward		220,000	603,436	823,436	664,778
Total funds carried forward		**234,521**	**647,245**	**881,766**	**823,436**

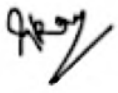
The Statement of Financial Activities includes all gains and losses recognised in the year. All the activities derive from continuing operations during the above periods.

12.3 BALANCE SHEET

Balance Sheet as at 31 December 2025

	Notes	Charity 2025 (£)	Group 2025 (£)	Charity 2024 (£)	Group 2024 (£)
Fixed assets					
Fixed assets	**4**	27,174	119,643	40,573	128,822
Total fixed assets		**27,174**	**119,643**	**40,573**	**128,822**
Current assets					
Debtors and prepayments	**5**	17,205	18,642	43,997	51,836
Cash at bank and in hand		1,022,526	1,036,793	661,841	672,323
Total current assets		**1,039,731**	**1,055,435**	**705,838**	**724,159**
Liabilities					
Creditors: amounts falling due within one year	**6**	293,312	293,312	28,285	29,545
Net current assets/(liabilities)		746,420	762,123	677,553	694,614
Total assets less current liabilities		**773,594**	**881,766**	**718,126**	**823,436**
Net assets		**773,594**	**881,766**	**718,126**	**823,436**
Funds of the charity					
Unrestricted funds		129,515	234,521	114,690	220,000
Restricted income funds	**7**	644,079	647,245	603,436	603,436
Total funds		**773,594**	**881,766**	**718,126**	**823,436**

The financial statements were approved and authorised for issue by the Trustees on 27/10/2026 and signed on their behalf by:



Gurmeet Kaur
Treasurer of the Board of Trustees

12.4 CONSOLIDATED CASH FLOW STATEMENT

For the year end 31 December 2025

	Notes	2025 (£)	2024 (£)
Cash flows from operating activities:			
Surplus - Net income / (expenditure)	**4**	**58,330**	**158,658**
Adjustment for:			
Decrease / (Increase) in debtors	**5**	33,194	-26,095
Increase / (Decrease) in creditors		263,767	12,640
Depreciation for the year		9,179	13,890
Exchange Rate Difference		-	-
Net Cash Increase for the period		**364,470**	**159,093**
Cash b/f at the start if the period		672,323	513,230
Cash and cash equivalent at 31 December		**1,036,793**	**672,323**
Components of cash and cash equivalents:	**6**		
Cash at bank and in hand		1,036,793	672,323
Cash at the end of the period		**1,036,793**	**672,323**



12.5 BASIS OF PREPARATION

Basis of preparation and accounting policies for year ended 31 December 2025

The financial statements have been prepared under the historical cost convention, unless otherwise stated in the relevant accounting policy, in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102), the Statement of Recommended Practice: Accounting and Reporting by Charities preparing their accounts in accordance with FRS 102 (Charities SORP (FRS 102), and applicable UK charity law.

The charity meets the definition of a public benefit entity under FRS 102.

The financial statements are presented in pounds sterling, which is the charity's presentation currency, and

1. ACCOUNTING POLICIES

This list of accounting policies has been applied by the charity.

Income	
Recognition of income	These are included in the Statement of Financial Activities (SoFA) when: - the charity becomes entitled to the resources; - it is probable that the economic benefits associated with the transaction or gift will flow to the charity; and - the monetary value can be measured with sufficient reliability
Income with related expenditure	Where income have related expenditure (as with fundraising or contract income) the income and related expenditure are reported gross in the SoFA.
Grants and donations	Grants and donations are only included in the SoFA when the charity has entitlement to the funds, receipt is probable and the amount can be measured reliably. Income subject to donor-imposed restrictions is recognised as restricted income and credited to the appropriate restricted fund. Where a grant or donation is subject to performance-related or other conditions that must be met before the charity is entitled to the resources, income is recognised only when those conditions have been met or are within the charity's control and there is sufficient evidence that they have been or will be met. Amounts received before the recognition criteria are satisfied are recognised as deferred income. Deferred income is released when the relevant recognition conditions are met. A restriction on the purpose for which funds may be used does not, of itself, constitute a condition requiring income to be deferred.
Tax reclaims on donations and gifts	Income from tax reclaims are included in the SoFA at the same time as the gift to which they relate.

Income (continued)

Donated goods, facilities and services	Donated goods, facilities and services are recognised as income when the charity has entitlement to the economic resources, it is probable that the resources will be received and their value can be measured reliably. Donated goods are measured at fair value unless it is impracticable to measure fair value reliably, in which case the cost to the donor or another appropriate measure may be used where permitted by FRS 102 and the Charities SORP. Donated facilities and services are recognised at the value of the benefit to the charity where this can be measured reliably. Where donated goods or services are consumed immediately, an equivalent amount is recognised as expenditure under the appropriate charitable activity so that the Statement of Financial Activities reflects both the donation received and the resources consumed. The contribution of general volunteers is not recognised as income because it cannot be measured reliably for accounting purposes. The nature and significance of volunteer contributions are described in the notes to the financial statements and/or Trustees' Annual Report.
Volunteer help	The value of any voluntary help received is not included in the accounts but is described in the trustees' annual report.
Investment income	This is included in the accounts when receivable.
Investment gains and losses	This includes any gain or loss on the sale of investments and any gain or loss resulting from revaluing investments to market value at the end of the year.

Expenditure and Liabilities

Liability recognition	Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to pay out resources.
Expenditure recognition	Expenditure is recognised once there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and is classified under headings that aggregate costs relating to the same category of activity. Expenditure on raising funds includes the costs incurred in generating voluntary income and other fundraising activities. Expenditure on charitable activities comprises those costs incurred by the charity in delivering its charitable activities and services, including grants payable and an allocation of support and governance costs.
Grants with performance conditions	Where the charity gives a grant with conditions for its payment being a specific level of service or output to be provided, such grants are only recognised in the SoFA once the recipient of the grant has provided the specified service or output.
Grants payable without performance conditions	These are only recognised in the accounts when a commitment has been made and there are no conditions to be met relating to the grant which remain in the control of the charity.
Support Costs	Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, e.g. allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

Assets

Tangible fixed assets for use by charity	Tangible fixed assets are initially measured at cost, including any expenditure that is directly attributable to bringing the asset into use. Individual items of expenditure costing more than £5,000 are capitalised where they are expected to have a useful economic life of more than one year. Depreciation is charged on a systematic basis so as to write off the cost of tangible fixed assets, less any estimated residual value, over their expected useful economic lives. Depreciation is provided at the following annual rates: • Motor vehicles: 20% The residual values and useful economic lives of assets are reviewed where there is an indication of a material change.
Investments	Investments quoted on a recognised stock exchange are valued at market value at the year-end. Other investment assets are included at trustees' best estimate of market value.
Stocks and work in progress	These are valued at the lower of cost or market value.

Fund Accounting

Fund accounting	Unrestricted funds are funds available for use at the discretion of the trustees in furtherance of the general charitable objectives of the charity and which have not been designated for other purposes. Restricted funds are funds subject to specific restrictions imposed by donors or arising from the purposes of an appeal. Expenditure that meets the conditions of a restricted fund is charged against that fund. Transfers between funds are made only where permitted by the terms of the funds and are disclosed in the notes to the financial statements where material.
Going concern	The trustees have assessed the group's and charity's ability to continue as a going concern for a period of at least 12 months from the date on which these financial statements are approved. In making this assessment, the trustees have considered the group's and charity's financial position, available cash resources, committed and expected funding, forecast income and expenditure and anticipated cash flows. The trustees consider that the group and charity have adequate resources to continue in operational existence for the foreseeable future. Accordingly, the financial statements have been prepared on the going concern basis. The trustees have not identified any material uncertainties that may cast significant doubt on the group's or charity's ability to continue as a going concern.

Debtors

Debtors	Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any discounts due. Debtors are reviewed for evidence of impairment at each reporting date and any impairment loss is recognised in the Statement of Financial Activities.
Creditors and provisions	Creditors are recognised where the group has a present legal or constructive obligation arising from a past event that is expected to result in the transfer of economic benefit and the amount can be measured or estimated reliably. Creditors are normally recognised at their settlement amount. Provisions are recognised when the group has a present legal or constructive obligation as a result of a past event, it is probable that settlement will require a transfer of economic benefits and the amount can be estimated reliably.
Financial instruments	The group has financial assets and financial liabilities that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction price, unless the arrangement constitutes a financing transaction, and are subsequently measured at amortised cost using the effective interest method where applicable.
Foreign currencies	Transactions denominated in foreign currencies are translated into the functional currency at the exchange rate ruling at the date of the transaction or at an appropriate rate that approximates the actual exchange rate. Monetary assets and liabilities denominated in foreign currencies at the reporting date are translated at the rate of exchange ruling at that date. Exchange gains and losses arising on translation are recognised in the Statement of Financial Activities. Where overseas operations have a functional currency different from the group's presentation currency, their results and financial position are translated into sterling in accordance with FRS 102. Exchange differences arising on consolidation are recognised in the appropriate component of funds. Critical accounting judgements and key sources of estimation uncertainty In preparing the financial statements, the trustees are required to make judgements, estimates and assumptions that affect the application of accounting policies and the reported amounts of assets, liabilities, income and expenditure. Estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimates are revised and in any future periods affected.



2. ANALYSIS OF INCOME AND ENDOWMENTS

	Analysis	2025 (£)	2024 (£)
Donations and Legacies	Restricted income	1,434,027	1,338,180
	Unrestricted income	86,592	100,742
		1,520,619	1,438,922
Income from investments	Unrestricted: Bank interest	5,509	6,665
	Restricted: Bank Interest	2,862	
		8,371	**6,665**
Total income and endowments		**1,528,990**	**1,445,587**



3. ANALYSIS OF RESOURCES EXPENDED

	Analysis	2025 (£)	2024 (£)
Costs of generating voluntary income	Staff costs	34,846	45,063
	Support costs	11,429	12,239
		46,275	**57,301**
Charitable activities	Staff costs	287,652	180,250
	Support costs	45,717	48,956
	Direct project costs	1,086,755	996,146
		1,420,125	**1,225,352**
Governance costs	Auditors fee	2,760	2,676
	Accounting advice & payroll services	1,500	1,600
		4,260	**4,276**
Total		**1,470,660**	**1,286,929**

4. TANGIBLE FIXED ASSETS

	Freehold land and buildings (£)	Other land and buildings (£)	Plant, machinery and motor vehicles (£)	Fixtures, fittings and equipment (£)	Total (£)
Cost			163,861		163,861
At 1 January 2025	-	-	-	-	
Additions	-	-	-	-	
At 31 December 2025	-	-	163,861	-	163,861
Depreciation					
At 1 January 2025	-	-	35,039	-	35,039
Charge for the year	-	-	9,179	-	9,179
At 31 December 2025	-	-	44,218	-	44,218
Net Book Value					
At 31 December 2025	-	-	119,643	-	119,643
At 1 January 2025	-	-	128,822	-	128,822

5. DEBTORS AND PREPAYMENTS

Analysis of debtors	Amounts falling due within one year (£)			
	Charty 2025	Charity 2024	Group 2025	Group 2024
Prepayments and accrued income	17,205	43,997	18,642	51,836
Total	**17,205**	**43,997**	**18,642**	**51,836**

6. CREDITORS AND ACCRUALS

Analysis of creditors	Amounts falling due within one year (£)			
	Charty 2025	Charity 2024	Group 2025	Group 2024
Loan and overdrafts	-	-	-	-
Accruals (various)	9,695	9,780	9,695	9,780
Accruals and deferred income	283,617	18,504	283,617	18,504
Total	**293,312**	**28,285**	**293,312**	**29,546**

7. RESTRICTED FUNDS

Fund Name	Purpose and Restrictions
Skin Cancer Prevention	Skin cancer prevention and treatment services for persons with albinism in Africa
Vision and Education	Delivery of low vision and education support for persons with albinism in Tanzania and Malawi.
Welfare and Livelihoods	Provision of psychosocial support, skills development and other economic empowerment activities for persons with albinism in Tanzania and Malawi
Umoja Children Centre	Building of a community centre for learning and healing targeting children and youth in Tanzania
Research and Data Management	Research into health outcomes for persons with albinism in Tanzania and Malawi
Awareness and Advocacy	Conducting advocacy and awareness to promote the rights, wellbeing and inclusion of persons with albinism in Africa



a. MOVEMENT OF MAJOR FUNDS 2025

Fund names	Fund balances brought forward 1 January 2025 (£)	Restricted Income (£)	Restricted outgoing resources (£)	Fund balances carried forward 31 December 2025 (£)
Skin Cancer Prevention	119,127	1,101,349	998,543	221,933
Vision and Education	3,117	40,079	21,876	21,320
Welfare and Livelihoods	25,796	138,825	66,083	98,538
Umoja Children Centre	145,399	15,000	7,545	152,854
Research and Data Management	-	83,037	37,077	45,960
Advocacy and Awareness	60,128	28,912	34,497	54,543
Core costs / overheads	249,869	29,687	227,459	52,097
Total Restricted Funds	**603,436**	**1,436,889**	**1,393,080**	**647,245**

b. MOVEMENT OF MAJOR FUNDS 2024

Fund names	Fund balances brought forward 1 January 2024 (£)	Restricted Income (£)	Restricted outgoing resources (£)	Fund balances carried forward 31 December 2024 (£)
Skin Cancer Prevention	16,889	878,187	775,951	119,125
Advocacy and Awareness	50,239	40,629	30,739	60,128
Vision and Education	-3,593	120,363	113,653	3,117
Umoja Children's Centre	138,091	21,250	13,942	145,399
Welfare & Livelihoods services	55,871	91,707	121,782	25,796
Core Costs	227,162	168,384	145,677	249,869
Total Restricted Funds	**484,659**	**1,320,521**	**1,201,744**	**603,434**

8. DETAILS OF CERTAIN ITEMS OF EXPENDITURE

Fees for examination of the accounts	2025 (£)	2024 (£)
Auditor's fees for reporting on the accounts	13,800	13,380
External accountancy services	1,500	1,600

9a. SUPPORT COSTS 2025

Support Costs Type	Fundraising activity (£)	Charitable Activity (£)	Governance Activity (£)	Total Cost (£)
Building costs	6,483	25,931	-	32,414
Communications	1,509	6,035	-	7,544
Legal & professional	489	1,954	-	2,443
Other costs	67	4,492	-	4,559
Financial costs	201	806	-	1,007
Depreciation	2,680	6,499	-	9,179
Total amount (£)	**11,429**	**45,717**	-	**57,146**

9b. SUPPORT COSTS 2024

Support Costs Type	Fundraising activity (£)	Charitable Activity (£)	Governance Activity (£)	Total Cost (£)
Building costs	6,759	27,038	-	33,797
Communications	1,395	5,581	-	6,976
Legal & professional	739	2,954	-	3,693
Other costs	423	1,691	-	2,114
Financial costs	145	580	-	725
Depreciation	2,778	11,112	-	13,890
Total amount (£)	**12,239**	**48,956**	-	**61,195**



10. GRANT-MAKING

Grants to individuals/institutions Purpose for which grants made	31 Dec 2025 Total amount (£)	31 Dec 2024 Total amount (£)
Beyond Suncare - Defending and promoting the life, health and security of people with albinism in Malawi (Ufulu Wanga)	-	17,246
Youth Net and Counselling (YONECO) - Defending and promoting the life, health and security of people with albinism in Malawi (Ufulu Wanga)	-	30,201
Girls Empowerment Network (GENET) - A model of support for improved socio-economic empowerment of person with albinism in Malawi (Titukulane)	18,787	-
Beyond Suncare - A model of support for improved socio-economic empowerment of person with albinism in Malawi (Titukulane)	15,527	-
Total amount (£)	**34,314**	**47,447**

There were no support costs associated with the charity's grant-making.

11. STAFF COSTS

Staff costs	Unrestricted	Restricted	2025 (£)	2024 (£)
Gross wages, salaries and benefits in kind	32,042	249,632	281,674	314,204
Employer's National Insurance, benefits and skills development levy	2,059	14,204	16,263	28,277
Pension costs	745	23,817	24,562	15,464
Total staff costs	**34,846**	**287,653**	**322,499**	**357,945**

The key management personnel of the group are those persons having authority and responsibility for planning, directing and controlling the activities of the group, directly or indirectly, including any Trustee and senior management, comprising the Executive Director, Head Programmes, Head of Manager and Communications Manager. The combined remuneration, including payments in lieu of notice, employer's N.I. and pension costs, accrued holiday and severance of these key management personnel was £171,734 in the year (2024 - £170,307).

The number of higher paid employees in the group at the end of the period under review was:

Staff costs	2025 No.	2024 No.
£60,001- £70,000	-	-
£70,001-£80,000	**1**	**1**



Average number of full-time equivalent employees in the year	2025	2024
The parts of the charity in which the employees work:		
SV UK	4	5
SV Tanzania	25	23
SV Malawi	12	11
Total	**41**	**39**

12. TRANSACTIONS WITH RELATED PARTIES

Name of trustee or connected party	Legal authority (e.g. order, governing document)	Amounts paid or benefit value	
		2025 (£)	2024 (£)
Harry Freeland *(Executive Director salary, plus employer's N.I. and pension costs, accrued holiday and severance)*	Governing document	72,686	72,340
	Expenditure related to carrying out role as Executive Director (not paid to employee).	7,941	12,458

There are no amounts owing to or from the charity's trustees or other related parties by the charity at the year end. All transactions undertaken by (or on behalf of) the charity in which a trustee or related party has a material interest have been disclosed in the Notes to the Accounts.




Standing
Voice