



Vision Programme

Annual Report 2018



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Introduction

Standing Voice is an international NGO with over 10 years' experience defending the rights of people with albinism (PWA) across Tanzania, Malawi and Africa more widely. Today Standing Voice promotes the welfare of this vulnerable population at local, national and international levels through programmes in Health (Skin Cancer Prevention and Vision), Education, Community and Advocacy.

Albinism is a genetic condition that inhibits the body's production of melanin, reducing pigmentation in the skin, eyes and hair. Albinism occurs globally but is approximately seven times more frequent in East Africa than across Europe and North America. People with albinism in Tanzania are commonly the victims of social exclusion, which has led to witchcraft-fuelled murder and marginalisation from health and education services.

In particular, reduced pigmentation in the eye causes light sensitivity and complex visual impairment in people with albinism. This is one of the biggest challenges faced by people with albinism as optometry services in Tanzania lack clinical knowledge of this unique visual impairment, and inadequate resources and infrastructure to test this knowledge and develop its applications in the field. Entrenched institutional discrimination against people with albinism compounds this problem, further narrowing access to care and rendering the majority of this population unsupported in their visual impairment. Uncorrected, visual impairment can have serious consequences for the educational and professional performance of people with albinism, damaging confidence and socioeconomic security later in life.

In 2014 Standing Voice established the Vision Programme to meet the expressed visual needs of PWA and to break the damaging cycle of poor eyesight and poor learning afflicting so

many people with albinism in Tanzania. This programme delivers a clinical service of care, education and training to improve the vision of people with albinism and increase the capacity of service providers positioned to enhance their welfare. Directed by Dr Rebecca Kramer (world-leading optometrist and specialist in the low vision of people with albinism), the Standing Voice Vision Programme activates and trains a network of Tanzanian optometrists and wider community members to provide vision care and education to people with albinism in Tanzania. The Programme particularly targets students.

The Vision Programme has now supported over 2,000 people with albinism in Tanzania through large-scale comprehensive vision clinics. Each large-scale clinic event provides patients with specialist low vision examination, assistive vision devices (including monocular telescopes and prescription glasses), and education in the management of low vision and use of assistive devices. The programme has innovated a scalable best practice reaching record numbers of a hitherto underserved population and building global knowledge of visual impairment in this group. The programme also trains and supports a network of schoolteachers as Vision Ambassadors tasked with monitoring and protecting the welfare of students with albinism in schools.

In 2018 Standing Voice's focus was on broadening impact by ensuring that knowledge gained by key stakeholders is shared widely through further mentoring and training. Dr Rebecca Kammer delivered two training workshops this year aimed at empowering our most experienced Tanzanian optometrists. Three optometrists that have been involved with the programme since inception became mentors to newly enrolled optometrists. Also in 2018, Standing Voice employed a Vision Ambassador Support Officer to support the expansion of the Vision Ambassador scheme and enable deeper engagement with schools. The Vision Ambassador Support Officer provided in-school training to other teachers not yet exposed to Standing Voice's programmes alongside Vision Ambassadors already trained. This trainer of trainers approach was delivered to great affect

In addition to two Vision Events were delivered in Shinyanga and Dodoma regions thus continuing our commitment to expand specialist low vision care to all people with albinism in Tanzania. This annual report provides a comprehensive review of all Vision Programme activities and achievements in 2018.



Harry Freeland
Executive Director

PROGRAMME ACTIVITIES





Programme Activities

2.1 Optometrist Training Workshop | Mwanza

26th - 28th February 2018

2018's Vision Programme activities began with a three-day workshop where nine Tanzanian optometrists were given training in the low vision of people with albinism and rehabilitative strategies. The workshop was delivered by Dr Rebecca Kammer, Standing Voice's Vision Programme Director, alongside American low vision expert, Bennett McAllister, and American orientation, mobility and visual impairment teacher, Stephanie Sherwood, to assist in the training.

2018 saw a change in the way Standing Voice's training is structured and carried out with three senior optometrists becoming mentors and delivering training alongside Dr Kammer. By enabling Tanzanian optometrists to themselves induct other optometrists into the Vision Programme, more healthcare professionals can be exposed to this specialism which ensures continuation and sustainability of care for people with albinism.

The three-day interactive training workshop accordingly assigned experienced programme optometrists to lead small group discussions and

problem-solving throughout the training. Participants first observed presentations on vision function and low vision exams before using their knowledge to take part in grand round sessions with a small number of patients. Following the workshop and practice, trainees joined the Standing Voice team to deliver low vision care to 50 students at Mkolani School and Lake View School.

"Through working with Standing Voice, I have received training on how to treat full refractive errors using a retinoscope and how to prescribe telescopes: these skills are instrumental to treating people with albinism."

Dr Daniel Ringo (Tanzanian optometrist)

Also in attendance was Nigerian optometrist Dr. Edi Onyinye, who travelled to attend the training. She expressed an interest in the Standing Voice Vision Programme as a model of best practice and hopes to replicate such a programme in Nigeria.



2.2 Vision Event | Shinyanga

1st - 6th March 2018

In the week following the training workshop the Standing Voice team travelled to Shinyanga to deliver a large-scale vision clinic to 322 patients, allowing two of the newly trained optometrists to be formally inducted into the Standing Voice Vision Programme.

All patients received a full clinical service including eye examinations, prescribed vision aids, education sessions and associated literature. During the event, 176 prescription glasses, 308 pairs of sunglasses and 241 monoculars were dispensed.

On the last clinic day, media outlets Azam TV and Channel Ten TV were in attendance and interviewed two students, one teacher and two Standing Voice staff members.

“Without Standing Voice, the coming years would have been very different and I really appreciate their presence in our lives. Today I met optometrists and was given devices that I could not have purchased on my own.”

**Evangelist Gasper William, 43
(patient at the Shinyanga Vision Event)**

2.3 Vision Event | Dodoma

6th - 13th May 2018

Another vision clinic was held in May – this time in Dodoma - that again combined albinism education, optometry services, teacher training and the provision of assistive vision devices. Optometry services were delivered by a team of three specialists: Drs Abdi Nyembo, Daniel Ringo and Nestory Massawe, two of which had been newly enrolled in the Standing Voice Vision Programme at the beginning of the year. Over the course of the event, the clinic reached 171 patients, disseminated 356 assistive vision devices and trained 24 teachers as Vision Ambassadors. As part of our wider efforts to increase awareness of visual impairment and its impact on people with albinism, Standing Voice worked with representatives of the Tanzania Albinism Society and the Regional Social Welfare Officer to attend a radio programme that was broadcast on Nyemo FM Radio on the 6th of May. This coincided with the vision event providing excellent exposure for the Vision Programme.

“The services you provide help us a lot. The education increased my knowledge on various issues concerning us people with albinism, and the devices will also improve my performance at university as well as in my daily activities.”

Josephat Suwandet, 23 (patient at the Dodoma Vision Event)



2.4 Further Optometrist Training and SV Team Development

September 2018

In September, Dr Rebecca Kammer returned to Tanzania to continue her mentoring of optometrists involved in the Vision Programme. During one-to-one sessions Dr Kammer built upon the progress made in the previous training workshop (in February) by offering insights into how optometrists themselves could provide additional support and deliver training to new optometrists.

“Optical aids for people with albinism are very expensive and often unavailable. It’s only with the help of NGOs like Standing Voice that we are able to provide the necessary instruments and deliver them at the appropriate time.”

Dr Abdi Nyembo (Tanzanian optometrist)

Following the optometrist training workshop, Dr Kammer shared a number of cutting-edge optometric developments with Standing Voice staff in the Mwanza office which she felt might prove useful in the development of operational strategy moving forward. Staff were further trained on notation and problem solving with spectacles in the inventory.

2.5 Expansion of the Vision Ambassador Programme

A key aspect of Standing Voice’s Vision Programme is the Vision Ambassador Training Scheme. Each school engaged by the programme nominates one teacher to undergo training to become a Vision Ambassador. Vision Ambassadors then advocate for the welfare of students with albinism in their schools, deepening understanding of the visual impairments associated with albinism and promote inclusive teaching practices. Vision Ambassadors also provide continued monitoring and evaluation of the Vision Programme through the submission of regular reports to Standing Voice.

With the help of the newly recruited Vision Ambassador Support Officer, Standing Voice was able to train 24 new Vision Ambassadors at the Dodoma Vision Event (to date, the Vision Programme has trained 105 teachers as Vision Ambassadors). The Vision Ambassador Support Officer keeps in regular remote communication with Vision Ambassadors via phone calls and WhatsApp messages and conducts follow up visits in person.

Moreover, in 2018 the Vision Ambassador Support Officer, together with already trained Vision Ambassadors, met with schools’ management and delivered in-school training to other teachers not yet exposed to Standing Voice’s training.

“I have been a teacher for 15 years. After today’s training, I understand why children with albinism should be put towards the front of the class and given extra help reading exercise books. I have also learned about how to support pupils with the use of a monocular. This knowledge will help my pupils with albinism get the most out of the classroom.”

Here Nzali (teacher at Hombolo Bomani School)



2.6 Creation of new teaching resources

Throughout 2018 Standing Voice developed numerous resources to support teachers. We worked closely with our Vision Programme Director Dr Rebecca Kammer, teachers, people with albinism and the Universities of Lancaster, Coventry and Worcester to develop a new resource for teachers entitled 'Albinism: an information booklet for teachers in Tanzania'. This booklet has been designed to help all teachers, not just those trained as Vision Ambassadors, and contains vital information about the genetic origins of albinism, as well as advice concerning best practice for supporting students with albinism and managing low vision and UV exposure. The booklet also contains a number of recommendations for headteachers as well as a matrix of common vision tasks to be utilised in the classroom alongside advice on how to help the students complete them. This booklet has been piloted across ten schools with 100 copies distributed and has elicited widespread positive response from all the schools involved. The booklet will be ready for wider dissemination in 2019.

Standing Voice has also partnered with Happy Made By, a collaboration of two Dutch illustrators passionate about the power of storytelling to bridge cultural divides and foster social inclusion. Standing Voice is the Tanzanian distributor for their recently published children's picture book called *Moon!* The book centres on the life of a fictional young girl with albinism called Moon. This vibrant and positive story based around facts aims to change the existing narrative surrounding albinism by sensitising the young, fighting stigma and subverting harmful beliefs before they can take root. This book has been piloted to positive effect across seven primary schools with 70 copies distributed by our Vision Ambassador Support Officer in 2018, with plans for its continual distribution throughout 2019.

PROGRAMME ACHIEVEMENTS



3.1 Continued to increase access to specialist eyesore services for people with albinism

The Standing Voice Vision Programme is committed to promoting social inclusion by ensuring that people with albinism have access to critical eye care services. 2018 saw two Vision Events take place, in Shinyanga and Dodoma, where comprehensive vision care was delivered to 493 patients. Neither of these regions had accessed Standing Voice’s Vision Programme previously.

This year a total of 270 pairs of glasses, 332 monoculars, 6 other magnifiers and 479 pairs of sunglasses were prescribed and dispensed, helping to improve patients’ vision. People with albinism in Tanzania generally lack access to such devices either due to cost or lack of availability. High quality vision devices are essential to enhance vision for people with albinism so they can learn and work effectively. Standing Voice is committed to ensuring that people with albinism are appropriately and freely equipped.

At the two vision events optometrists explained to patients the nature of their visual impairment. Those attending the clinic were also instructed on how to use the devices prescribed to them and were given the opportunity to practice using them under supervision, ensuring that all those prescribed with a device would be able to utilise those devices effectively.

2018 Vision Event Outputs

	Shinyanga (March)	Dodoma (May)	Total
Total number of patients	322	171	493
Number of students	265 (82.3%)	91 (53.5%)	356 (72.2%)
Number of non-students	57 (17.7%)	80 (46.5%)	137 (27.8%)
Total number of glasses prescribed and dispensed	176	94	270
Total of number of monoculars prescribed and dispensed	241	91	332
Total number of other magnifiers prescribed and dispensed	6	0	6
Total number of sunglasses prescribed and dispensed	308	171	479

Historical Vision Event Outputs

	2016	2017	2018	Total
Number of Vision Clinics	3	5	2	10
Total number of patients	572	1,204	493	2,269
Number of students	463 (80.1%)	697 (57.9%)	356 (72.2%)	1,516 (66.8%)
Number of non-students	109 (19.9%)	507 (42.1%)	137 (27.8%)	753 (33.2%)
Total number of glasses prescribed and dispensed	238	607	270	1,115
Total number of monoculars prescribed and dispensed	463	546	332	1,341
Total number of other magnifiers prescribed and dispensed	0	83	6	89
Total number of sunglasses prescribed and dispensed	572	1,001	479	2,052



3.2 Improved wellbeing of beneficiaries

During semi-structured interviews many patients cited an increase in confidence and comfort since receiving vision care from the Vision Programme. Below is a patient testimony revealing the positive impact of the support received on general wellbeing and, in this instance, school performance.

“I feel very grateful to be receiving support from Standing Voice today. From now on, I won’t need to stand in front of the class to read the blackboard clearly. Previously, in certain subjects, I could not write my own notes because I could not see the board. After class ended, I used to borrow notes from my friends in order make sure I didn’t get left behind. Thanks to my new vision devices, I won’t have to borrow notes again. I am sure this will mean I perform much better in class.”

Kassim (Patient at the Shinyanga Vision Event)

In addition to the individual Vision Events, students with albinism were supported through the Vision Programme’s Vision Ambassador scheme. Vision Ambassadors monitored and recorded students’ confidence and wellbeing throughout the year. When asked about this following their teachers’ training by Standing Voice, students largely responded that a difference in the approach of their teachers had allowed them to greatly improve their academic ability. Students particularly cited that their teachers would now take more time to make sure they were able to see the blackboard, making it far easier to comprehend what was being taught. These students also referenced feeling better able to keep up with their peers, which has huge implications for their self-worth.

3.3 Increased educational attainment among students with albinism

72.2% (356) of patients seen in 2018 were students. Many of these have reported that an improved ability to read and conduct school work independently has contributed to their success in school. Programme data showed that 62% of students supported by the Vision Programme saw an improvement in their grades. It was also found that 33% of these students now received top grades compared to 15% before their involvement in the programme. The dramatic improvement in the grades of students involved in the programme serves as testimony to the improved vision of students and the effect of inclusive education on the academic development of students with albinism.

“Without the vision devices given and my teacher’s support I could not have succeeded in my exams. Right now I am getting good grades because of the help I received. I don’t know where I would be without this help.”

Enock Kusekwa John (patient at the Shinyanga Vision Event and student at Shinyanga Secondary School)

3.4 Continued to increase teachers' capacity to support academic development of students with albinism

Number of Vision Ambassadors trained (2016-2018)				
	2016	2017	2018	Total
Number of Vision Ambassadors trained	18	63	24	105

In 2018 Standing Voice trained 24 more teachers as Vision Ambassadors tasked with monitoring and protecting the welfare and academic performance of students with albinism in schools. Teachers were trained in the use and storage of assistive vision devices, classroom adjustments and strategies for encouraging children with albinism who underperform. Standing Voice has now trained 105 teachers as Vision Ambassadors since 2016.

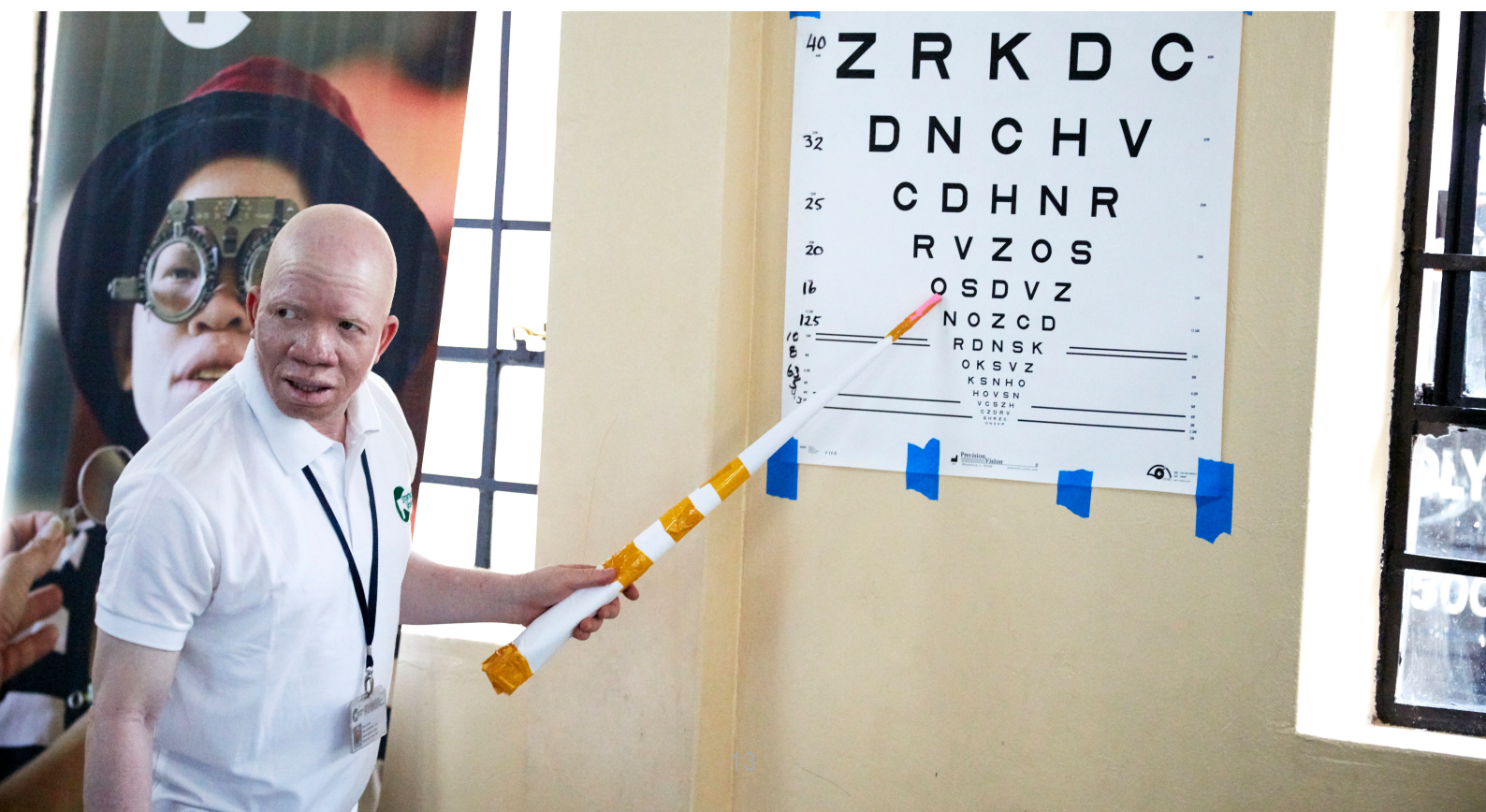
This year Standing Voice focused on empowering Vision Ambassadors with the skills and resources to train other teachers working at their schools who hadn't received training from Standing Voice. This, alongside the distribution of our recently developed resource booklet, has helped to broaden the scope of our Vision Ambassador scheme, ensuring knowledge is propagated as widely as possible.

The dramatic improvement in the grades of our student beneficiaries serves as evidence of the increased capacity of the Vision Ambassadors to deliver and promote inclusive education. Additionally, numerous testimonies were collected from Vision Ambassadors over the year through semi-structured interviews, monitoring and evaluation forms and feedback following training. Many teachers reported

that they are more mindful of the names students with albinism are called in class and challenge any name calling more frequently than before. There were also multiple instances where Vision Ambassadors stated that they felt more confident in managing low vision by enabling students with albinism to choose their most comfortable seating position in class. Previously teachers placed students with albinism in the front row of the class without consulting them as to their preference. For example, due to their visual impairment some students prefer to sit to the side of the class in addition to being towards the front. Vision Ambassadors also reported that they understand their role as advocates for people with albinism in society more generally and feel empowered to challenge stigma in their communities.

“Our training and the resources provided came at a good time as we had new teachers who joined us and they were not aware of how to handle students with albinism. Through the training I know they have learnt many things. The booklet in particular covers everything that a teacher who teaches students with albinism needs, we really thank all who were involved in preparing this booklet.”

Mrs Suzan, Old Moshi Secondary School Teacher



3.5 Increased clinical capacity of Tanzanian optometrists to serve the complex vision needs of people with albinism

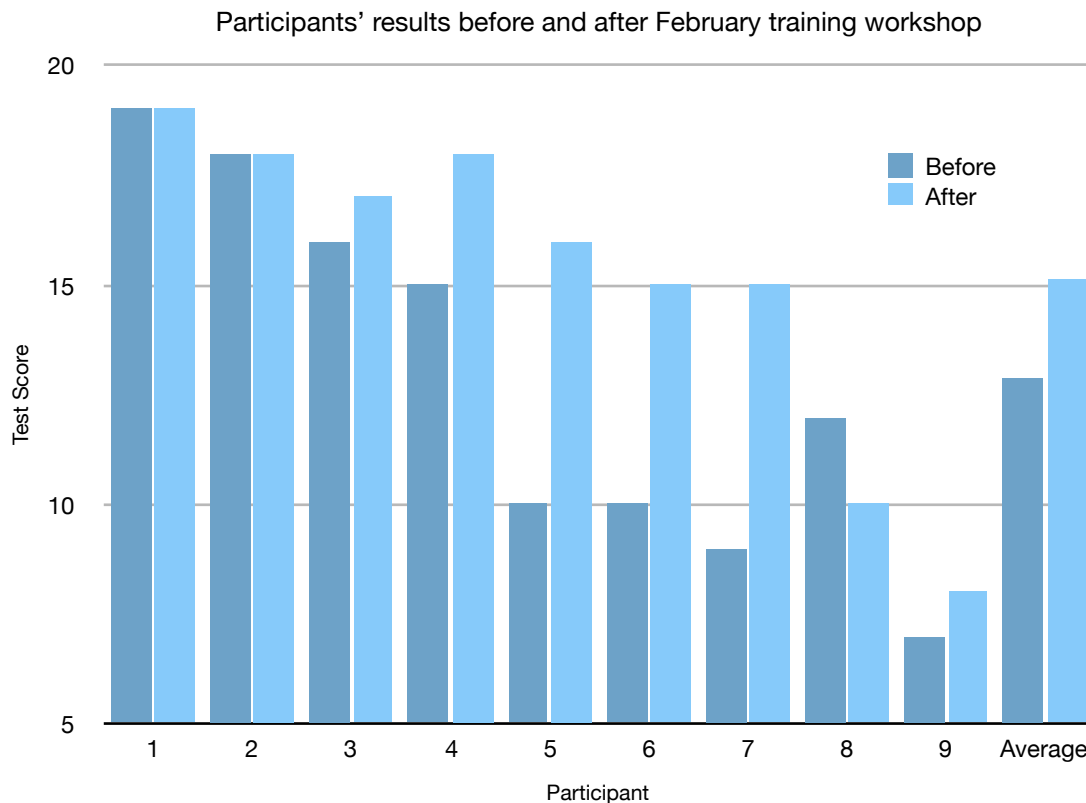
Through examining and treating a wide range of PWA, the Standing Voice Vision Programme has developed an unparalleled understanding of the clinical aspects of the visual impairments that occur in patients with albinism, as well as the appropriate rehabilitative strategies required. Standing Voice Vision Programme Director Dr Rebecca Kammer is a world leading specialist in the low vision of PWA and under her guidance the Standing Voice Vision Programme continues to contribute to the advancement of global knowledge around the unique visual impairments of people with albinism.

This year, Standing Voice was able to provide training to a selection of optometrists, leading to the induction of two new optometrists into the Vision Programme, another significant achievement as we continue to develop local capacity to care for the distinctive vision needs of people with albinism.

Overall, there was a notable improvement in the knowledge of participants who attended Standing Voice's training workshops. Trainees' skills and understanding of the low vision of people with

albinism were observed to have increased significantly. These workshops were another step forward for Standing Voice in our effort to build a network of optometrists equipped to provide specialist care for persons with albinism across Tanzania.

The development of participants' knowledge and skills was well evidenced at our first training workshop in February. Participants were given two similar tests with a total score of 20 points, covering topics such as the identification of prevalence and type of albinism found in Tanzania, to refractive trends found in Dr Kammer's studies. A score of 15 out of 20 was considered an acceptable metric of learning. On average, participants' scores increased by 2.2 points (from 12.9 to 15.1 points), representing a corresponding increase in participants' knowledge following the training workshop. The three optometrists with a long history with the programme scored highly pre-training (16+), leaving little room for improvement. Significant improvement was made in four of the students, who gained an average of 4 points each on the test post-training.



3.6 Empowered Vision Ambassadors and optometrists with the skills to train and mentor further teachers and optometrists

Standing Voice's Vision Ambassador Support Officer worked closely with Vision Ambassadors to enable them to deliver training to their peers. Giving Vision Ambassadors a platform to become trainers themselves helps contribute to the programme's sustainability and ensures that the information provided in initial training sessions is shared widely throughout schools. This 'trainer of trainers' approach has been extremely successful as it positions the Vision Ambassadors as having expertise; enabling them to deliver sections of the workshops with confidence, becoming advocates for students with albinism within their schools. 184 teachers attended these training sessions this year, with the vast majority of attendees being teachers who have not received any training on albinism prior to this. Key components of these training sessions included albinism awareness, managing low vision in class and promoting self-esteem of students.

"The education session is very valuable as it teaches us about albinism, the devices, how to use them and how to keep them safe...we are having a seminar next week at our school about albinism/disabilities in general and how to help students in education."
Arnold Pandapanda (teacher at Shinyanga Secondary School)

In September Dr Kammer returned to meet with three senior optometrists assigned as mentors in order to provide them with the teaching skills necessary for successfully training and mentoring further optometrists. The network of people with the knowledge and ability to train others widens as a result of this model, ensuring that the excellent training provided by world-leading experts within the context of the Vision Programme can be shared.

3.7 Continued to deepen government engagement in the provision of vision care to people with albinism

Key to Standing Voice's approach to catalysing societal change is engaging the Tanzanian government in our programme delivery. High profile district and regional government officials attended both of this year's vision events, and also provided logistical assistance and patient transportation. At the Dodoma Vision Event, Standing Voice were grateful to receive significant support from local government and District Social Welfare Officers who were instrumental in mobilising patients by, amongst other things, organising media engagements to publicise the event. Upon arrival in Dodoma the Standing Voice team was welcomed by the Dodoma Regional Administrative Secretary, and the Regional Social Welfare Officer worked tirelessly to ensure that the Standing Voice team could carry out their vital work without any constraints on the service. On the final day of the Dodoma Vision Event the Regional Social Welfare Officer delivered a note of thanks on behalf of the Dodoma regional government.

At the Shinyanga Vision Event we were supported by District Social Welfare Officers from Kahama and Msalala, who provided two land cruisers from district council centres to transport patients to the event.

"The sessions you provide are very helpful to people with albinism. They receive devices that they need and, most importantly, they are taught better ways of using them. I will visit the schools that the students attend to talk to teachers on how to take care of them and make follow up visits to monitor their progress."
Agnes Gineton (Msalala District Social Welfare Officer, visited the Shinyanga Vision Event)

"It has been a good opportunity for me to attend today's clinic, as I have been able to learn more about albinism and Standing Voice... I have witnessed excellent services, education about albinism and also my people have received devices like sunglasses and monoculars that mean their lives will improve from now on."
Richard Kiwale (District Social Welfare Officer, visited the Dodoma Vision Event)



3.8 Promoted societal awareness of the vision needs of people with albinism through media engagement

This year our vision events received extensive media coverage across a number of mainstream broadcasters, who relayed testimonials of patients, optometrists and other stakeholders. Media outlets such as Azam TV and Channel Ten TV put out numerous pieces which will raise vital awareness of the needs of people with albinism - alleviating stigma in communities nationwide.

3.9 Continued to deepen school engagement in the provision of vision care to people with albinism

The Vision Ambassador Support Officer has been conducting one-to-one meetings with schools' management. This has proved extremely valuable as it is imperative that school management is committed to improving welfare and educational outcomes for students with albinism in their schools. Through this work the relationship between the Headteacher and Vision Ambassadors has also been strengthened, resulting in a positive impact upon the culture of the schools with regards to inclusive teaching practices for students with albinism.

"The booklets you provided today and the wider training we received gave us new insight and reflection on how to handle students with albinism inside and outside the classrooms. We insist you to visit us frequently and feel at home in our school."

Sr. Maduhu (Mwereni Special Needs School Headteacher)



Programme Plans for 2019

In 2019 Standing Voice aims to deliver five Vision Events across Tanzania. The approach of empowering experienced Tanzanian optometrists to share their own skills and expertise with other optometrists will continue through these Vision Events, giving them the platform to mentor and support newer optometrists in the programme.

Vision Ambassador training will be conducted increasing the network of teachers that are capable of supporting the academic development of students with albinism. Whilst those already trained will

continue to be supported in their roles, particularly with regards to training and assisting other teachers within their schools.

The distribution of the Teachers Booklet and the picture book *Moon!* will continue throughout 2019, strengthening our relationships with schools and increasing their capacity to support students with albinism.



A Note of Thanks

2018's achievements have been realised with the support of our committed partners for which we are immensely grateful. Heartfelt thanks to Essilor Vision For Life, the St James Place Charitable Foundation, Souter Charitable Trust, participating schools, the Government of Tanzania represented through District and Regional Authorities and through the Ministries of Health and Education, Tanzania Albinism Society, KCMC School of Optometry and Under the Same Sun. Thanks also to the wonderful Standing Voice team, including Dr Rebecca Kammer and our Tanzanian optometrists, Kanuti Siarra, Abdy Nyembo and Hanifa Joshua in particular who have become mentors within the programme. Lastly, sincere thanks to the participating patients with albinism, their families and teachers without whom this service would not exist.

